Disenfranchised Grief: Professionals Recognizing, Owning and Working Through Loss

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Objectives

• Define Disenfranchised Grief, including the five categories

• Discuss the reasons healthcare providers are at risk for Disenfranchised Grief

• List at least 3 interventions and/or resources that healthcare providers can utilize to prevent and/or deal with grief
Disclosure

“I have no financial or other conflicts of interest related to this presentation. Any mention of off-label use of drugs will clearly be mentioned as such.”
The Invitation
By Oriah Mountain Dreamer
Why Focus on Nurses?

Nurses:

- Care for dying patients and are the survivors of many losses
- Interact with both the dying and survivors of the dying more than any other professional group
- Focus on care-related tasks, nurturing, support, ‘maternal’ or ‘paternal’ behaviors

Helping nurses deal with death and the grieving process guards against compassion fatigue and burnout.

(Lev, 1989; Furman, 2002; Broche, 2003)
Why Focus on Healthcare Professionals?
Dr. Kenneth J. Doka

• Prof of Gerontology - College of New Rochelle, NY
• Editor - Omega Journal, Journeys Newsletter
• Published over 100 articles and chapters
  • Living With Grief: After Sudden Loss
  • Living With Grief: When Illness is Prolonged
  • Living With Grief: Who We Are, How We Grieve
  • Living With Grief: Children, Adolescents, and Loss
  • Living with Grief: Loss in Later Life
  • Living With Grief: At Work, at School, at Worship
Dr. Kenneth J. Doka

- AIDS, Fear and Society
- Caregiving and Loss: Family Needs, Professional Responses
- Children Mourning, Mourning Children
- Men Don’t Cry…Women Do: Transcending Gender Stereotypes of Grief
- Death and Spirituality
- Disenfranchised Grief: New Directions, Challenges, and Strategies for Practice
- Disenfranchised Grief: Recognizing Hidden Sorrow
- Disenfranchised Grief: Living With Life-Threatening Illness
Disenfranchised Grief: A Definition

How would YOU define Disenfranchised Grief?
Definitions

Dis·en·fran·chise: ("dis-in-'fran-"chIz): to deprive of a franchise, of a legal right, or of some privilege or immunity; especially: to deprive of the right to vote

Grief: is an individual’s reaction or personal response to a significant loss. Grief has emotional, physical, behavioral, cognitive, social, cultural and spiritual dimensions.

Disenfranchised Grief: Grief that persons experience when they incur a loss that is not or cannot be socially sanctioned, openly acknowledged or publicly mourned

(Merriam-Webster’s Online Dictionary, 2010; Worden, 1991, Rando, 1984; Doka, 1989)
Grieving Rules
The concept of disenfranchised grief recognizes that society has a set of norms that attempt to specify:

- Who
- When
- Where
- How
- How long

(Doka, 1989)
Are All Losses Death Related?
Losses

- Divorce
- Relocation
- Adoption, foster care
- Job loss
- Incarceration
- Property loss, robbery, fire, flood...
- Loss of limb, body part, health
- Life threatening diagnosis
- Others?
Disenfranchised Grief Categories
Relationship is not Recognized
## Relationship is not Recognized

Underlying assumption is that closeness exists only with spouses and immediate kin

<table>
<thead>
<tr>
<th>Therapist/patient</th>
<th>Neighbors</th>
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</thead>
<tbody>
<tr>
<td>Teacher/coach</td>
<td>Colleagues</td>
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<tr>
<td>Same sex partner</td>
<td>Foster parents</td>
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<tr>
<td>Lover/partner</td>
<td>Step parent/children</td>
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<tr>
<td>Extramarital affair</td>
<td>In-laws</td>
</tr>
<tr>
<td>Pets</td>
<td>Nursing home roommate</td>
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<tr>
<td>Ex-spouse</td>
<td>Celebrities</td>
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<tr>
<td>Friends</td>
<td>Others...</td>
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</tbody>
</table>
Loss is Not Acknowledged
Loss is Not Acknowledged

This category considers losses that are NOT socially defined as significant

- Perinatal deaths
- Abortions
- Pets
- Psychological
  - Brain activity / organic brain syndrome
  - Mental illness
  - Significant personal transformations (addictions, conversion)
Griever is Excluded
Griever is Excluded

This category identifies persons not socially defined as capable of grief

- Persons with developmental disabilities
- Mental illness
- Dementia
- Elderly
- Very young
- Mentally disabled
Ineffective Coping Strategies
Helpful Strategies
How Individuals Grieve

Intuitive Griever

• Experiences strong affective reaction
• Expression mirrors inner feelings
• Adaptation involves expression and exploration of feelings

Instrumental Griever

• Experience is primarily cognitive or physical
• Often expressed cognitively or behaviorally
• Adaptation generally involves thinking, doing
Issues with Disenfranchised Grief

• Intensified feelings
• Ambivalence and concurrent crisis
• No role in planning of funeral ritual
• No bereavement leave
Physicians

- Focus is cure-related
- Society rewards life-saving and technical achievement
- What education and support is offered during formal program?

(Lev, 1989)
Nurses’ Grief

Response to situations affect by:

• Previous unresolved losses
• Actual or potential losses
• Feelings of guilt
  • Inability to provide care
  • Difficulty meeting family needs
  • Unable to be present at time of death

(Lev, 1989)
Who Helps the Helper?

- Concept analysis that clarifies grieving process for nurses
  - Antecedents
  - Defining characteristics
  - Consequences
- Many articles and studies written in relation to nurses helping patients and/or families work through grief
- Public perception – we are specially trained to deal with and teach the grieving process to lay persons

(Brunelli, 2005)
Professional Caregivers

• Caring for the professional caregiver before and after the death

• Compassionate care and ability to give of oneself without being destroyed in the process
  • Anticipatory grief
  • Denial of grief
  • Distorted or masked grief
  • Chronic grief

(Vachon, 2007)
Disenfranchised Grief Across the Spectrum

- 14 Greek oncologists, 16 pediatric oncology nurses
- Cultural context – disease is not named
- Physicians didn’t feel emotionally supported by colleagues
- Nurses found support among colleagues
- Healthcare professionals’ grieving process was affected by:
  - Role perception
  - Interventions
  - Contributions

(Papadatou, D., Papazoglou, I., Bellali, T. & Petraki, D., 2002)
Determinants of Grief

- Personal experience
- Mode of death
- Relationship
- Social, economic, cultural and religious factors
- Social support
- Other life stressors and opportunities
- Closeness of the mourner to the deceased
- Extent to which mourner believes the death may have been prevented
- Death encountered early in career or as a student

(Lev, 1989; Parkes, 2002)
## Manifestations of Grief

<table>
<thead>
<tr>
<th>Physical</th>
<th>Cognitive</th>
<th>Emotional</th>
<th>Behavioral</th>
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</thead>
<tbody>
<tr>
<td>Headaches</td>
<td>Depersonalization</td>
<td>Anger</td>
<td>Impaired performance</td>
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<tr>
<td>Dizziness</td>
<td>Diff concentrating</td>
<td>Guilt</td>
<td>Crying</td>
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<tr>
<td>Exhaustion</td>
<td>Disbelief</td>
<td>Anxiety</td>
<td>Withdrawal</td>
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<tr>
<td>Muscle aches</td>
<td>Confusion</td>
<td>Helplessness</td>
<td>Avoiding reminders</td>
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<tr>
<td>Sexual issues</td>
<td>Idealization</td>
<td>Sadness</td>
<td>Carrying reminders</td>
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<tr>
<td>Loss of appetite</td>
<td>Search meaning</td>
<td>Shock</td>
<td>Over reactivity</td>
</tr>
<tr>
<td>Insomnia</td>
<td>Dreams</td>
<td>Yearning</td>
<td>Relationship changes</td>
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<tr>
<td>Tightness, hollow</td>
<td>Preoccupation</td>
<td>Numbness</td>
<td></td>
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<tr>
<td>Breathlessness</td>
<td>Fleeting hallucinations</td>
<td>Self-blame</td>
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<tr>
<td>Tremors</td>
<td></td>
<td>Relief</td>
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<td>Shakes</td>
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<tr>
<td>Sensitive to noise</td>
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(Doka, 1989; Corless in Ferrell, 2006)
Coping Mechanisms

Coping or so we think...

- Psychic numbing
- Withdrawal
- Isolation
- Restriction of person involvement with patients

*Desire to leave current job or healthcare profession*
Mentoring Professional Caregivers

Comfort-Ability Growth & Development Scale in Coping with Professional Anxieties in Death & Dying

Stage I Intellectualization – 1-3 mths
Stage II Emotional Survival - 3-6 mths
Stage III Depression – 6-9 mths
Stage IV Emotional Arrival – 9-12 mths
Stage V Deep Compassion – 12-24 mths
Stage VI The Doer – 8-10 yrs beyond Stage V

(Harper, 1994)
Your Profession

- Philosophy
- Passion
- Commitment
- Assessment
- Mentoring
Strategies/Interventions
Self Awareness and Self Appraisal

- Dealing with own attitudes
- Unresolved losses
- Personal loss history
- Learning to balance between identification & detachment
- Spirituality

(Doka, 2002; Medland et al., 2004; Vachon, 2006; Kearney Weininger, Vachon, Harrison & Mount)
Self-Care

- Self-care based on self-awareness
- Physical activity
- Art
- Hobbies
- Reflective writing
- Mindfulness Based Meditation – Kabat-Zin
- Any form of enjoyment, rejuvenation

(in Kearney, Weininger, Vachon, Harrison and Mount; Vachon, 2006; Kabat-Zinn, 1990)
Buddha was asked, "What have you gained from meditation?"
He replied, "Nothing!"
However, Buddha said, let me tell you what I lost:
Anger, Anxiety, Depression, Insecurity, Fear of Old, Age and Death."
Education and Rejuvenation

- Education regarding the needs of dying patient & families

- Conferences
  - Clinical
  - Retreats

(Doka, 2002; Medland, et al., 2004; Vachon, 2006; ELNEC Core)
Education and Support

Palliative resources education & support enriching nursing care with ELNEC

(adapted from ELNEC Core with permission)
The Windsor Experience
LEAP for Nurses
Learning Essential Approaches to Palliative Care
Windsor Inter-professional Experience LEAP
Retreats

- For staff
- Structured programs with themes, outcomes and next steps
- Medland – Circle of Care
Bereavement Programs

• Formal structured programs
  • Cards
  • Phone calls
• Scrapbooks
• Celebrations
Team Approach

• Frequent informal discussions with colleagues
• Structured debriefing sessions
• Case Reviews
• Team Meetings
• Mentoring
• Mindfulness-Based Stress Reduction for Team

(Kearney, Weininger, Vachon, Harrison and Mount)
Rituals

- Highly symbolic acts that confer transcendental significance
- Meaning
- Provide structure
- Opportunity to contain and express emotions
- Significance is both social and personal

(Doka, 1989)
Rituals

• Attending a funeral – a question for you and your colleagues
• Funeral ritual
• Alternative rituals
  • Continuity
  • Transition
• Reconciliation
• Affirmation

(Doka, 1989)
"We must never forget that we may also find meaning in life even when confronted with a hopeless situation, when facing a fate that cannot be changed...

When we are no longer able to change a situation, we shall be challenged to change ourselves."