



Disenfranchised Grief: Nurses Acknowledging & Dealing with Loss

October 9, 2009

RN-AIM

Fourth Annual Conference & Assembly
Plymouth, MI

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Objectives

- ◆ Define disenfranchised grief, including the five categories
- ◆ Describe three reasons nurses are at risk for disenfranchised grief
- ◆ List at least 3 interventions and/or resources that nurses can utilize to prevent and/or deal with grief



Dr. Kenneth J. Doka

- ◆ Developed the concept of Disenfranchised Grief
- ◆ Graduate Prof. 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



Definitions

dis·en·fran·chise

Pronunciation: "dis-in-'fran-"chIz

Function: *transitive verb*

:to deprive of a franchise, of a legal right, or of some privilege or immunity; *especially*: to deprive of the right to vote

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 Dictionary, 2007)

Grieving Rules

The concept of disenfranchised grief recognizes that society has a set of norms that attempt to specify

- ◆ When
- ◆ Where
- ◆ How
- ◆ How long
- ◆ For whom

people should grieve

(Doka, 1989)





Not all Losses Are Death Related

- ♦ Divorce
- ♦ Relocation
- ♦ Giving up a child for adoption or foster care
- ♦ Job loss
- ♦ Incarceration
- ♦ Loss of property in robbery, fire, flood...
- ♦ Loss of a limb or body part
- ♦ More...

(Doka, 1989)



Categories of Disenfranchised Grief



Relationship is Not Recognized

- ◆ Underlying assumption that closeness exists only with spouses or immediate kin
 - ◆ Friends
 - ◆ Neighbors
 - ◆ Colleagues
 - ◆ Foster parents
 - ◆ Step parents
 - ◆ Step children
 - ◆ In-laws
 - ◆ Ex-spouse
 - ◆ Therapist/patient
 - ◆ Teacher/coach
 - ◆ Homosexual partner
 - ◆ Lover/partner
 - ◆ Extramarital affairs
 - ◆ Pets
 - ◆ Nursing home roommates
 - ◆ Celebrities

(Doka, 1989)



Loss is Not Acknowledged

- ◆ Not socially defined as significant
 - ◆ Perinatal deaths
 - ◆ Abortions
 - ◆ Pets
 - ◆ Psychological death:
 - ✧ brain activity
 - ✧ mental illness
 - ✧ organic brain syndromes
 - ✧ significant personal transformations (addiction, conversion)

(Doka, 1989)



Griever is Not Recognized

- ◆ Person not socially defined as capable of grief
 - ◆ Persons with developmental disabilities
 - ◆ Persons with mental illness or dementia
 - ◆ Elderly
 - ◆ Youth
 - ◆ Mentally disabled

(Doka, 1989)



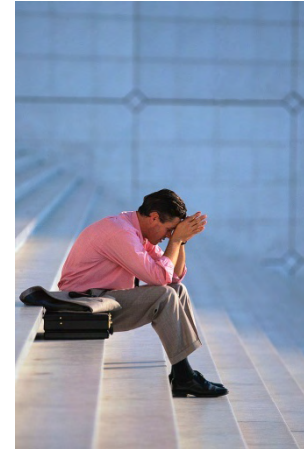
Disenfranchising Deaths

- ◆ Circumstances associated with stigma, uncomfortable and/or unusual death
 - ◆ Homicide
 - ◆ Executions
 - ◆ Martyrdom
 - ◆ Suicide
 - ◆ HIV/AIDS

(Doka, 1989)

Ways Individuals Grieve

- ♦ Intuitive Grief
 - ♦ Experiences strong affective reaction
 - ♦ Expression mirrors inner feelings
 - ♦ Adaptation involves expression and exploration of feelings



- ♦ Instrumental Grief
 - ♦ Experience is primarily cognitive or physical
 - ♦ Often expressed cognitively or behaviorally
 - ♦ Adaptation generally involves thinking or doing



(Doka, 1989)

Special Problems of Disenfranchised Grief

- ♦ Intensified feelings
- ♦ Ambivalence and concurrent crisis
- ♦ No role in planning funeral ritual
- ♦ No bereavement leave



(Doka, 1989)

Physicians

- ◆ Physicians focus on cure-related tasks
- ◆ Society rewards life-saving and technical achievement



Nurses' Grief

- ◆ Nurses:
 - ◆ care for dying patients and are the survivors of many losses
 - ◆ interact with both dying and survivors of the dying more than any other professional group
 - ◆ focus on care-related tasks, nurturing, support, 'maternal' or 'paternal' behaviors



(Lev, 1989)

Nurses' Grief

- ◆ Response to situations are affected by previous unresolved loss
 - ◆ actual or potential death of patient
 - ◆ feelings of guilt
 - ✧ inability to provide care
 - ✧ difficulty meeting family needs
 - ✧ unable be present at time of death

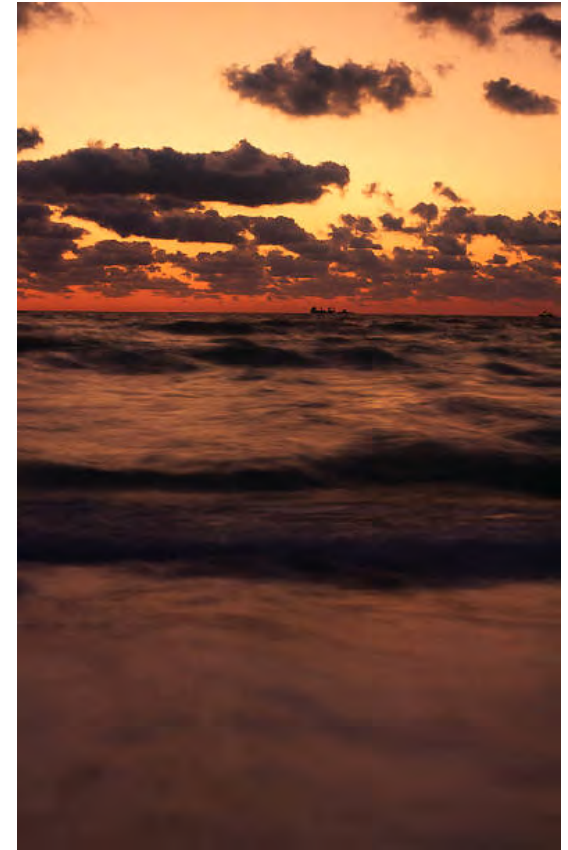


(Lev, 1989)

Nurses' Grief

- ♦ Who helps the helper?
- ♦ Concept analysis that clarifies the grieving process for nurses
 - ♦ Antecedents
 - ♦ Defining Characteristics
 - ♦ Consequences
- ♦ Many articles and studies written in relation to nurse helping patient &/or family work through process
- ♦ Nurses are specially trained to deal with and teach the grieving process to lay persons
- ♦ "Hey, we hurt too."

(Brunelli, 2005)





Nurses' Grief

- ♦ Greek nurses who care for children dying from cancer
- ♦ Crying, sadness, anger, & recurring thoughts of the dying conditions (pain & suffering) & actual death
- ♦ Support found from other nurses – recalling positive attributes of child & discussing positive contributions the nurse had made
- ♦ Most frequently, nurse avoided grief, a curtain was drawn down, pain was forgotten, or pain was placed in a drawer and closed away

(Papadatou & Bellali, 2002)

Nurses' Grief

- ◆ Consequences of not going through the grieving process
 - ◆ Burnout
 - ◆ Potentially harmful addictions
 - ◆ Even thoughts of suicide
- ◆ Helping nurses deal with death and process their grief
 - ◆ Guards against burnout
 - ◆ Maintains a therapeutic presence
 - ◆ Leads to better patient care



(Broche, 2003; Furman, 2002)

Professional Caregivers

- ♦ Caring for the professional caregivers:
before and after death
 - ♦ anticipatory grief
 - ♦ denial of grief
 - ♦ distorted grief
 - ♦ chronic grief
- ♦ Cumulative grief
- ♦ A good death



(Marino, 1998; Saunders & Valente, 1994; Vachon, 2007)



Determinants of Grief

Which May Determine Outcomes

- ♦ Personal experience
- ♦ Mode of death of the deceased
- ♦ Relationship with the deceased
- ♦ 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)



Nurses at Risk

- ♦ Who is at risk?
- ♦ Coping mechanisms
 - ♦ psychic numbing
 - ♦ withdrawal
 - ♦ isolation
 - ♦ restriction of personal involvement with patient (especially those in pain)

Desire to leave current job or the healthcare field

(Lev, 1989)

Our Profession

- ◆ ONS
 - ◆ Standards
- ◆ Social Policy Statement
 - ◆ Four Essential Features
 - ◆ Phenomenon of Concern



(ANA, 2003; Boyle, et al., 2004)

Our Profession

- ◆ Philosophy
- ◆ Mentoring
- ◆ Our Passion
- ◆ Our Commitment
- ◆ Assessment



(ANA, 2003; Boyle, et al., 2004)



Assessment & Nursing Diagnosis

- ◆ Common to people who are grieving:
 - ◆ crying
 - ◆ feeling depressed
 - ◆ difficulty concentrating
 - ◆ expressions of anger
 - ◆ anxiety
 - ◆ fatigue
 - ◆ headaches
 - ◆ insomnia
 - ◆ loss of appetite

(Rando, 1984)

Nursing Diagnosis

- ◆ Anxiety
- ◆ Fatigue
- ◆ Ineffective Coping
- ◆ Caregiver Role Strain
- ◆ Anticipatory Grieving



(Rando, 1984)

Nursing Diagnosis

- ◆ Ineffective Role Performance
- ◆ Impaired Social Interaction
- ◆ Chronic Sorrow
- ◆ Hopelessness
- ◆ Powerlessness
- ◆ Risk for Spiritual Distress



(Rando, 1984)

Interventions & Evaluation

- ♦ Dealing with own attitudes
- ♦ Frequent informal discussions with colleagues
- ♦ Mental health days to recover
- ♦ Learning to balance between identification & detachment



(Doka, 2002; Medland, et al., 2004)

Interventions & Evaluation

- ♦ Posting a photograph, scrapbook
- ♦ Attending a patient's funeral
- ♦ Sending a card or calling
- ♦ Debriefing sessions or conferences
- ♦ Education regarding the needs of dying patient and family



(Doka, 2002; Medland, et al., 2004)

Interventions & Evaluation

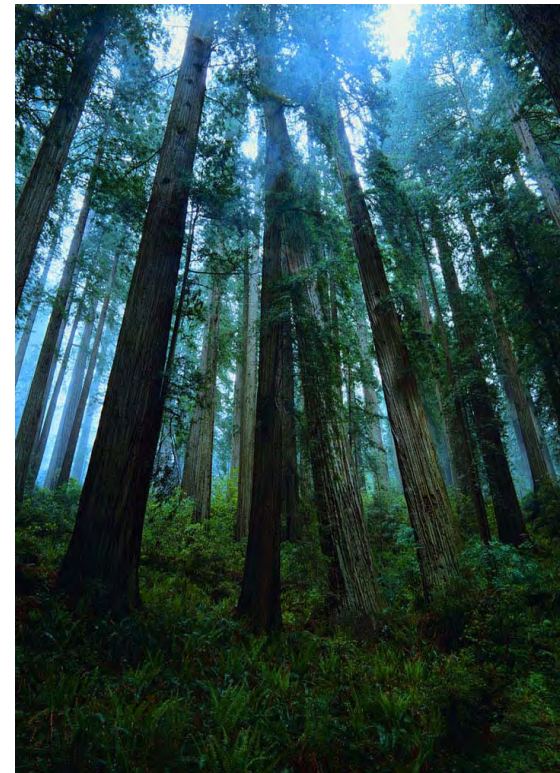
- ◆ Funeral ritual
- ◆ Alternative rituals
 - ◆ continuity
 - ◆ transition
 - ◆ reconciliation
 - ◆ affirmation



(Doka, 1989; Russ, 2005; Silverman & Klaus, 1996)

Interventions & Evaluation

- ◆ Continuing bonds
- ◆ Labor of love
- ◆ Team appreciation ceremony



(Doka, 1989; Russ, 2005; Silverman & Klaus, 1996)



*"To make a great dream come true,
the first requirement is a great capacity to dream:
the second is persistence
— a faith in the dream"*

- Hans Selye



First Alternative Ritual

- ♦ BMT Team Appreciation Ceremony
- ♦ Not a memorial service but instead acknowledging loss & grief while also celebrating strengths & attributes of the team
- ♦ Choosing a theme and steps in the ritual
- ♦ Leadership support & participation
- ♦ Obtaining feedback



Alternative Ritual

An Annual Event

- ♦ Changing the themes to be more positive after the first year
- ♦ Including more team members
- ♦ Remembering support staff and all those who come in contact with the BMT patients & their families
- ♦ Giving participants a token representing the theme of the ceremony
- ♦ More time at the reception afterwards



Adding another intervention...



Education & Support

- ♦ End of Life Nursing Education Consortium (ELNEC)
 - ♦ National education initiative to improve end-of-life care in the U.S.
 - ♦ ELNEC project administered by the American Association of College of Nurses (AACN) and the City of Hope National Medical Center
 - ♦ Curriculum focuses on core areas in end-of-life care reflecting AACN's 1998 publication, *'Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care'*
- ♦ ACE – Advocating for Clinical Excellence: Transdisciplinary Palliative Care Education



PRESENCE

Enhanced ELNEC Curriculum

- ♦ Palliative Care Nursing – Moral Imperative
- ♦ Communication
- ♦ Symptom Management
- ♦ Psychosocial Considerations*
- ♦ Spiritual Aspects*
- ♦ Pain Management
- ♦ Ethical & Legal Issues
- ♦ Cultural Considerations
- ♦ Loss, Grief & Bereavement
- ♦ Final Hours



Nursing Research

- ◆ Demographics
- ◆ Nursing Attitudes Survey
- ◆ Nursing Knowledge Survey
- ◆ Comments & Responses



More Education & Support

- ♦ ACE – Advocating for Clinical Excellence: Transdisciplinary Palliative Care Education
- ♦ EPEC-O Education in Palliative and End-of-Life Care for Oncology (NCI)
- ♦ CAPC – Center to Advance Palliative Care
- ♦ CAPEWAYNE
- ♦ Palliative Care Certification
- ♦ More...



Remember...

*"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 are challenged to change ourselves"*

Frankl, 1984