

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



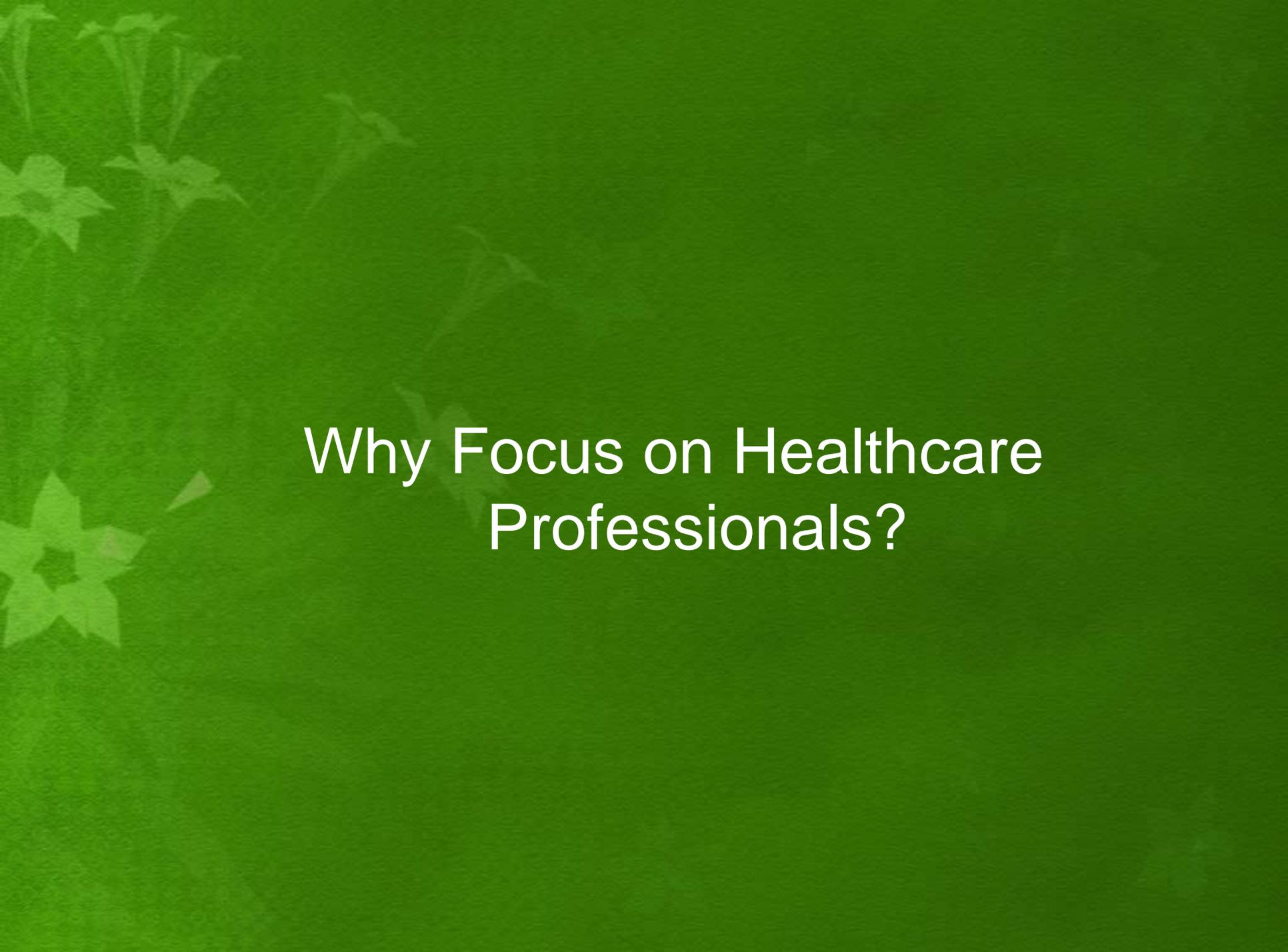
Why Focus on Nurses?

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)

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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-"chlz): 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

Grieving Rules



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?

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Disenfranchised Grief Categories

Relationship is not Recognized

Relationship is not Recognized

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

- Therapist/patient
- Teacher/coach
- Same sex partner
- Lover/partner
- Extramarital affair
- Pets
- Ex-spouse
- Friends
- Neighbors
- Colleagues
- Foster parents
- Step parent/children
- In-laws
- Nursing home roommate
- Celebrities
- Others...

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

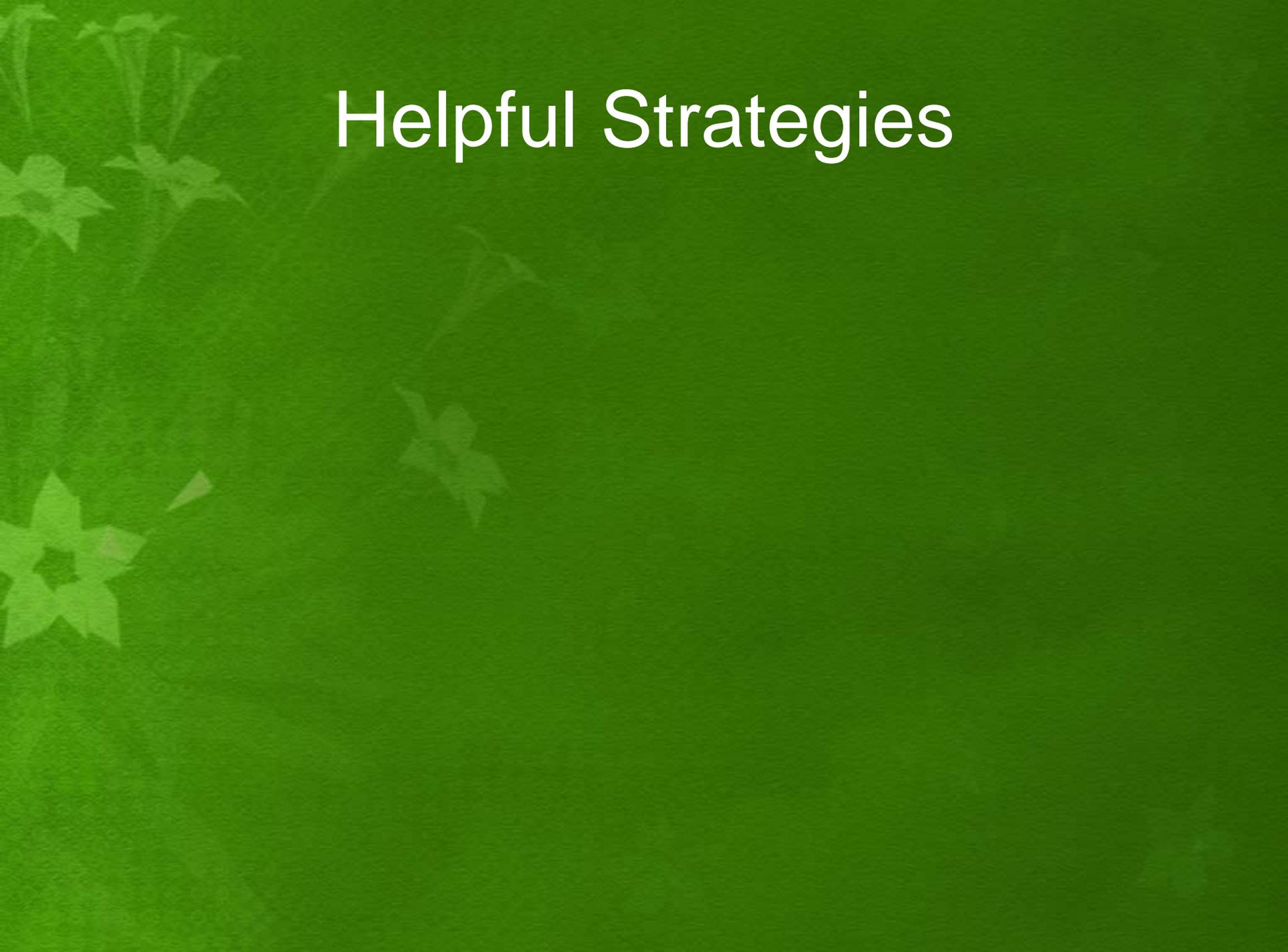
Griever is Excluded

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

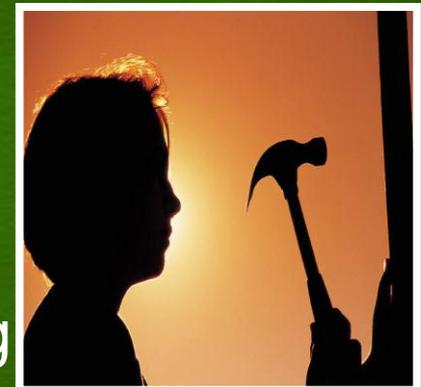
Intuitive Griever

- 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?



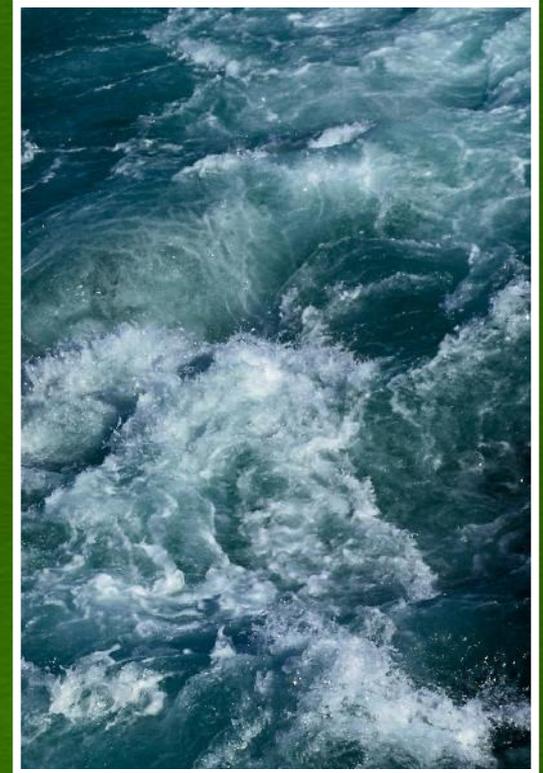
(Lev, 1989)

Nurses' Grief

Response to situations affect by:

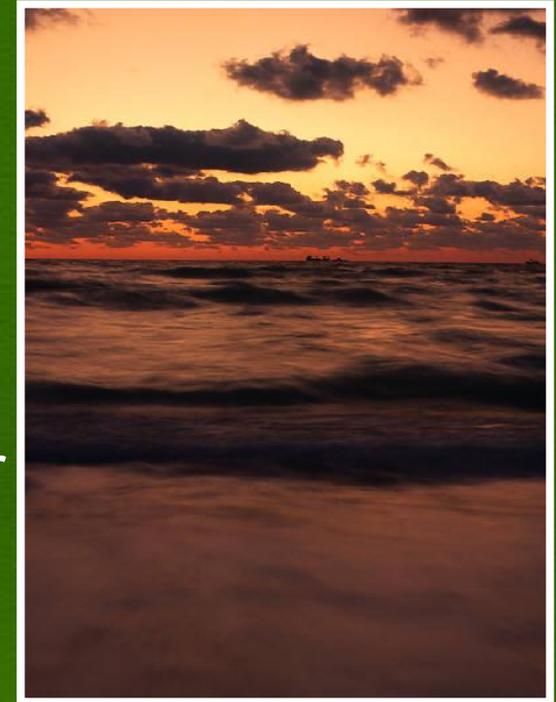
- Previous unresolved losses
- Actual or potential losses
- Feelings of guilt
 - Inability to provide care
 - Difficulty meeting family needs
 - Unable to be present at time of death

(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



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

Physical	Cognitive	Emotional	Behavioral
<ul style="list-style-type: none"> • Headaches • Dizziness • Exhaustion • Muscle aches • Sexual issues • Loss of appetite • Insomnia • Tightness, hollow • Breathlessness • Tremors • Shakes • Sensitive to noise 	<ul style="list-style-type: none"> • Depersonalization • Diff concentrating • Disbelief • Confusion • Idealization • Search meaning • Dreams • Preoccupation • Fleeting hallucinations 	<ul style="list-style-type: none"> • Anger • Guilt • Anxiety • Helplessness • Sadness • Shock • Yearning • Numbness • Self-blame • Relief 	<ul style="list-style-type: none"> • Impaired performance • Crying • Withdrawal • Avoiding reminders • Carrying reminders • Over reactivity • Relationship changes

(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



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



Education and Support

Palliative

The Karmanos Experience

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



Tell us what you know: PRE-TESTS



Windsor
Cancer
Program



EPEC-O

Retreats

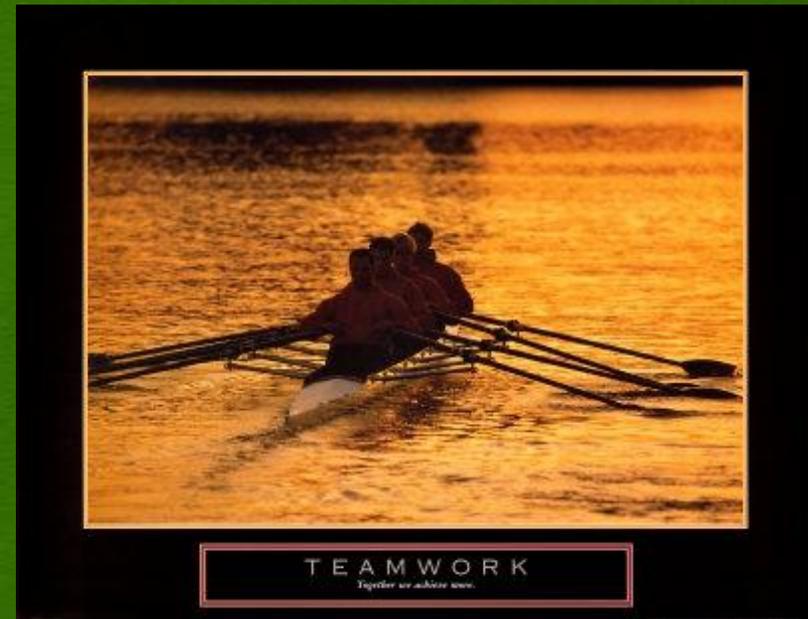
- For staff
- Structured programs with themes, outcomes and next steps
- Medland – Circle of Care

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)

Learn and Play Together



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

Staff Ceremony – Alternative Ritual



*"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,*