



**Delaware
End-of-Life Coalition**

Presents

**An Evening Program on
End-of-Life Care**



**“Supporting the
Dying and Bereaved:
New Understandings
of the Grief Experience”**

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Presenter

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Objectives

- Define commonly used terminology related to grief and bereavement
- Describe new understandings of the grief experience based on research and practice
- Distinguish among anticipatory, normal, complicated and disenfranchised grief
- Identify ethical and methodological issues in death-related research

Definitions

Grief

An individual's personal reaction to a loss; reactions vary among individuals and need to be understood in their social and cultural context.

Reactions to loss can only be interpreted within the context of those factors that surround the particular loss for the particular mourner in the particular circumstances in which the loss took place.

Rando (1993)

Grief Manifestations

- Physical
 - Sleep disturbances
 - Changes in eating patterns
 - Stomach aches
 - Breathing disturbances

Grief Manifestations

- Cognitive
 - Nightmares/dreams
 - ↓ attention span
 - Hyper/hypoactivity
 - Magical thinking



Grief Manifestations

- Behavioral
 - Regressive behaviors
 - Aggressive behaviors
 - Withdrawal/passivity
 - Drug use increase

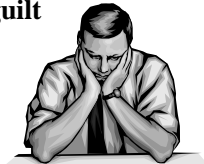


Grief Manifestations

- Behavioral (cont.)
 - Sexual promiscuity
 - Self-destructive behaviors
 - Attention getting behaviors
 - “Perfect” child or “Bad” child syndrome

Grief Manifestations

- Emotional
 - Self-blame, guilt
 - Fear
 - Anxiety
 - Numbness
 - Anger
 - Helpless/hopeless



Grief Manifestations

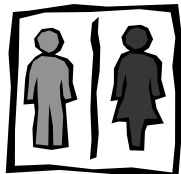
- **Spiritual**
 - Utilization of one's spiritual belief system as a supportive component of grieving
 - Abandonment of one's spiritual belief system as a supportive component of grieving

Reminder! Gender Differences

- Female
- Male



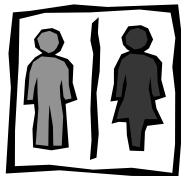
Beware of gender stereotypes.



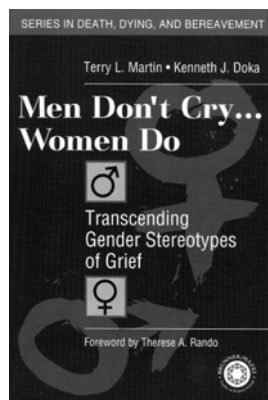
**Instrumental
Intuitive**



**Pattern of adapting to loss
is related to gender not
determined by it.**



Met slide



**Influencing Factors on Grief
Reactions/Bereavement**

- Nature of the attachment or the perceived loss felt by the bereaved
- Way in which the loss occurred; concurrent circumstances of the bereaved
- Coping strategies used for previous losses

**Influencing Factors on Grief
Reactions/Bereavement
(cont.)**

- Lifespan developmental tasks that confront the bereaved
- Social support received by the bereaved

(Corr, Nabe, & Corr, 2000, p. 218)

**Culture as an
Influencing Factor**

Cultural Differences

- **Society**

- Cultural groups
- Racial groups
- Ethnic groups
- Social groups
- Religious groups



Dilemma:

**We say each person is unique
and
then look for ways to
generalize his/her death-
related beliefs, attitudes,
responses, practices.**

Beware of stereotyping!

Listen, ask, learn

**Helpful to read about
Japanese Americans,
African Americans, etc.
BUT, there are differences
within groups and
differences among
individuals in each group.**

**Cultural Considerations in
E-O-L Care: Resources**

- **Death and Bereavement Across Cultures – *Parkes & Young (Eds)***
- **Death and Bereavement Around the World – *Morgan & Laungani (Eds)***
- **Ethnic Variations in Dying, Death and Grief – *Irish, Lundquist, & Nelsen (Eds)***

**Cultural Considerations in
E-O-L Care: Resources (cont.)**

- **Honoring Differences: Cultural Issues in the Treatment of Trauma and Loss – *Nader, Dubrow, & Stamm (Eds)***
- **Transcultural Health Care: A Culturally Competent Approach – *Purnell & Paulanka (Eds)***

Mourning

**The patterned expression
of behavior following a loss
that is determined by
religious and cultural
traditions.**

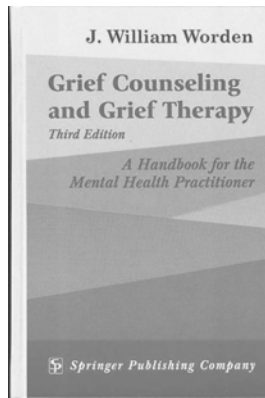
!CAUTION!

Few definitive answers

Much work to be done

Tasks of Mourning (*Worden*)

- To accept the reality of the loss
- To experience the pain of grief
- To adjust to a new environment in which the deceased is missing
- To emotionally relocate the deceased and move on with life



**Latest
Edition**

Tasks of Grief for Children

- **Understanding**
 - Accepting that the loss is real
- **Grieving**
 - Working through the feelings
 - the mourning after

(Fox, '85)

Tasks of Grief for Children

(cont.)

- **Commemorating**
 - Formal or informal acts, celebrations, rituals, remembrances that mark the loss
- **Moving on**
 - Engaging in life again; often requires permission

(Fox, '85)

Reminder!
Children are NOT
miniature adults.



Delaware End-of-Life Coalition
Death Education Task Force

Supporting Grieving Children
and Family Web Site

www.udel.edu/dsp/SGCF

*(hosted and maintained by the
University of Delaware
as a DEOLC partner)*

Kübler-Ross “Stages”

**Beware of the term
“stages.”**

Stages
Phases
Tasks

“Relearning the World”

“Meaning Reconstruction”
Robert Neimeyer

**Grieving
is
ACTIVE**

Involves choices

**What matters is not what
life does to you but rather
what you do with what life
does to you.**

Edgar Jackson

**Processes in Mourning
Rando's 6 "R" Processes**

- 1 – Recognize the loss-acknowledge and understand death.**
- 2 – React to the separation – experience the pain of the loss; feel, identify, accept, and give expression to all of the psychological reactions to the loss; and identify and mourn secondary losses.**

**Processes in Mourning
Rando's 6 "R" Processes (cont.)**

- 3 – Recollect and re-examine the deceased and the relationship – review and remember realistically; revive and re-experience one's feelings.**
- 4 – Relinquish old attachments to the deceased and the old assumptive world.**

Processes in Mourning
Rando's 6 "R" Processes (cont.)

5 – Readjust to move adaptively into the new world without forgetting the old – revise the assumptive world, develop a new relationship with the deceased, adopt new ways of being in the world, and form a new identity.

6 – Reinvest.

Rando, T. A. (1993). Treatment of Complicated Mourning.

Outcome?

Resolution X

Recovery X

Completion X

Instead . . .

**Adaptation
or
* Integration**

Disenfranchised Grief

Disenfranchised Grief

**Grief that is experienced
when a loss is not or cannot
be:**

- **Openly acknowledged**
- **Publicly mourned**
- **Socially supported**

Doka (1989). Disenfranchised Grief: Recognizing
hidden sorrow.

Disenfranchised Grief (cont.)

**Examples of Loss Not
Recognized (loss itself not
deemed socially significant)**

- **Perinatal Death**
- **Abortion**
- **Giving Up a Child for Adoption,
Foster Care**

Disenfranchised Grief (cont.)

Examples of Loss Not Recognized (loss itself not deemed socially significant)

- Surrogate Motherhood
- Separation, Divorce
- Pet Loss



Disenfranchised Grief (cont.)

Examples of Griever Not Recognized (griever not socially defined as capable of grief)

- Young Children
- Mentally Disabled
- Aged Individuals
- Incarcerated

Disenfranchised Grief (cont.)

Examples of Relationships Not Recognized (society defines “legitimate” grievers as primarily familial)

- Extramarital
- Cohabitation
- Gay/Lesbian
- Neighbor

Disenfranchised Grief (cont.)

**Examples of Relationships
Not Recognized** (society
defines “legitimate” griever
as primarily familial)

- Colleague
- Roommates (as in nursing homes)
- Teachers/School Personnel
- Healthcare providers

Disenfranchised Grief (cont.)

Additions (2002)

Circumstances of the Death

- Nature of the death
 - (suicide, AIDS)
- Death that provoke anxiety or embarrassment
 - (autoerotic asphyxiation, execution of prisoner)

Disenfranchised Grief (cont.)

Additions (2002)

Ways Individuals Grieve


- Intuitive
 - (feeling)
- Instrumental
 - (cognitive, physical, behavioral)

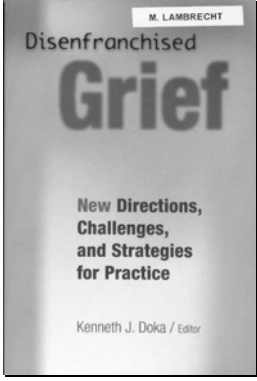
Grieving “rules”
- largely culturally prescribed -

Intuitive Grievers
(disenfranchised late)

Instrumental Grievers
(disenfranchised early)

U.S. Society
Kin-based





Latest Resource

“Normal” vs. Complicated Grief Reactions

- **Dependent on many factors**
 - Type of relationship with the deceased
 - When there is attachment, there is grieving.
 - Negative ties bind just as strongly as positive ties.

“Normal” vs. Complicated Grief Reactions (cont.)

- **Dependent on many factors**
 - **Death circumstances**
 - Personality/coping skills
 - Life circumstances
 - Concurrent stressors
 - Financial problems
 - Physical/mental status

Statistics

- **2 million plus deaths per year in U.S.**
- **Each death affecting 8-10 significant others (much greater numbers in school settings)**
- **One in three bereavements result in abnormal patterns of grief.**

*Potential exists for 5 to 6 million new cases of complicated grief per year (*Raphael, Redmond*)

Rule of Thumb:

***Can or can't manage
day-to-day living.**

**High Risk Factors for
Complicated Grieving
(Mourning)**

- Suddenness
- Violence, mutilation, destruction
- Preventability, randomness
- Multiple death
- Personal threat of death (robbery, survivor of airline crash)

**High Risk Factors for
Complicated Grieving
(Mourning) (cont.)**

- Shocking encounters of death of others (see burning bodies)
- Antecedent variables
 - difficult premorbid relationship with the deceased
 - previous or concurrent losses
- Specific types of death such as loss of a child

Reminder/Red Flag:

**Assure adequate medical care -
assess for PTSD**

**Issues Related to
Death Circumstances**

Sudden vs. Expected Death



Sudden Death:

- **No preparation**
- **No goodbye**
- **Unfinished business**

Sudden Death: Suicide

- **Overwhelms the survivors**
- **Sense of unreality**
- **Search for the Why?**
- **Sense of helplessness**
- **Feelings of rejection, abandonment**

Sudden Death: Suicide (cont.)

- **Issue of “preventability”**
- **Feelings of guilt, anger, rage**
- **Feelings of extreme vulnerability**
- **Unfinished business**

Note: This type of death may prolong the grief experience and may place the survivors at higher risk for complicated grief.

Sudden Death: Homicide

- **Feelings related to the senselessness, brutality of the act**
- **Fright related to rage at person who committed the act, sometimes desire to violently destroy this person**
- **Feelings of fear, loss of control, violation**

Sudden Death: Homicide (cont.)

- Heightened sense of personal vulnerability
- Involvement with judicial system “secondary victimization”
- Media involvement which is often personally intrusive

Sudden Death: Homicide (cont.)

- Prolonged, intense period of rumination to work it through (why?)

Note: This type of death and the involvement of the legal system (often over a period of years) places the survivors at higher risk for complicated grief.

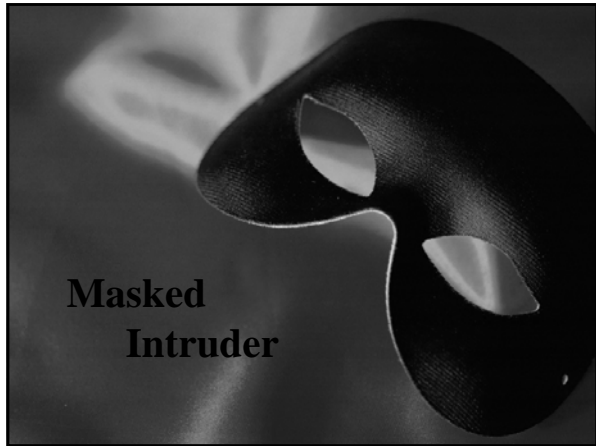
Accident

- Many of the same issues apply:
 - No goodbye
 - Range of emotions
 - Involvement of media, police, courts
 - Unfinished business

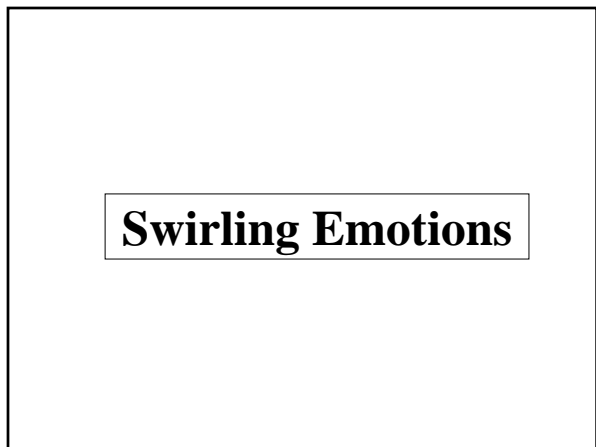
The Journey











A Roller Coaster Ride



Bereavement Support

Definition:

An approach that facilitates the accomplishment of grief work (tasks of grief) thus promoting continued integration of the loss experience.

**Clinical Perspectives
Necessary for Facilitating
Uncomplicated Mourning**

- Clinical Perspectives
Necessary for Facilitating
Uncomplicated Mourning**
- Remember that you cannot take away the pain from the bereaved.
 - Do not let your own sense of helplessness restrain you from reaching out to the bereaved.
 - Expect to have to tolerate volatile reactions from the bereaved.

- Clinical Perspectives
Necessary for Facilitating
Uncomplicated Mourning (cont.)**
- Recognize the critical therapeutic value of your presence (BEING vs. Doing).
 - Make sure to view the loss from the bereaved's unique perspective.

**Clinical Perspectives
Necessary for Facilitating
Uncomplicated Mourning (cont.)**

- Let genuine concern and caring show.
- Do not let your personal needs determine the experience for the bereaved.

**Clinical Perspectives
Necessary for Facilitating
Uncomplicated Mourning (cont.)**

- Do not attempt to explain the loss in religious or philosophical terms.
- Do not suggest that the bereaved feel better because there are other loved ones still alive.

**Clinical Perspectives
Necessary for Facilitating
Uncomplicated Mourning (cont.)**

- Do not attempt to minimize the situation.
- Do not forget to plant the seeds of hope.



**Clinical Perspectives
Necessary for Facilitating
Uncomplicated Mourning (cont.)**

- Do not encourage action or responses antithetical to health mourning.
- Maintain an appropriate therapeutic distance from the bereaved (focus on client needs).

**Clinical Perspectives
Necessary for Facilitating
Uncomplicated Mourning (cont.)**

- Do not fail to hold out the expectation that the bereaved ultimately will successfully accommodate [integrate] the loss and that the pain will subside at some point.

-Rando (1993)

**Guidelines for
Professionals Providing
Bereavement Support**

- The role of the professional is to:
 - Act independently and/or as a member of a team to facilitate grief integration
 - Provide specific bereavement counseling services

Guidelines for Professionals Providing Bereavement Support (cont.)

- **Provide referrals to self-help groups, community resources, and/or other professional services as needed**
- **Provide follow-up services**

Death-Related Research



Ethical Issues in Death-Related Research

- **Unique aspects of death-related research**
 - Sensitive issues/applied research/qualitative studies
 - Researcher qualifications
 - Are the dying or bereaved able to give informed consent?
 - Is the information presented to them in “ordinary” language?

**Ethical Issues in
Death-Related Research (cont.)**

- **Unique aspects of death-related research (cont.)**
 - What are the risks/harms as a consequence of participation?
 - Not unusual for bereaved to show emotions during an interview
 - Just because no contact was made by the individual after participation, one should not assume no ill effects ensued

**Ethical Issues in
Death-Related Research (cont.)**

- **Unique aspects of death-related research (cont.)**
 - **Must address boundaries between research and counseling**

Excerpts from "A Checklist of Ethical Criteria that Bereavement Should Meet" (Parkes, 1995)

**Excerpts from "A Checklist of Ethical
Criteria that Bereavement Research
Should Meet" (Parkes 1995)**

- IV. The individual who is to interview bereaved people for purposes of research has received sufficient training in counseling to ensure that he or she will do no harm. The interviewer will receive regular supervision of his or her work from someone with advanced-level training and experience in counseling the bereaved.**

**Excerpts from “A Checklist of Ethical
Criteria that Bereavement Research
Should Meet” (Parkes 1995)**

(cont.)

VI. When a respondent becomes distressed, the interviewer will be guided by the respondent and by his or her own understanding in deciding whether to interrupt the interview. If tape recorders or video cameras are used, the respondent will be reminded that they will be turned off on request.

**Excerpts from “A Checklist of Ethical
Criteria that Bereavement Research
Should Meet” (Parkes 1995)**

(cont.)

VIII. Apart from giving emotional support, the interviewer will confine him or herself to the research, and will not proselytize, advertise, or advocate particular treatments. . .



**Excerpts from “A Checklist of Ethical
Criteria that Bereavement Research
Should Meet” (Parkes 1995)**

(cont.)

VIII. . . . On the other hand, when help seems needed, the interviewers should be able to point the bereaved person to possible sources of impartial assessment and advice.

Colin, M. P. (1995). Guidelines for conducting ethical bereavement research. *Death Studies*, 19(2), 171-181.

Methodological Concerns in Death-Related Research

- Small sample size
- Nature of the independent variable not clearly defined (death anxiety, death fear, etc.)
- Lack of random assignment

Methodological Concerns in Death-Related Research (cont.)

- Instrumentation problems
- Validity, reliability
- Misnamed
- Timing, few longitudinal studies

How Are Research Instruments Developed?

- Most constructed using rational methods of instrument construction
 - Reliance on “expert panels” to select items (validity by assumption, Guildford, 1954)
 - This procedure negatively effects tool validity

How Are Research Instruments Developed? (cont.)

- **Better to develop instruments using empirical methodology**
 - “experts” are those who have experienced the phenomenon

Hogan, Greenfield, & Schmidt 2000)
article describes the - *Hogan Grief Reaction Checklist* -developed empirically from data collected from bereaved adults who experienced the death of a loved one.

Objectives

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