Normative and Prolonged Grief Disorder: Proven and Effective Interventions to Help Your Clients Process Grief and Loss

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One	Define and differentiate both normative and prolonged grief
Two	Identify and work effectively with individuals who experience disenfranchised losses
Three	Describe how stage models of the grieving process are outdated and learn new theories of the grieving process
Four	Discuss and describe how bereavement is addressed in the DSM-V-TR/ICD
Five	Use a case study to learn how to make differential diagnoses to ensure the use of appropriate interventions
Six	Learn multiple, creative, and proven techniques to support bereaved clients

Objectives

Outline

I. Definitions
    a. Normative
    b. Prolonged grief

II. Risk factors for prolonged grief disorder

III. Disenfranchised grief

15-minute break

IV. Grief theories
    a. Older theories
    b. Modern theories
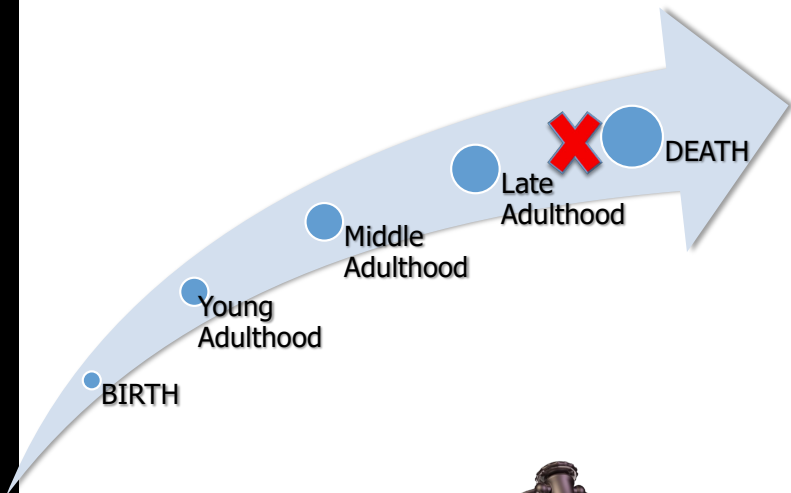
V. Cultural and spiritual considerations

60 Minute Break for Lunch

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Outline

VI. DSM-V-TR/ICD and differential diagnoses

VII. Assessment – Gathering information
        * Case Study

15-minute break

VIII. Treatment planning for uncomplicated bereavement

IX. Interventions
        * Interactive activity

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BIRTH

Young
Adulthood

Middle
Adulthood

Late
Adulthood

DEATH

BUNGEE

SKYDIVING

MY BUCKET LIST

What is "grievable?"
What is a Loss?

We experience a sense of loss when someone or something, very dear to us, has been taken from our lives. This loss leaves a sense of emptiness and deprivation.

Loss is an experience of our own human condition. And…we experience different types of losses throughout our lives.

What are some examples of non-death related losses?

Normative Grief

Grief: Isn't it Always Complicated?

- Yes, but not in the clinical sense!

- Reduction of grief reactions, separation distress, and intensity over time, with allowances for exacerbation (sudden transitory upsurge of grief - STUG) and *non-linear grieving processes*

- Growing acceptance of reality of the death/loss and its implications. Gradual adaption and integration to new life without deceased

- Continued bond with deceased – a different relationship (if culturally appropriate)

- Life goals redefined

- Gradual return and reinvestment of new interests, activities, relationships, etc.

- "If only" thoughts diminish

- Meaning reconstruction/post-traumatic growth

(Harris & Winokuer, 2016; Jamison, 2009; Neimeyer, 2016; Neimeyer, et al., 2019; Rando, 1993; Shear, et al. 2011; Worden, 2018)

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Normative Grief

Acute Grief

- Shortly after loss
- Intense yearning, longing, sorrow
- All-encompassing, painful emotional, physical, cognitive, spiritual, and interpersonal reactions
- Natural adaptive reaction
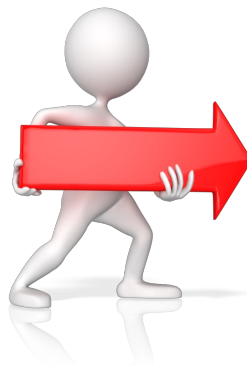
Integrated Grief

- Lasting form of grief
- Feelings and behaviors are integrated into a "new" normal
- Reality of loss is accepted
- Bittersweet memories
- Grief does not dominate
- New interests

(Doka & Tucci, 2017; Simon, et al., 2011) 9

7 Domains of Grief Responses

- Psychological
- Physical
- Emotional
- Cognitive
- Behavioral
- Interpersonal
- Spiritual

Grief Responses

Prolonged Grief Disorder

When Grief Goes Awry

Acute Grief

- Shortly after loss
- Intense yearning, longing, sorrow
- All-encompassing, painful emotional, physical, cognitive, spiritual, and interpersonal reactions
- Natural adaptive reaction

Prolonged Grief Disorder
- Persistent form of intense grief
- Maladaptive thoughts
- Dysfunctional behaviors
- Acute grief does not end

Integrated Grief

- Lasting form of grief
- Feelings and behaviors are integrated into a "new" normal
- Reality of loss is accepted
- Bittersweet memories
- Grief does not dominate

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(Doka & Tucci, 2017; Simon, et al., 2011)

The Missing Piece - PGD

Characterized by severe separation distress, dysfunctional thoughts, feelings or behaviors related to the loss that complicate the grieving process and prevent the griever from adapting to the loss, not acknowledging the reality of the loss, not reconnecting with others, and not moving forward with aspirational goals.

Not a form of depression – it is more trauma based

Pathological and unique enough to have its own diagnostic disorder (PGD)

Psychobiological dysfunction of the brain, reduced heart rate, impaired autobiographical memory, and problem-solving

(Horwitz, et al., 2009; Shear et al., 2011; Zisook et al.,

Prolonged Grief and DERAILERS (Shear)

- **D**ifficulty letting go of doubts that you did enough for person who died
- **E**mbracing ideas about grief that make you want to change or control it
- **R**uminating about ways that the death was unfair or wrong
- **A**nger and bitterness you can't resolve or let go of

- "**I**f only" thoughts about imagined alternative scenarios
- **L**ack of faith in the possibility of a promising future
- **E**xcessive efforts to avoid grief and/or reminders of the loss
- **R**esistance to letting others help, feeling hurt and alone
- **S**urvivor guilt; it feels wrong or uncomfortable to be happy or satisfied

(Shear, 2020)

These are *normal* responses to loss, especially at the beginning of the grieving process. But if unrelenting, *could* lead to prolonged grief.

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Risk Factors

I. Personal psychological vulnerability
a. Pre-loss or co-morbid psychological disorders
b. Extreme separation distress
c. Non-integrated previous losses
d. Low self-esteem
e. Worry/anxiety
f. High negative cognitions
g. Poor coping skills
h. Trauma history
i. Tendency to avoid
j. Intolerance of uncertainty
k. High emotionality
l. Women more than men

(Tofthagen, et al., 2017)

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Risk Factors

II. Circumstances of death
   a. Untimely
   b. Unexpected
   c. Violent/traumatic
   d. Feels preventable
   e. Stigmatized
   f. Drug overdose

III. Context in which the death occurs
   a. Low social support/ problematic
   b. Disenfranchisement
   c. Concurrent stressors
   d. Multiple losses

(Neimeyer, 2024; Tofthagen, et al., 2017)

Risk Factors

IV. Relationship dynamics
   a. Dependent relationship
   b. Loss of child/spouse
   c. Insecure attachment style

(Tofthagen, et al., 2017)

Disenfranchised Grief

When a bereaved individual or group of individuals are denied the right to grieve, the social support essential to integrating loss, and deprived of the social validation in order to heal

(Doka, 2002)

1 **Significance of relationship is rejected, minimized, or not recognized**

2 **Loss is not recognized because it is non-human, abstract, or inanimate**

3 **Griever is not recognized as being capable of forming significant relationships or recognizing the loss (griever is excluded)**

4 **Circumstance of death or loss is stigmatized**

5 **Grieving style is unacceptable**

(Attig, 2004; Doka, 2002)

Theories of Grief

Stage Models

I. Bowlby and Parkes' (1970)
   4 stage model
   A. Shock-numbness
   B. Yearning-searching
   C. Disorganization
   D. Reorganization

Kübler-Ross' Stage Model of *Dying*

II. Elisabeth Kübler-Ross' (1969) five stage model
   A.   Denial
   B.   Anger
   C.   Bargaining
   D.   Depression
   E.   Acceptance
   F.   (Meaning Making) – new stage added by David Kessler (2020)

Stage Model Criticisms

- People do not move through stages in a fixed, linear progression. They are useful in describing *some* of commonly found reactions

- Little room for individual, family, religious, societal, cultural, and contextual factors (e.g., not everyone experiences anger/bargaining)

- Cannot apply theory of dying (Kubler-Ross) of terminal illness to theory of grieving process. This theory of dying process has now been discredited as well

- May unintentionally imply a fixed process that the individual should be at a particular place on a continuum despite intervening variables. Actually, the "stages" are more like defense mechanisms/responses and even those are simplistic

- Lack of empirical support, absence of clear research concepts, and not culturally sensitive. 200 interviews of terminally ill middle-aged people

(Corr, 2021; Friedman & James, 2008;Kelley, 2010: Metzger, 1979; Schultz & Adermna, 1974)

"The attempt to expand this model [Kubler-Ross'] to what experts have learned is unjustified, potentially dangerous, and contrary to what experts have learned about loss, grief, and bereavement during the past 30 to 40 years…attempts to employ the five stages of grief (whatever they are thought to mean) in either education or practice should be promptly abandoned and never resuscitated."

~ Charles Corr

Phase Theories

- Models are more pliable than stage models

- Allows for symptoms of one phase to overlap the symptoms of the next—or even regress to a previous phase

- Bowlby and Parkes' model is sometimes put into this category because it is a more flexible stage model

Sanders' Phase Model

- Sanders' five-phase model states phases can co-exist, with one or more being more intense than others at different times
- Each phase has psychological, cognitive, and physical symptoms
- Recognizes individual nature of grief
- Individuals have choices in grief. Not just passive coping with little control

(Doka, 2005-2006; Sanders, 1999)
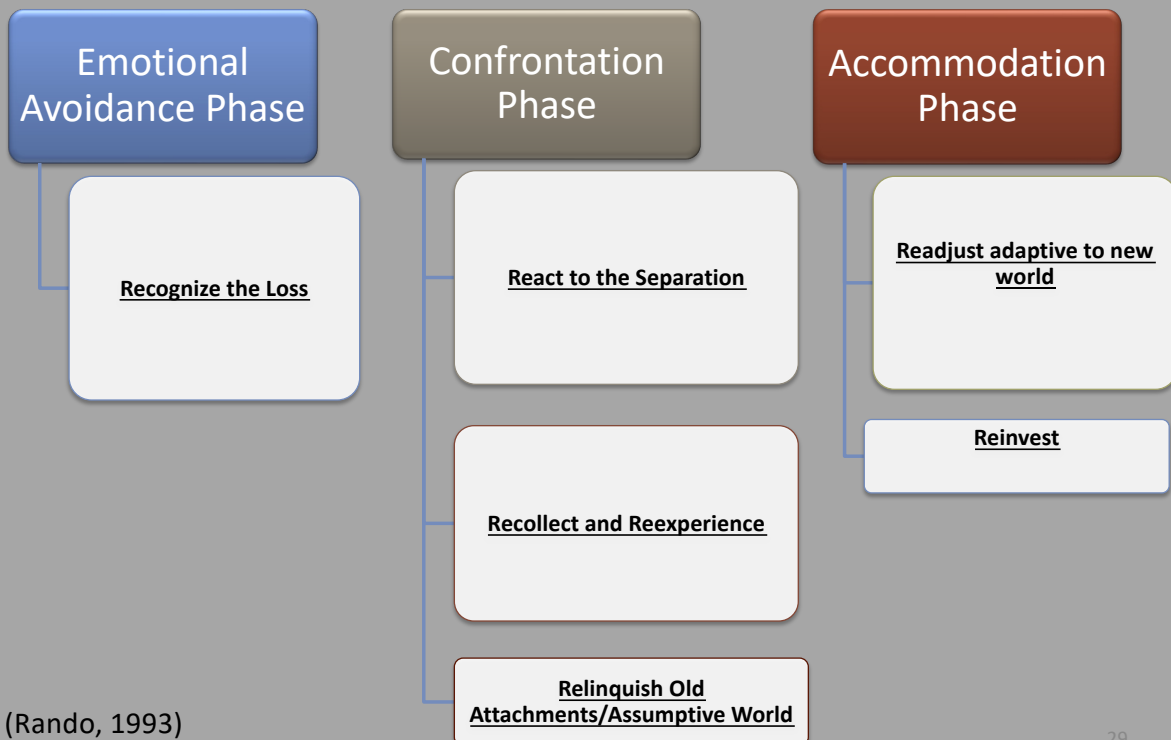
Sanders' Phase Model

1. Shock
2. Awareness of the loss
3. Conservation-withdraw
4. Healing – The Turning In Point
5. Renewal

** Sanders was developing a sixth phase called Fulfillment, but she died before her work was finished. Doka (2006) published her work for her. **

6. Fulfillment

(Doka, 2005-2006; Sanders, 1999)

Rando's Six R's of Mourning

Emotional Avoidance Phase

- Recognize the Loss

Confrontation Phase

- React to the Separation
- Recollect and Reexperience
- Relinquish Old Attachments/Assumptive World

Accommodation Phase

- Readjust adaptive to new world
- Reinvest

(Rando, 1993)

Worden's Task Model

Worden's (2018) Tasks of Mourning approach

  A. States stages and phases implies mourner *passes through* grieving

  B. Completing tasks refers to the concept of the mourner can *actively* do something about his/her process

  C. Tasks do not need to be accomplished in a particular order, but within definitions of each, some ordering is suggested

(Worden, 2018)

Worden's Task Model

1. Accept the reality of the loss

2. Work through the pain of grief

3. Adjust to an environment in which the deceased is gone
      I. Three types of adjustments
          a.   External – everyday functioning
          b.   Internal – sense of self
          c.   Spiritual - sense of world, values, and fundamental beliefs, meaning making, existential issues

4. Relocate the dead person, relationship, etc. within one's life and find ways to memorialize the person

"To find a way to remember the deceased in the midst of embarking on the rest of one's journey through life" (Worden, 2018, p.51)

(Worden, 2018)

Neimeyer's Meaning Reconstruction Model

- Constructivist, narrative approach model that is an active process of meaning reconstruction
- Loss assaults assumptive world:
  1. In day-to-day functioning
  2. Values and priorities
  3. Identity
  4. Social and interpersonal relationships
  5. Spiritual, religious, or philosophical views
- Holds that loss disrupts self-narratives and sets individual into a quest for meaning making

(Neimeyer, 2001; 2016)

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Neimeyer's Meaning Reconstruction Model

Three activities to reconstruct meaning

1. Sense making – Comprehending the loss; find benign explanation (e.g., spiritual reason)
2. Benefit finding – "Silver lining" (e.g., increased empathy)
3. Identity change – Reconstruct self, especially when response to loss is adaptive

(Neimeyer, 2001; 2016)

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Neimeyer's Meaning Reconstruction Model

- Identity seen as successful narrative achievement established through stories we tell ourselves and others ("live in stories, not statistics") where meaning is woven in

- Author our own stories - reflect, interpret, and reinterpret what happened

- Emphasizes idiosyncratic nature in each griever's reactions – each person writes his/her own story

- Therapist comes from place of "not knowing"

(Gillies & Neimeyer, 2006)

"Perhaps the most important contribution to the current conceptualization of grief reactions is the recognition of the uniqueness of the grieving process to each individual and family. The empirical literature has not supported the concept of linear stages or phases in mourning. Bereaved individuals often experience contrasting emotions at the same time and oscillate between them. Instead of focusing on ensuring individuals are grieving the *correct* way, the emphasis now is on recognizing the multiple variables that affect the grieving process, as well as the particular individual style of expressing grief. Thus the main goal of grief and bereavement care is to support the individual's unique and personal grieving process without a preconceived notion of how that process should present or develop."
~ Strada, 2016

Cross-Cultural Bereavement

- Have prescribed norms of what is considered an appropriate emotional expression to loss and expectations of behavior during/after loss

- Mourning rituals, traditions, and taboos culturally prescribed

- Contingent upon gender roles, religious beliefs, nature of the relationship, nature of the death

- Behavior exhibited varies considerably from culture to culture…and even sub-cultures within a predominant culture.

Cross-Cultural Bereavement

- Influences what is considered appropriate support and interventions

- Affects how deceased is thought of (e.g., to be beneficial to the bereaved or not to be spoken of)

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Grief Within Cultural Framework

- Expression and continue bonds regulated (policing)

- Subtly or overtly

- Tied to gender roles

- Differences in loss-orientation and restoration-oriented coping (e.g., Chinese lean towards restoration)

- Expression norms on a continuum, influenced by if death is a community event (e.g., India) vs. those that are more private (e.g., Britain)

(Klass & Chow, 2011; Laungani & Young, 1997)

Grief Within Cultural Framework

- Handling of body, laying out body, transportation to cemetery/crematorium, arrangement for funeral services, if body can/cannot be cremated, who performs which rituals - all related to norms and practices

- How openly death, dying, and grief is discussed is culturally bound

- Prescribes what constitutes death. Dichotomous event? Gradations?

- How long death is "spread out." How long person remains earthbound. where they can be "found" (e.g., nowhere, shrine, cemetery, etc.)

- Secondary rituals helps mark steps in responsibilities in grief (e.g., end of obligation to mourn and move forward)

(Laungani & Young, 1997; Parkes, 1997)

Clinical Considerations

- No absolute guidelines for specific cultures.

- Westerners often apply their norms, customs, etc. as being "normal." Give as much acceptance to other cultures as we do ours

- Length, rules, and expectations of mourning varies by culture.

- Theories, resolution of grief, and techniques culturally bound

- Events and loss have universal components, but responses and what are considered symptoms are expressed within the specific culture context that may or may not fit clinician's expected symptoms

- What is considered "help" is different cross-culturally

- Client may defer to clinician's definition of abnormal grief and acquiesce (clinician as police)

- Attend to judgments about grief responses in one's own family and communities. Cultural self-awareness necessary

- Attend to restoration or loss orientation differences

(Klass & Chow, in Neimeyer et al., 2011; Parkes, 1997; Stamm, et al., 2004)

Religion and Spirituality

Religion and Spirituality: Definitions

Religion

- "An institutionalized pattern of beliefs, behaviors, and experiences, oriented toward spiritual concerns and shared by a community and transmitted over time in traditions" (Canda & Furman, 1999, p. 73)

Spirituality

- "An innate human need to find meaning and purpose in life and to have a relationship with something outside of, and larger than, oneself" (Moremen, 2005, p. 310)

- To seek an answer to the question, "How can you make sense out of a world which does not seem to be intrinsically reasonable?"

- How one's soul experiences connection with that which is greater than oneself

(Burke & Neimeyer, 2014; Canda & Furman, 1999; Chapple, et al., 2011; Currier, et al., 2013; Kelley & Chan, 2012; Krieglstein, 2006; Moremen, 2005; Wortman & Park, 2008)   43

Spirituality of Grieving

- Bereavement can be catalyst for spiritual growth - creates imbalances that must be addressed

- Forced to engage in efforts to create meaning to reintegrate and find balance. Leads to personal transformation

- Spiritual needs can fluctuate throughout the mourning process

- Affected by one's individual development and cultural modes of expression

- Can give hope, comfort, strength, inner resources, and support

Religion, Spirituality, and Grief

- "Global conceptualizations of religion do not adequately capture the complete nature of religion in people's lives" (Wortman & Park, 2008, p. 703)
- Provides perspectives on death
- Loss may lead to fundamental shifts in belief systems – with changed, increased, or deceased faith
- Provides framework and coping resources (e.g., clergy, community, rites and rituals, prayers, behaviors, ceremonies, structure)
- Resource for understanding/coping with loss
- May support meaning making
- Religious coping, private religious practices, and organizational religious activity is factored into post-traumatic growth (PTG)
- Grief can deepen spiritual beliefs and enhance PTG, most especially with violent loss survivors
- Can help reframe loss; be a form of solace; help interpret events differently
- Engaging with beliefs and spiritual leaders can support this process
- May provide comfort and guidance regarding existence beyond physical existence
- Secure attachment to one's Higher Power (one who is consistently available and responsive) predicts positive religious coping, meaning making, stress-related growth, and reduces depression and anxiety (belief in benevolent Higher Power)

(Burke & Neimeyer, 2014; Chapple, et al., 2011; Currier, et al., 2013; Kelley & Chan, 2012; Wortman & Park, 2008)

Clinical Considerations

- Explore how clients draw on beliefs and spiritual convictions to navigate grieving process. Be a companion in exploration, not offer definitive answers

- Deal with difficult topics courageously and honestly. Do not shy away

- Explore and reinforce those beliefs, remembering they are a source of strength

- Be aware and attend to the spiritual crisis that may occur as a result of the loss

- Be open to exploring the various ways that religious beliefs encourage guidance in finding meaning in suffering; support hope and compassion

- Welcome client to share post-death encounters (i.e., extraordinary experiences)

- Be willing to hear experiences and beliefs foreign to you

- Become more familiar with religious and spiritual traditions

- "Develop the necessary comfort and skill to deal with client's spiritual concerns in ways most helpful to the client" (Tedeschi & Calhoun, 2006, p. 111)

- Remember religious beliefs may not always be helpful, and may lead to self-blame and other painful feelings and experiences

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(Burke & Neimeyer, 2014; Chapple, et al., 2011; Currier, et al., 2013; Tedeschi & Calhoun, 2006)

Enjoy Your Lunch!

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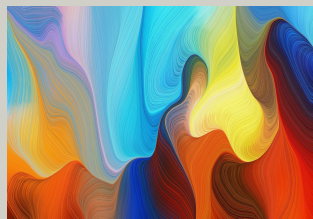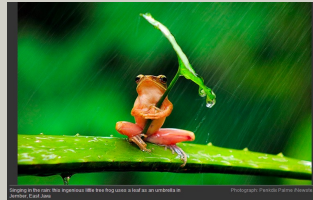
DSM/ICD and Differential Diagnoses

Adjustment Disorders

Criterion A	• Development of emotional or behavioral symptoms in response to an identifiable stressor(s) occurring within 3 months of the onset of the stressor(s)
Criterion B	• Causes significant impairments in social, occupational, or other important areas of functioning
Criterion C	• Does not meet criteria for another disorder or exacerbation of current disorder
Criterion D	• Does not represent normal bereavement
Criterion E	• Once stressor or consequences have terminated, symptoms do not persist for more than an additional 6 months

Criteria for Prolonged Grief Disorder

Criterion A	• The death, at least 12 months ago, of a person who was close to the bereaved individual (for children and adolescents, at least 6 months ago).
Criterion B Since the death, the development of a persistent grief response characterized by one or both of the following symptoms, which have been present most days to a clinically significant degree. In addition, the symptom(s) have occurred nearly every day for at least the last month:	• Intense yearning/longing for the deceased person • Preoccupation with thoughts or memories of the deceased person (in children and adolescents, preoccupation may focus on circumstances of the death)
Criterion C Since the death, at least 3 of the following symptoms have been present most days to a clinically significant degree. In addition, the symptoms have occurred nearly every day for at least the last month:	• Identity disruption (e.g., feeling as though part of oneself has died) since the death • Marked sense of disbelief about the death • Avoidance of reminders that the person is dead (in children and adolescents, may be characterized by efforts to avoid reminders)

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(APA, 2022)

Criteria for Prolonged Grief Disorder

Criterion C (Cont'd)	• Intense emotional pain (e.g., anger, bitterness, sorrow) related to the death • Difficulty reintegrating into one's relationships and activities after the death (e.g., problems engaging with friends, pursing interests, or planning for the future) • Emotional numbness (absence or marked reduction of emotional experience as a result of the death) • Feeling that life is meaningless as a result of the death • Intense loneliness as a result of the death
Criterion D	• The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning
Criterion E	• The duration and severity of the bereavement reaction clearly exceeds expected social, cultural or religious norms for the individual's culture and context

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(APA, 2022)

Criteria for Prolonged Grief Disorder

Criterion F	• The symptoms are not better explained by a major depressive disorder, posttraumatic stress disorder, or another mental disorder, or attributable to the physiological effects of a substance (e.g., medication, alcohol) or another medical condition

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(APA, 2022)

Prolonged Grief Disorder in ICD-11

Follows death of partner, parent, child, or other person close to the deceased

At least one if the following	• Persistent and pervasive longing for the deceased • Persistent and pervasive preoccupation with the deceased
Accompanied by intense emotional pain	• Examples include sadness, guilt, anger, denial, blame • Difficulty accepting death • Feeling one has lost part of one's self • Inability to experience positive mood • Difficulty engaging with social or other activities
Time and Impairment	• More than 6 months following loss • Clearly exceeding expected cultural, social, or religious norms • Significant impairment in personal, family, occupational, and other important areas of functioning

DSM-V-TR/ICD-10-CM

On October 1, 2024, EHR systems changed DSM-V-TR codes to match ICD-10-CM codes.

So, how does this impact mental health diagnosing?

The Z code of 63.4 is no longer the name used for uncomplicated bereavement in the EHR because in the ICD-10-CM, the Z Code 63.4 is for disappearance and death of a family member. *However*, it is listed as such:

Disappearance and death of family member

• Assumed death of family member

• Bereavement

Therefore, continue to use this code for uncomplicated bereavement. NO OTHER Z CODE FITS!

Bereavement vs. MDD

Characteristic	Bereavement	Major depressive episode
Pattern	Waves or pangs of grief associated with thoughts or reminders of the deceased that are likely to spread further apart over time	Negative emotions experienced continually over time
Predominant affect	Emptiness and loss accompanied by occasional pleasant emotions	Pervasive depressed mood and the inability to anticipate happiness or pleasure
Self-esteem	Typically preserved, but if self-derogatory thoughts are present they usually involve perceived failings in relationship to the deceased (e.g., not visiting the deceased more often, failing to communicate their love enough to the deceased)	Critical toward self, feelings of worthlessness, and self-loathing
Sociability	Maintains connections with family and friends who have ability to console	Withdraws from others physically and emotionally and has difficulty being consoled
Thoughts	Preoccupation with thoughts and memories of the deceased; tends to be hopeful	Self-critical or pessimistic thoughts; tends to be hopeless
Thoughts of death or suicide	Thoughts of death and dying focused on the deceased and perhaps reuniting with the deceased	Explicit suicidal thoughts related to feelings of worthlessness, a belief that one is undeserving of life, or a sense that one is no longer able to cope with the pain of depression
Triggers	Depressed mood triggered by thoughts or reminders of the deceased	Depressed mood not tied to specific thoughts or preoccupations

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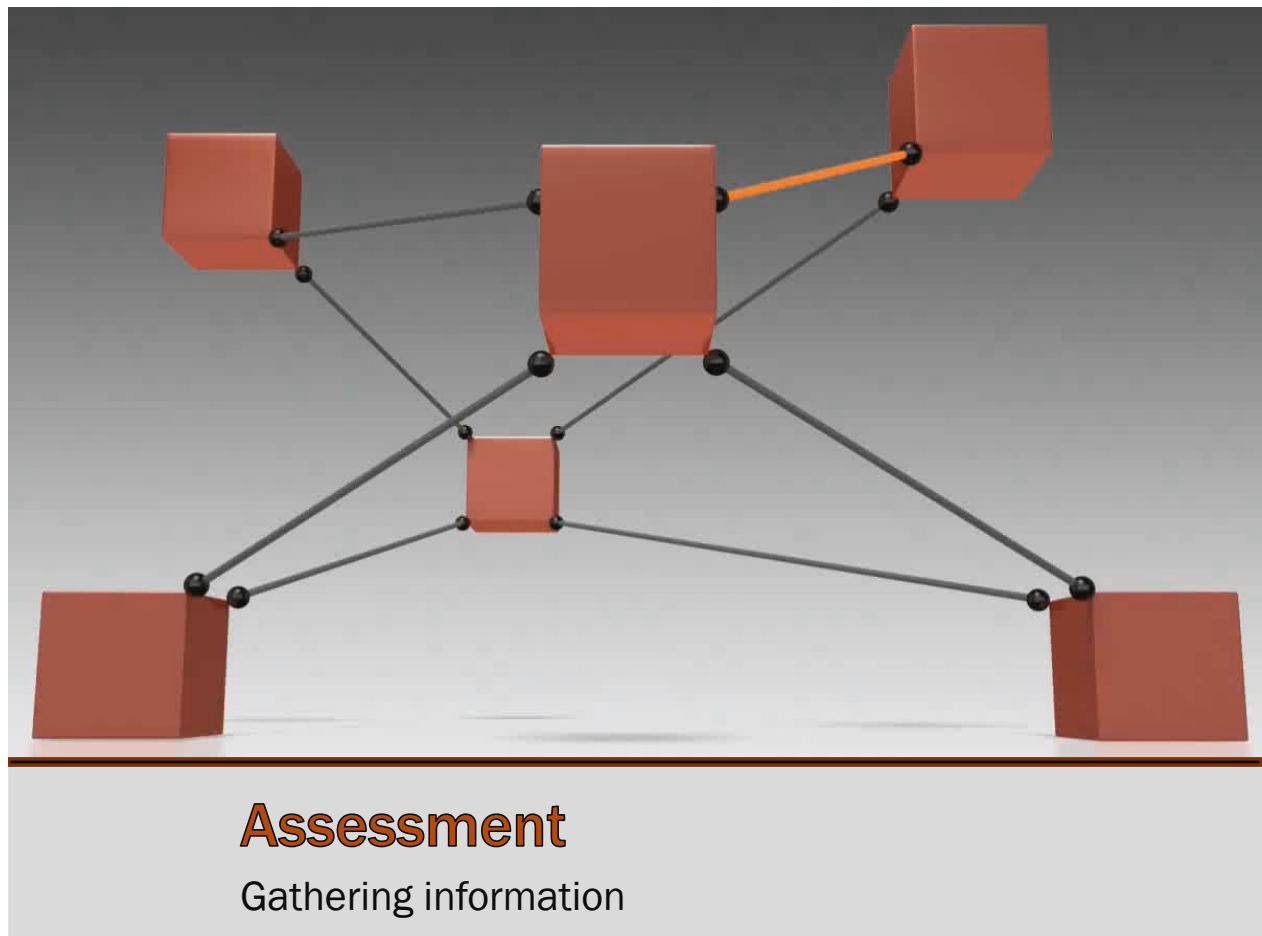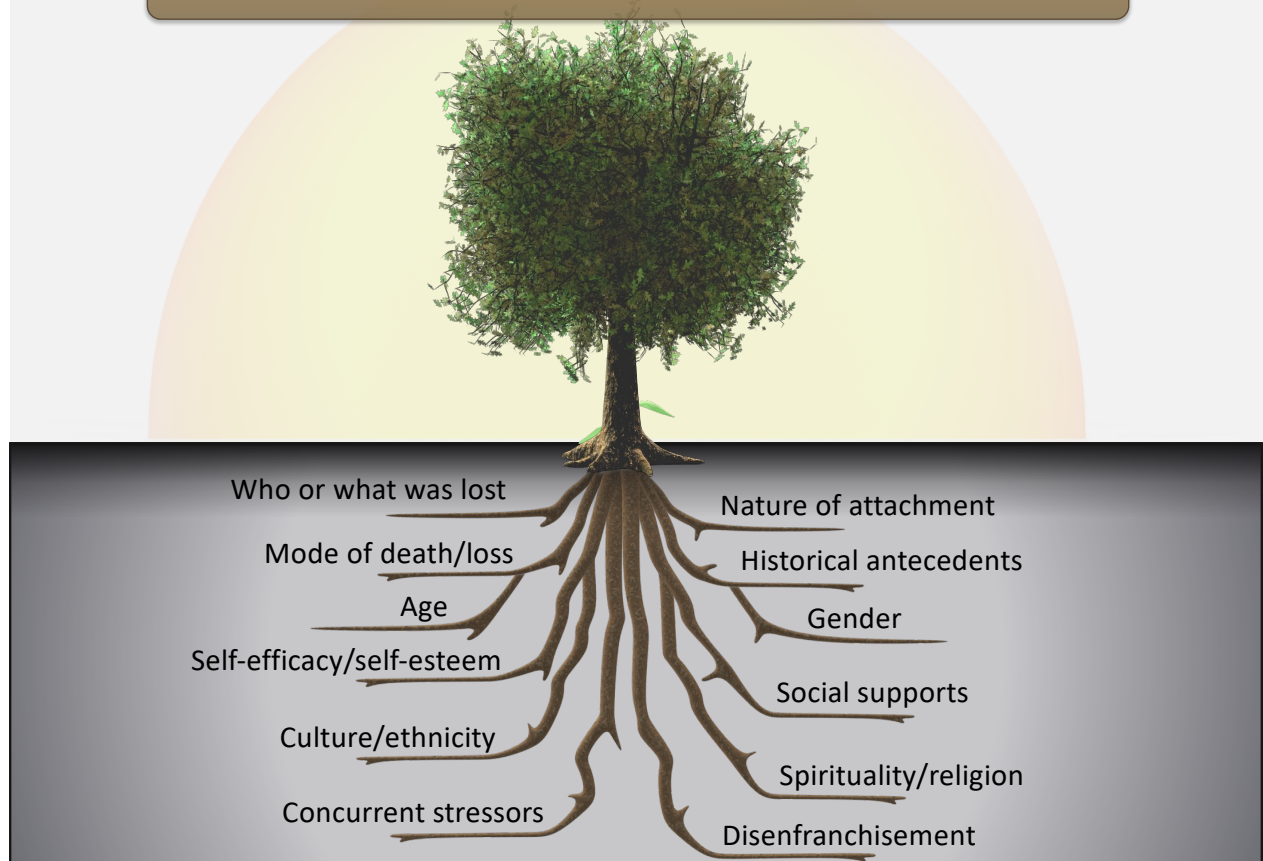
(Kavan, 2014)

What Does the "Note" Say?

- In distinguishing grief from a major depressive episode (MDE), it is useful to consider that in grief the predominant affect is feelings of emptiness and loss, while in a MDE it is persistent depressed mood and the inability to anticipate happiness or pleasure. The dysphoria in grief is likely to decrease in intensity over days to weeks and occurs in waves, the so-called pangs of grief. These waves tend to be associated with thoughts or reminders of the deceased. The depressed mood of a MDE is more persistent and not tied to specific thoughts or preoccupations. The pain of grief may be accompanied by positive emotions and humor that are uncharacteristic of the pervasive unhappiness and misery characteristic of a MDE. The thought content associated with grief generally features a preoccupation with thoughts and memories of the deceased rather than the self-critical or pessimistic ruminations seen in a MDE. In grief, self-esteem is generally preserved, whereas in a MDE feelings of worthlessness and self-loathing are common. If self-derogatory ideation is present in grief, it typically involved perceived failings via-a-via the deceased (e.g., not visiting frequently enough, not telling the deceased how much he or she was loved). If a bereaved individual thinks about death and dying, such thoughts are generally focused on the deceased and possibly about "joining" the deceased, whereas in a MDE such thoughts are focused on ending one's own life because of feeling worthless, undeserving of life, or unable to cope with the pain of depression. (APA, 2022, p.142)
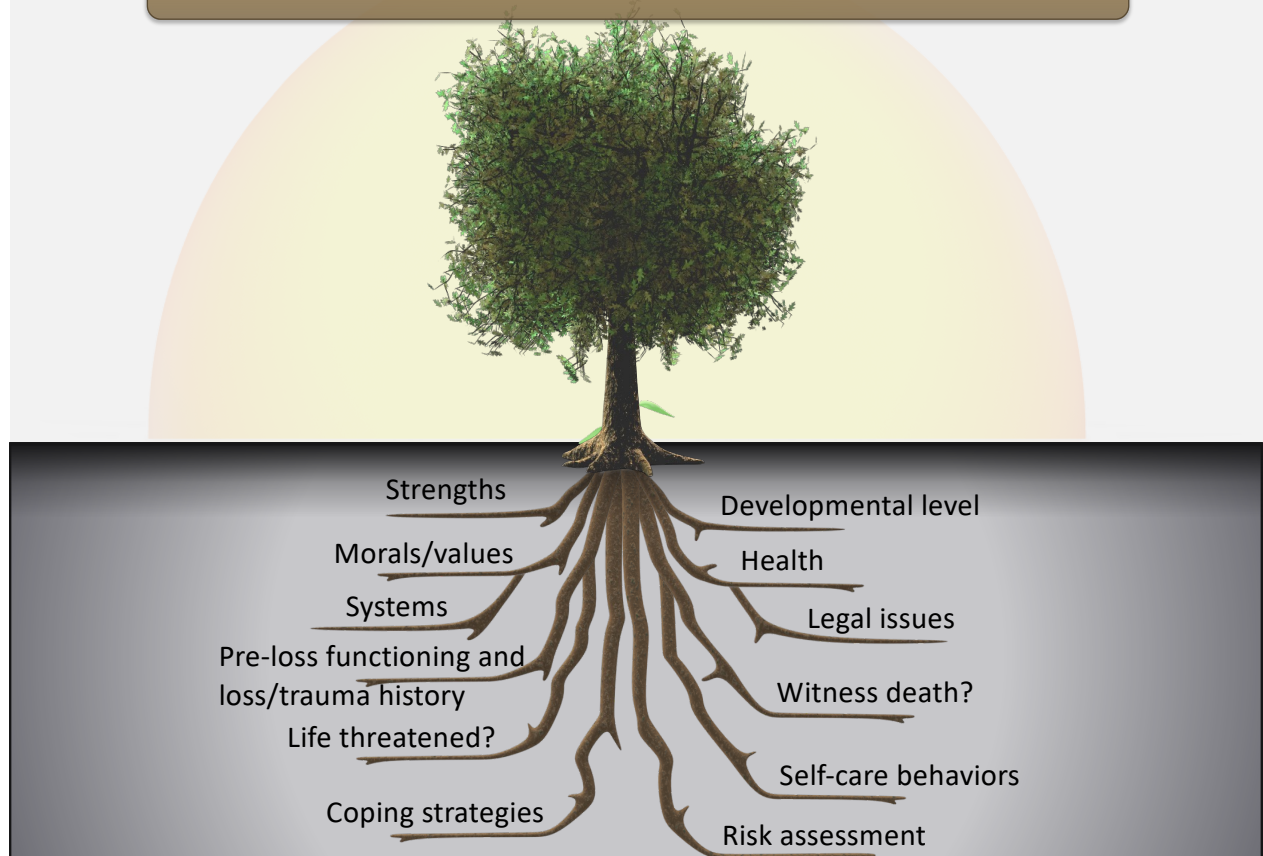
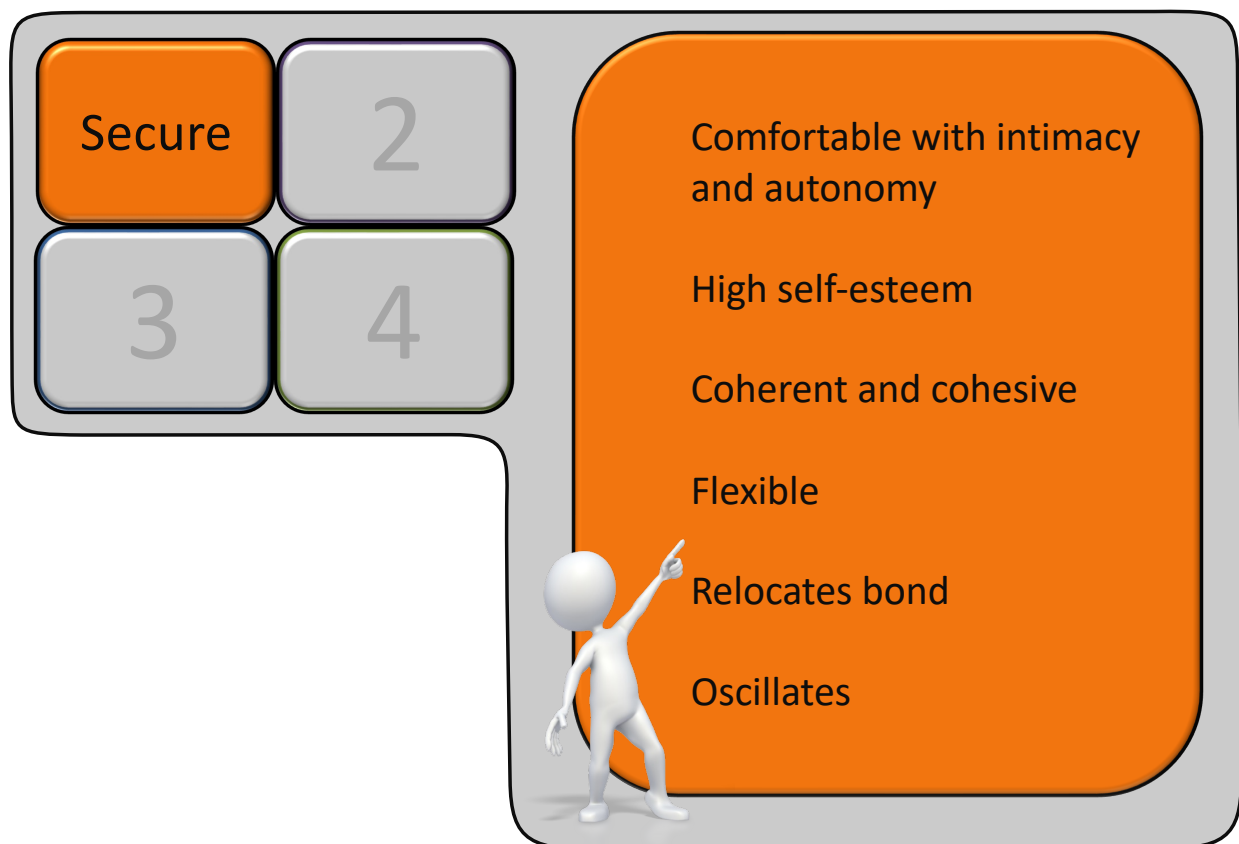| Differential Diagnosis of prolonged grief disorder, major depressive disorder, and post-traumatic stress disorder			
Characteristic	**Prolonged Grief Disorder**	**Major Depressive Disorder**	**Post-Traumatic Stress Disorder**
Affective Symptoms			
Depressed mood	Prominent; focused on loss; diagnostic criterion	Prominent; diagnostic criterion	May be present
Disbelief about death	Prominent; focused on loss; diagnostic criterion	Not usually present	May be present
Anhedonia	Not usually present	Prominent and pervasive; diagnostic criterion	Prominent and pervasive; diagnostic criterion
Anxiety	May be present; focused on separation anxiety	May be present	Prominent and pervasive; diagnostic criterion; focused on fear of recurrent danger
Yearning and Longing	Prominent and pervasive; diagnostic criterion	Not usually present	Not usually present
Guilt	Common; diagnostic criterion; related to regrets with deceased	Usually present; related to feelings of being undeserving and worthless	Prominent and pervasive; diagnostic criterion; usually focused on event or aftermath
Cognitive and Behavioral Symptoms			
Difficulty concentrating	Not usually present	Common; diagnostic criterion	Common; diagnostic criterion
Preoccupying thoughts	Common; Focused on thoughts and memories of the deceased; diagnostic criterion	May be present, focused on negative thoughts about self, other, the world	Negative, exaggerated, distorted thoughts related to the event; diagnostic criterion
Recurrent preoccupying images or thoughts	Common; focused on thoughts/memories of deceased; diagnostic criterion	May be present	Common; focused on event; associated with fear; diagnostic criterion
Avoidance of reminders of loss	Common; focused on reminders of the finality if the death; diagnostic criterion	May be present, but usually focused on social withdrawal	Common; focused on loss of safety or reminders of the event; diagnostic criterion
Loss of meaningful life	May feel meaningless without deceased; diagnostic criterion	May be present	May be present
Seeking proximity to the deceased	Common; diagnostic criterion	Not usually present	Not usually present

Assessment

Gathering information

Mediators

Who or what was lost
Mode of death/loss
Age
Self-efficacy/self-esteem
Culture/ethnicity
Concurrent stressors

Nature of attachment
Historical antecedents
Gender
Social supports
Spirituality/religion
Disenfranchisement

Mediators

Strengths
Morals/values
Systems
Pre-loss functioning and loss/trauma history
Life threatened?
Coping strategies

Developmental level
Health
Legal issues
Witness death?
Self-care behaviors
Risk assessment

Evaluation of Self

Evaluation of Others

++	+-
-+	--

Attachment Styles

Secure	2
3	4

Comfortable with intimacy and autonomy

High self-esteem

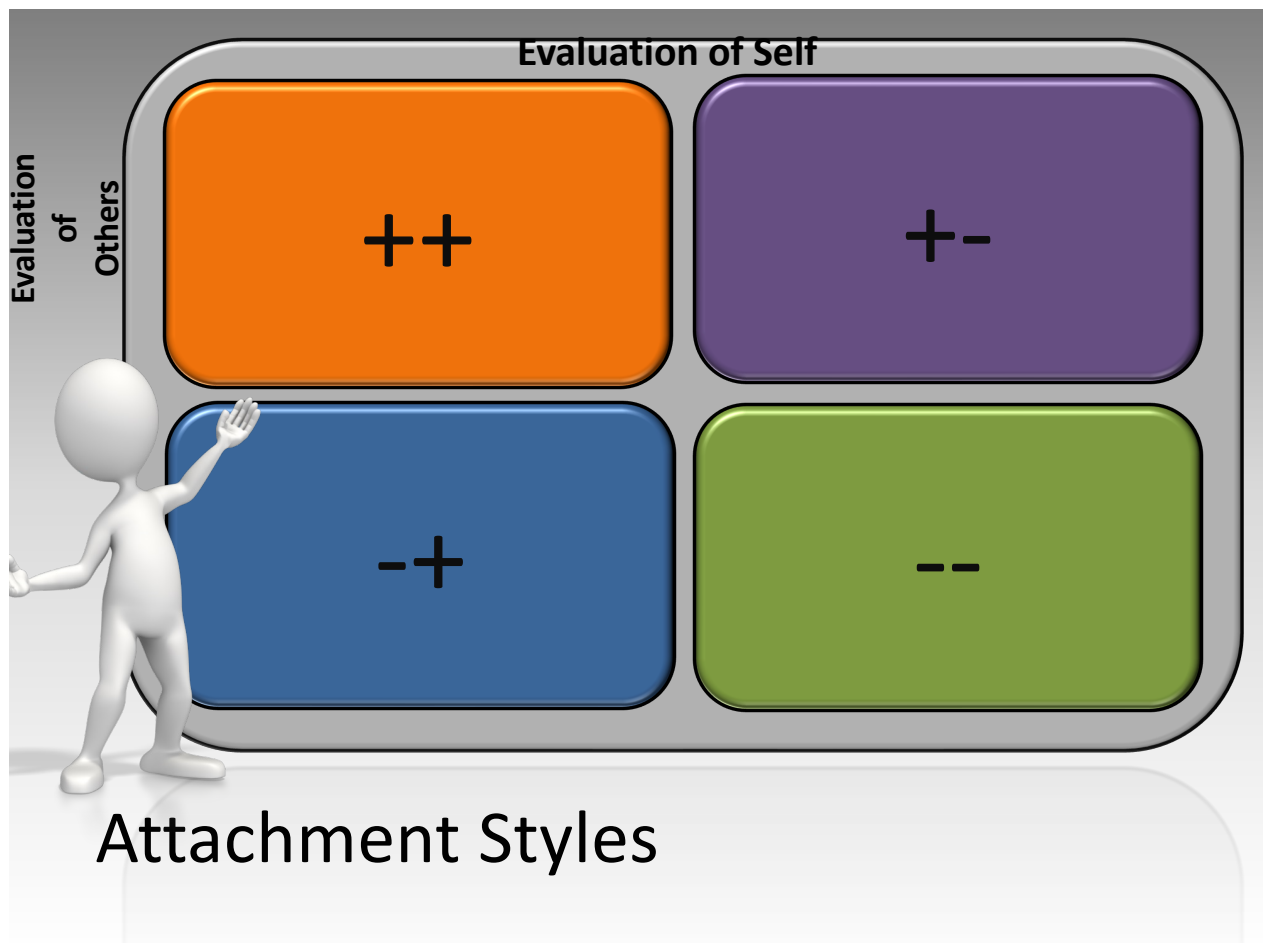Coherent and cohesive

Flexible

Relocates bond

Oscillates

1	Preoccupied/ Anxious
3	4

Preoccupied with relationship

Low self-esteem

Unable to cope constructively

Stuck in emotional response

High risk of PGD

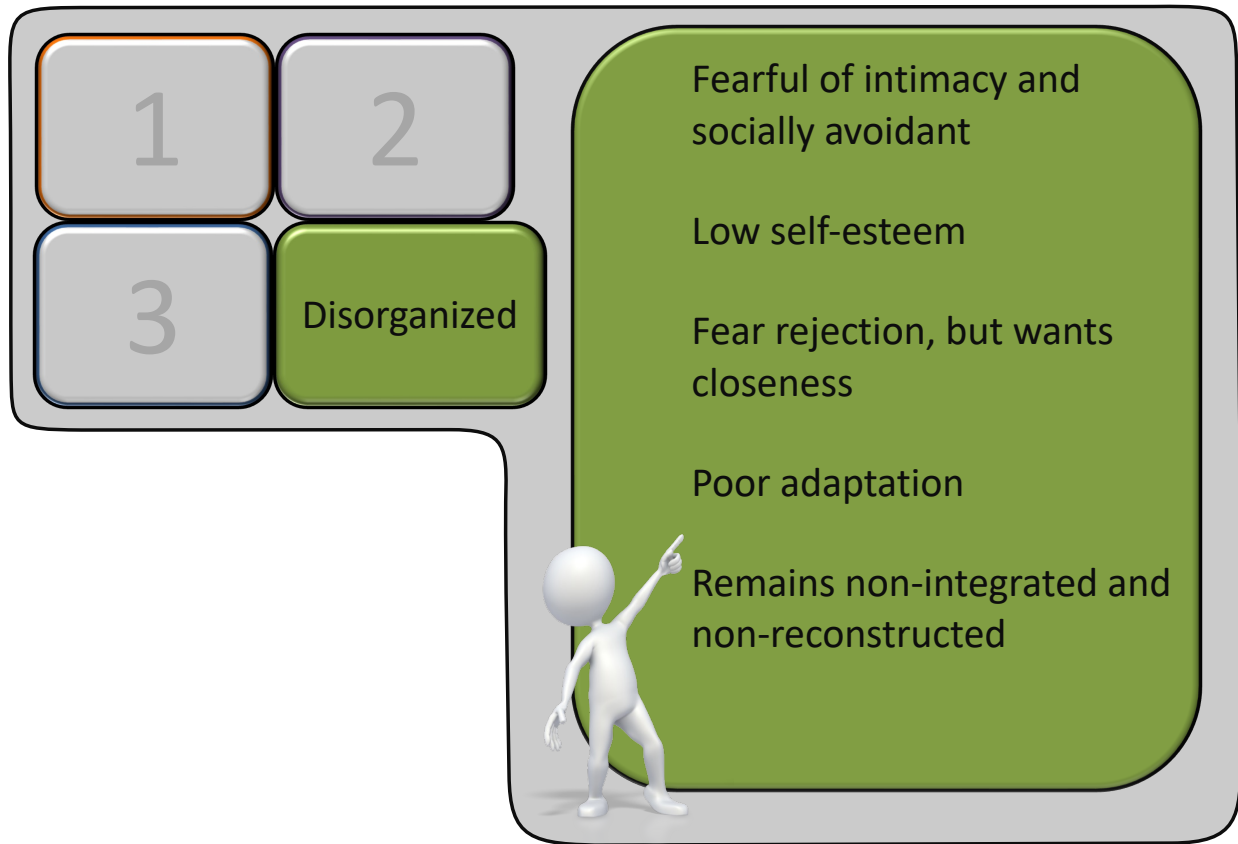| 1	2
Dismissive/ Avoidant	4

Dismissing of relationships and intimacy

High self-esteem

Lack of trust

Independent

Avoids emotions

Restoration focused

1	2	Fearful of intimacy and socially avoidant
3	Disorganized	Low self-esteem

Fear rejection, but wants closeness

Poor adaptation

Remains non-integrated and non-reconstructed

Martin & Doka's Adaptive Grieving Styles

Intuitive   Instrumental

Combination of both surmount crises better

(Doka, 2011)   67
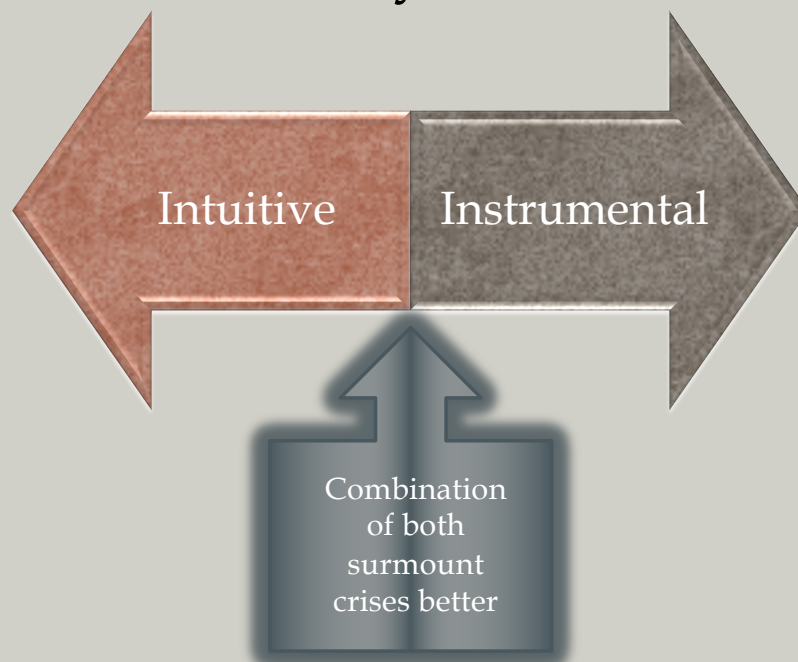
Formal Assessment Measures

- Do not just use scale or questionnaire. Study research, focus, and appropriateness

- Choices should be tailored

- May be used throughout the course of treatment.

- Many in public domain, but some require purchase and training

---

Stengths Assessment Measure

Strengths

https://www.viacharacter.org/survey/account/register

Intake Questionnaires

1. **Grief and Mourning Status Interview and Inventory (GAMSII) (Rando)**

Offers:

a. Part I: Basic demographic information

b. Part II: Main parts of history, MSE, and premorbid characteristics

c. Part III: Structured interview with loss-related topic areas based on Rando's 6 R's mourning processes

GAMSII and accompanying chapter provided in handout for this certification

(Permission granted by Therese Rando)

(Rando, 1993)

Intake Questionnaires

1. **Two-Track Bereavement Questionnaire on Life Following Loss (Rubin, Nadav, & Malkinson)**

Self-report assesses response to loss over time. Constructed in accordance with the Two-Track Model of Bereavement.

Offers:

a. Track I: Biopsychosocial functioning

a. Track II: Ongoing relationship to memories, images, thoughts, and feeling states associated with the deceased.

(Rubin, Nadav, & Malkinson, 2009)

Prolonged Grief Measure

PG-13: Inventory of Prolonged Grief - R (Prigerson et al.)

https://endoflife.weill.cornell.edu/sites/default/files/pg-13.pdf

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Complicated Spiritual Grief Measure

3. Inventory of Complicated Spiritual Grief 2.0 (Burke, et al.)

"a spiritual crisis during bereavement that compromises the griever's sense of relationship to God and/or the faith community, such that he or she struggles to reestablish spiritual equilibrium following the loss" (Burke, et al., 2021)

Measures:

      a. Insecurity with God

      b. Estrangement from spiritual community

      c. Disruption in religious practices

https://www.tandfonline.com/loi/udst20

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Sarah's Case

Sarah is a 43-year-old, divorced, heterosexual, cisgendered, Italian American, Christina female who resides in Philadelphia, PA with her two children, Sabastian (8 years old) and Katie (6 years old). Sarah and her ex-husband, Jason, lost their 3-year-old son, Jacob, to cancer 2 years ago after a 6-month battle with lymphoma. His death significantly impacted their relationship, eventually leading to the end of their 10-year marriage. They share equal, joint custody of their surviving children.

While Jacob was sick, Sarah resigned from her 7-year position as an office manager at a law firm to care for Jacob, taking him to and from the hospital, staying with him when he was inpatient, and so on. Sarah and Jason were bedside with Jacob when he died (which Sarah felt was traumatic for her). Sarah felt relieved that the hospital pastor was present when Jacob died, even though Jason felt differently about her presence. Sabastian and Katie were not informed of many details surrounding Jacob's illness as their parents felt they "would not understand what was happening anyway and we don't want this to be harder on them as it already is."

Sarah's Case

The family's income was severely impacted, and they lost their secondary insurance which led to high medical bills that she and her ex-husband are still trying to pay off.

After the divorce, Sarah presented to therapy endorsing the following symptoms: intense yearning for Jacob, deep guilt for "not being able to keep him alive," anger and shock at her higher power and ex-husband, preoccupation with thoughts of Jacob and his dying process, feeling as if part of her has died, being socially isolated and not engaging in activities she used to enjoy, refuses to drive past the hospital, and has begun to believe if she were to die then her children would be better off and maybe she would be reunited with Jacob.

QUESTIONS:
1. What diagnosis would you give Sarah?
2. What mediators are you assessing? How do you think they are impacting Sarah's grieving process?
3. What information still needs to be collected?
4. How do you feel about how the surviving children were treated?
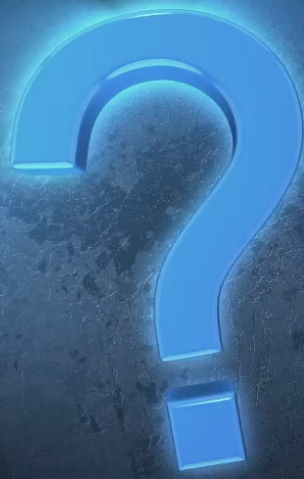
Questions?? Comments?

AAAAAAND BREAK TIME!

Treatment Planning

Counseling vs. Therapy

Counseling

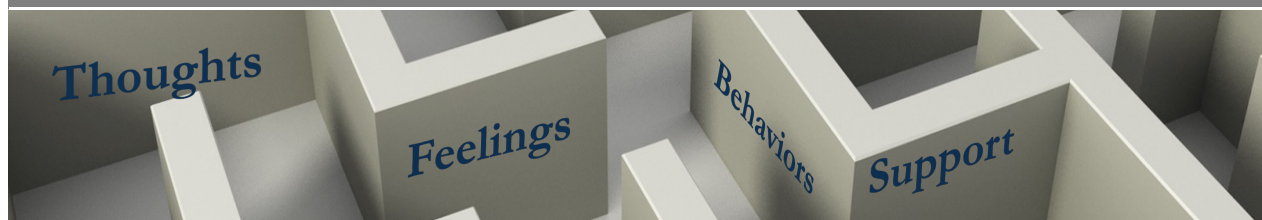~ facilitate normative grief to healthy integration

Therapy

~ uses specialized techniques that help with abnormal or prolonged grief reactions

~ helps resolve conflicts of separation, avoidance, and adaptation

~ trauma work (developmental, acute, etc.)

Thoughts

Feelings

Behaviors

Support

Treatment Plan: Uncomplicated Grief

- Walk along side, do not lead

- Fingerprint analogy - flexible

- Must consider attachment style

- Natural, adaptive, non-pathological

- Maintain process

- Grief facilitation

Treatment Plan: Uncomplicated Grief

1. Accept reality and permanence of death
2. Experience painful emotions of the death
3. Recognize and resolve ambivalent feelings
4. Adjust to changes in everyday life
5. Identify and preserve positive memories of deceased

6. Redefine relationship with deceased as one of memory
7. Develop new relationships and deepen existing ones
8. Make meaning from the loss
9. Foster enhanced problem-solving and conflict resolution

(Cohen, et al., 2001: Worden , 2018)

Treatment Plan: Meaning Reconstruction

- Process event story, its implications, and make sense of it (interventions go here)
- Access the back story of relationship to restore a sense of grounding and security (interventions go here too!)
- Resolve unfinished business (and MORE interventions!)
- Re-attach in a new way
- Integrate deceased's absence in a way the preserves the attachment

(Neimeyer, 2018)

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Interventions

BREATHE, DARLING.
THIS IS JUST A CHAPTER.
IT'S NOT YOUR
WHOLE STORY.

S. C LOURIE

tinybuddha.com

"When someone is going through a storm, your silent presence is worth more than a million empty words."
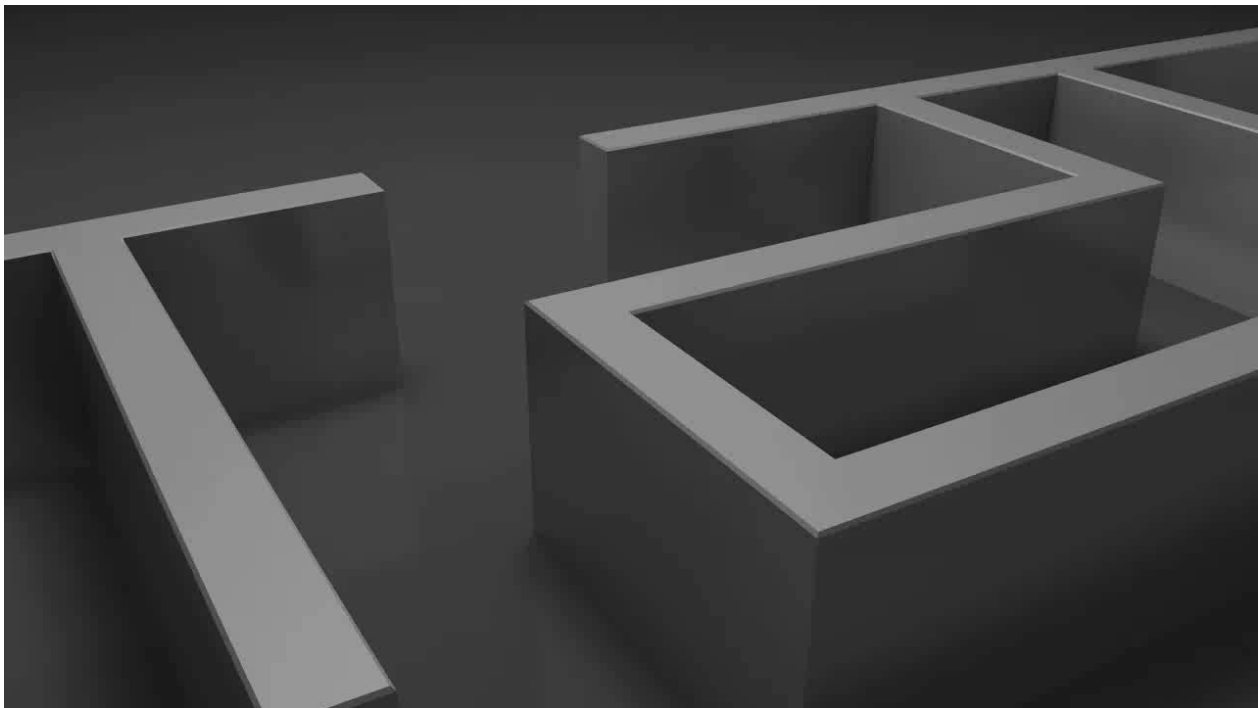
~ Thema Davis
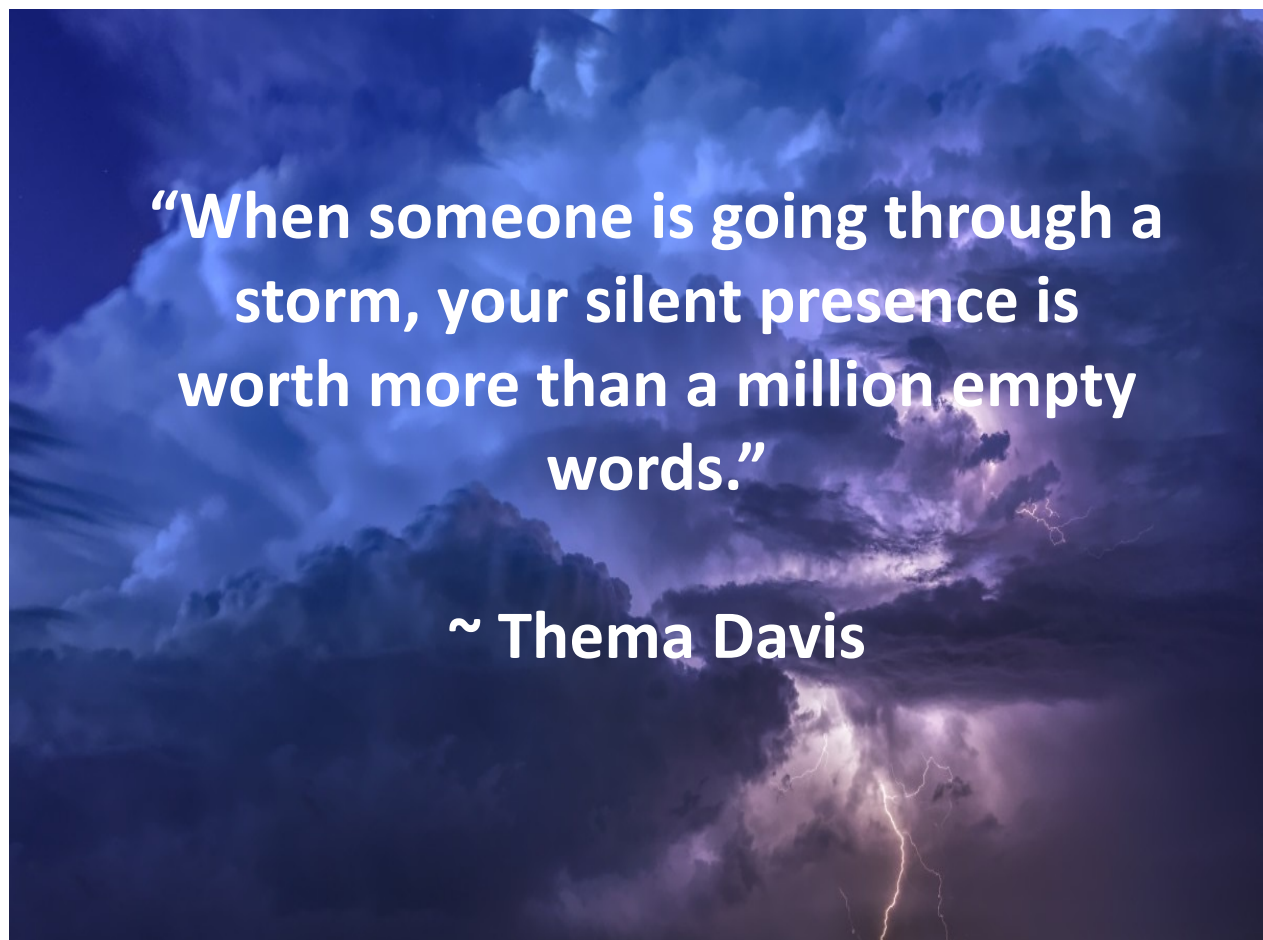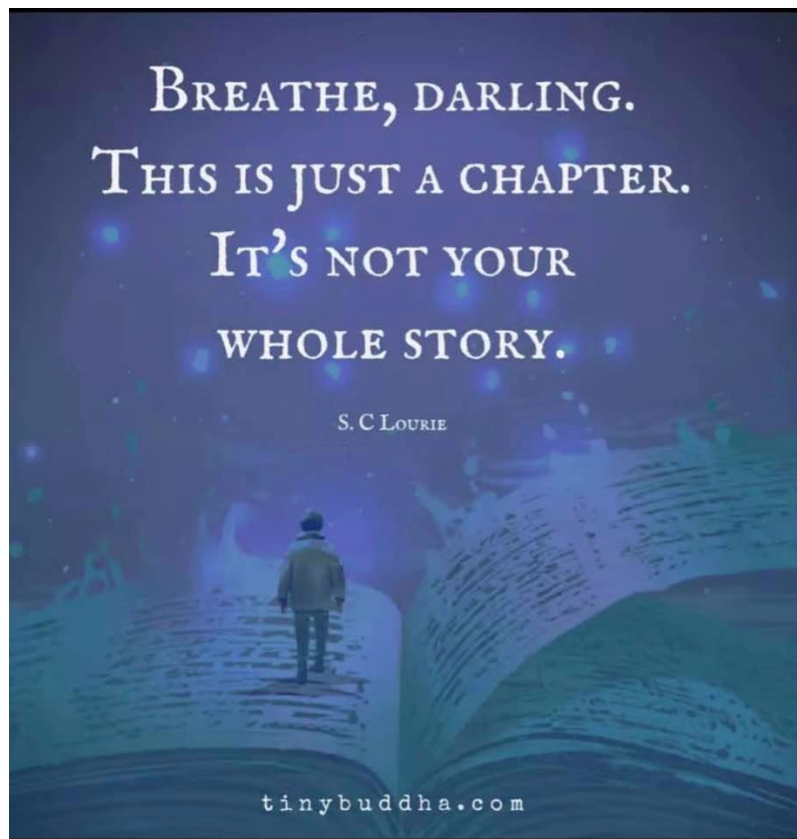
Dual Process Model of COPING

Loss Orientation (confronting the loss)

Restoration Orientation (Attending to life changes)

Oscillation

(Stroebe & Schut, 1999)

Medications

To Use or Not Use? THAT is a GOOD Question!

Key symptoms (i.e., profound separation distress, preoccupation with the death, meaninglessness in the absence of the loved one) are not analogous to depression, but have more in common with anxiety

PGD has different neural profiles when compared to MDD or PTSD. (e.g., nucleus accumbens activated in PGD, but not depression or PTSD)

Neurobiology of PGD involves same circuitry as reward pathway ("reward dysfunction disorder")
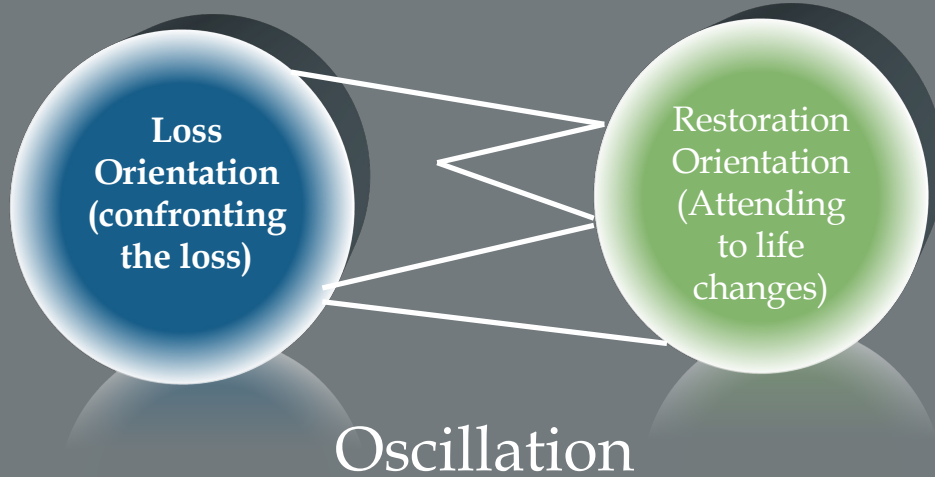
Current research focusing on addiction approach; drugs that work on dopamine receptors and competes against opioid receptors

Does not touch core symptomology, may provide more energy to engage in self-help

May ameliorate symptoms of depression and anxiety, but NOT grief

Tricyclic antidepressants and benzodiazepines not been proven effective for PGD

Naltrexone, which is currently used to treat alcohol and opioid dependence, being studied

Could prevent professionals, social support, and clients to pursue others forms of support and coping that are as effective as medications

Bui, et al., 2012; Gang, et al., 2021; Neimeyer, 2021)

Restorative Retelling

- Narrative Process
- Three narratives:
  1. External narrative (event focused) "What happened?"
  2. Internal narrative (emotion-focused view) "What's happening in you?"
  3. Reflexive narrative (meaning focused) "What are you making of what is going on here?"

Goal is to weave all together to create a stronger "through line." Make sense of themselves and the event

(Neimeyer, 2024; Neimeyer, 2016)

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Restorative Retelling

- Three steps
  1. Bracing – modulation and support (in and outside session; before session ends)
  2. Pacing – *GO SLOW*, dose (leave 15 minutes before end of session to stop and process)
  3. Facing – Victim > navigator, witnessing, seeking empowerment

Retell for 15 minutes starting when death was imminent or announced

Reconstructing and relearning as the person is now with more resources that can be used to bear the pain

"The only thing we can do is change the past by assigning different meanings." Restoration happens in this reconstruction

(Neimeyer, 2016)

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Linking Objects

Journaling

Journaling - Guidelines

- Focus on loss that is most upsetting/traumatic

- Write about aspects of experience discussed least adequately with others

- Write from standpoint of deepest thoughts and feelings, then shift to event

- Do not worry about grammar, spelling, penmanship

- 20 minutes, 4 days

- Schedule transitional activity

(Neimeyer, 2016)

Journaling - Precautions

- Secure privacy

- Postpone journaling until stable instead of directly after loss if needed

- Share (with consent) after relationship is secure with therapist

(Neimeyer, 2016)

If-Onlys and Shoulds

"If only..."

- Examine or experiment with ruminative thoughts – do not dismiss
- Empty chair (self)
- Reconstruction by focusing on deceased (deceased) e.g., "What do you feel that person would think and feel?"
- "What would be there if the ___ was not?" (others)
- Legacy work (event)

(Neimeyer, Pitcho-Prelorentzos, & Mahat-Shamir, 2021)

Mindfulness and Meditation

- Non-judgmental attention to emotions, thoughts, and inner experiences in the present moment
- Acceptance and openness to moment-by-moment experience
- Observing without overwhelming reactions
- Avoid making assumptions
- Through multiple modalities:
    1. Sitting meditation
    2. Body scan
    3. Visualization
    4. Progressive relaxation
    5. Guided imagery
    6. Walking meditation

"**Mindfulness cultivates a compassionate attitude, which in turn safeguards against the pernicious effects of negative feelings such as guilt and self criticism, and facilitates well-being**" (Hollis-Walker & Colosimo, 2011, p. 226)

(Sedighimornani, Rimes, & Verplanken, 2019)

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Correspondence with deceased

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Photonarratives

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Photographs/Family Albums

Life Imprint

1. Person whose imprint I want to trace _____
2. This person has had the following impact on:
3. The imprints I'd like to affirm and develop are: ____
4. The imprints I would most like to relinquish or change are: ____

(Neimeyer, 2016)

Loss Line

Age 20 - Moved

Age 37 - Divorce

1993

1999   2010

Age 21 – Sister died

Age 12 - Grandfather died

1985

Age 5 - Dog died

1973
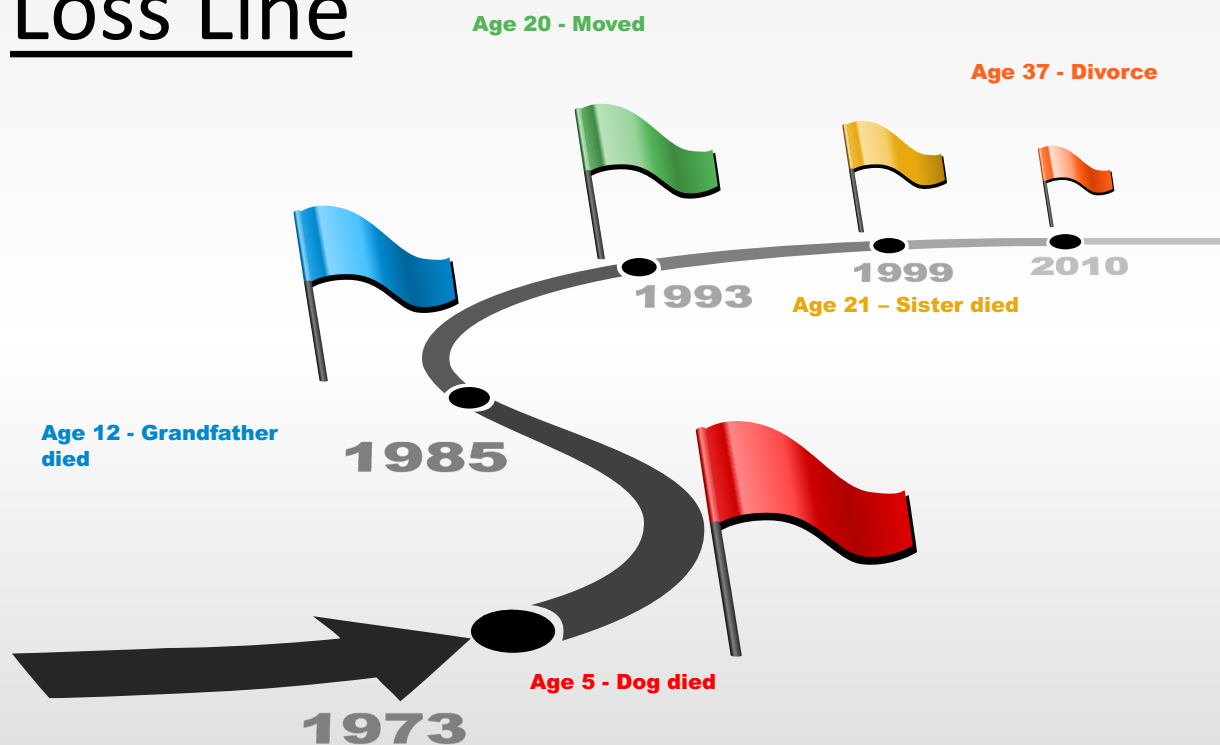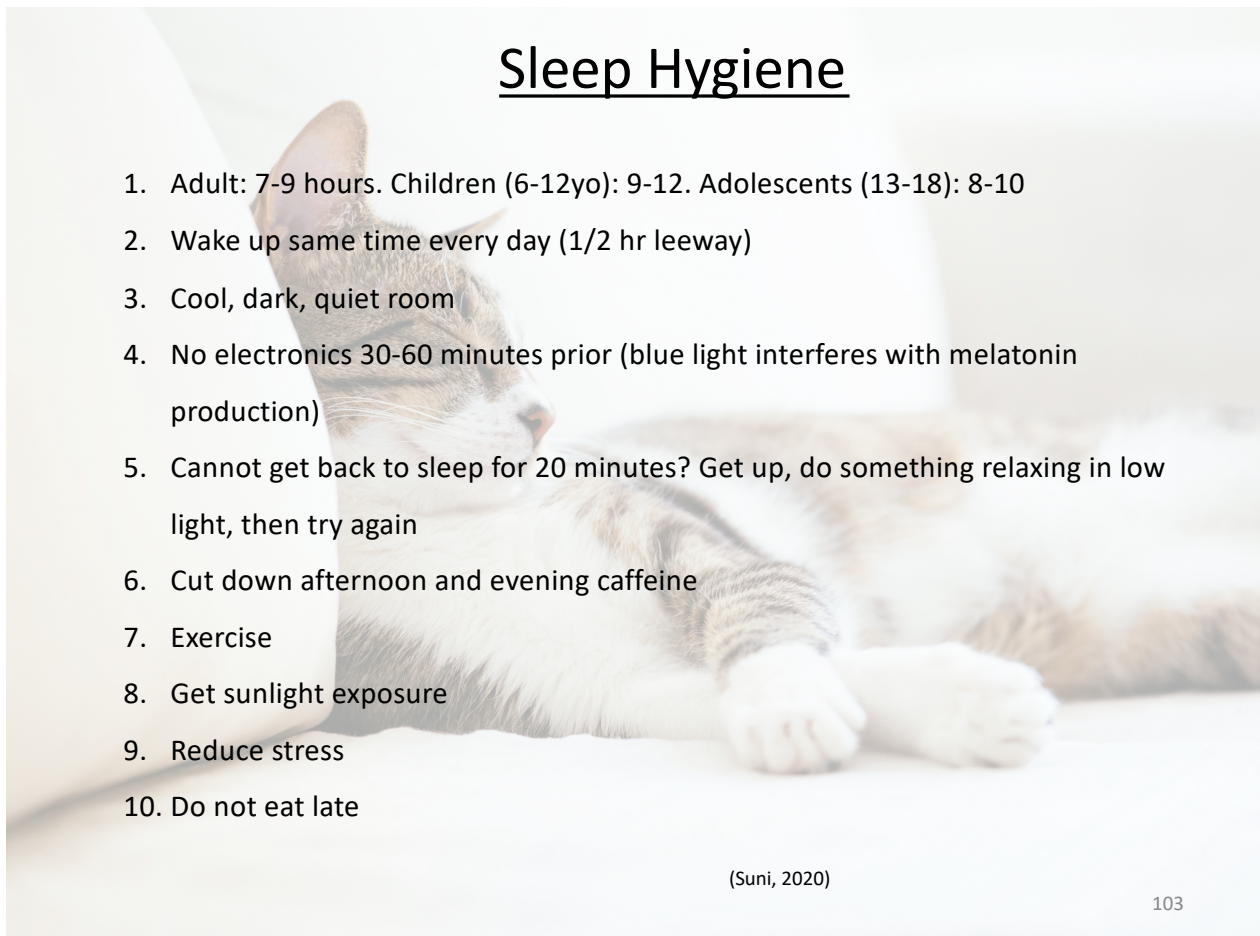
Music Interventions

- Linked to improved executive functioning (Zuk, et al., 2015)

- "Expression of deep feelings of sorrow by singing can...lead to an emotional shift" (Smeijsters & van den Hurk, 1999, p. 249).

- Raises dopamine levels (Salimpoor, 2011)

- Playing with playlists, singing (Austin 2008; Iliya, 2015)

Sleep Hygiene

1. Adult: 7-9 hours. Children (6-12yo): 9-12. Adolescents (13-18): 8-10

2. Wake up same time every day (1/2 hr leeway)

3. Cool, dark, quiet room

4. No electronics 30-60 minutes prior (blue light interferes with melatonin production)

5. Cannot get back to sleep for 20 minutes? Get up, do something relaxing in low light, then try again

6. Cut down afternoon and evening caffeine

7. Exercise

8. Get sunlight exposure

9. Reduce stress

10. Do not eat late

(Suni, 2020)

- Physical health often declines after loss. However, there are barriers that include guilt, lack of time, fatigue, and no motivation

- Research supports higher likelihood of hospital visits, longer hospital stays, cardiovascular problems, increase cortisol levels, reduces productivity and functioning at work

- Based on meta-analysis by Williams, et al., (2021), exercise benefits health outcomes and positively impacts the bereavement process:
    1. Alleviates depression
    2. Reduces anxiety
    3. Reduces PTSD symptoms
    4. Creates a sense of freedom
    5. Enables emotional expression
    6. Provides distractions
    7. Escape from grief
    8. Increases social engagement, cohesion, and reduced loneliness
    9. Improves quality of life and life satisfaction
    10. "Let's off stream"
    11. Decreases stress
    12. Decrease fatigue (emotional and physical)
    13. Increases motivation
    14. Improved adaptation to adverse life events
    15. Improves sleep quality and decreases insomnia
    16. Reduces aggression
    17. Increases self-efficacy

Me: omg I'm so tired from all that crossfit this morning

Friend: it's pronounced croissant... and I'm not sure how you managed to eat 12

Food is Medicine

I'M NOT SURE HOW MANY COOKIES IT TAKES TO BE HAPPY, BUT SO FAR IT'S NOT TWENTY SEVEN.

- Anticipate and prepare ahead of time

- Intentional ritual

- Acknowledgement and connection

- Meaningful event

- Social support

- Something pleasurable

- Honor continued bonds

- Care for self and let others care for you as well
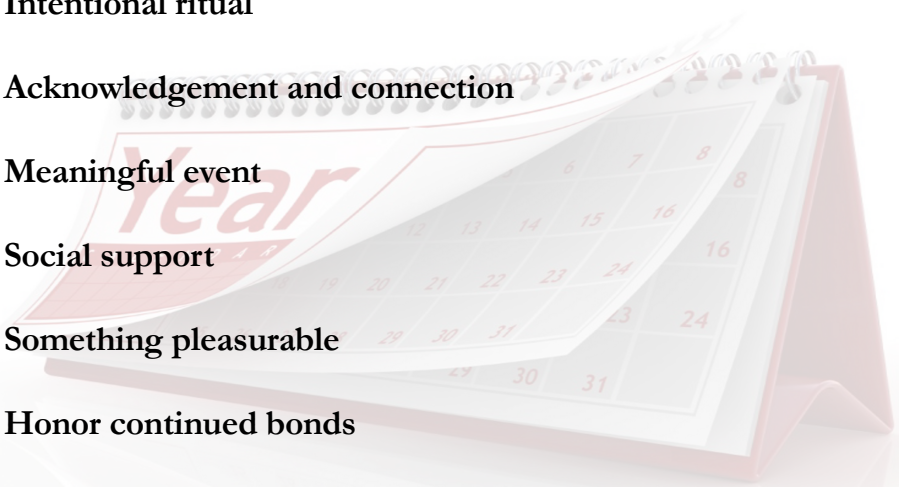
Holidays/Anniversaries

(Shear, 2015)
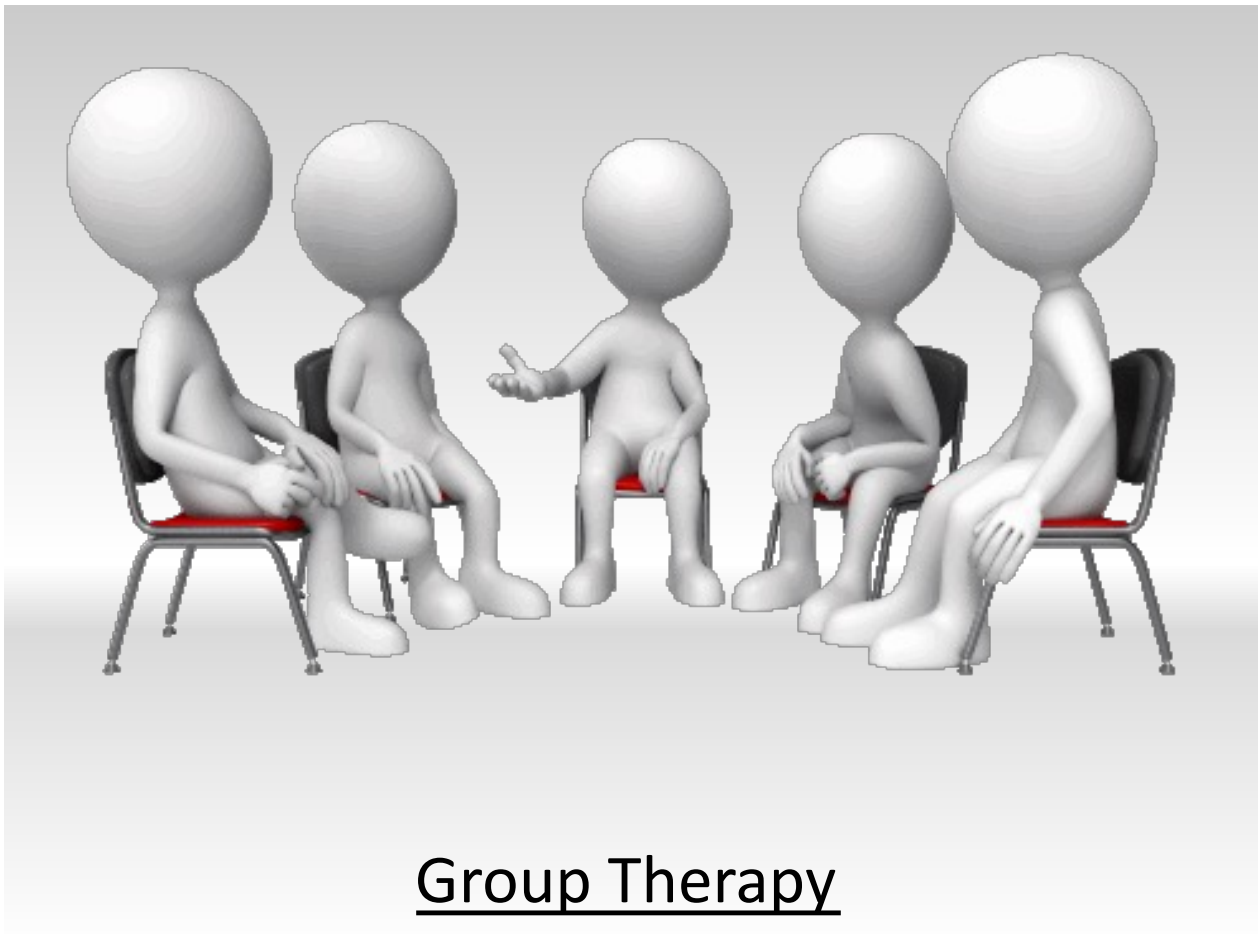
Group Therapy

Closed vs. Open Groups

Closed Group
- All members start and end together
- No drop-ins
- Tend to be time-limited
- Smaller group size
- Therapeutic
- Run by trained professionals
- Leads towards homogeneity
- Usually vetted
- Usually has a "syllabus"

(DeLeo & Cimitan, 2014)

Open Group
- Participants can drop in and out, unpredictable attendance
- Not time limited
- Can be small or large
- Supportive
- Run by trained professionals or volunteers
- Can be homogenous or heterogeneous
- Not usually vetted
- Not usually planned out

Ideal Grief Group Recommendations

I. Informational issues
    a. Inform how to find groups and their affiliation
    b. Communicate aim and structure

II. Organizational Issues
    a. Be explicit about possibilities and limits
    b. Competent leadership
    c. Homogenous group
    d. Flexible or restricted groups pragmatically practiced
    e. Time for attendance may vary

(Dyregrov, et al., 2013)

Ideal Grief Group Recommendations

III. Issues Concerning Content

a. Semi-standardized content

b. Content to promote hope and reduce rumination

(Dyregrov, et al., 2013-2014)

Example 8-Week Group

Week #:

1. Telling the story
2. Worries and fears
3. Anger and hurt
4. Releasing the trauma
5. Memories and bonds
6. Rebuilding
7. Creating a memorial
8. Good-byes and transitions

Couple of helpful resources:

Models of Adult Bereavement Support Groups (Sherman, N.)

Bereavement Groups and the Role of Social Support: Integrating Theory, Research, and Practice (Hoy, W.)

(Walijarvi, et al., 2012)

Behavior and Natural Environments

1. **Challenges accustomed patterns of functioning, feeling, and problem-solving.**

2. **Impartial, holding no criticalness or negative feelings and, therefore, it is a safe place to be authentic and non-defensive.**

3. **Relative predictability leads to a sense of control, therefore relaxed and open to learning.**

4. **Openness leads to genuine self-expression.**

5. **Not interacting with another person and the variables associated with the relationship, one has a greater sense of personal control and clarity of feelings.**

(Davis, 1998; Kaplan & Kaplan, 1998; Knopf, 1987)

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Therapeutic Bereavement Rituals

1. Emotional reactions identified with feelings of person represented by symbol.

2. Symbolic actions comparable to changes in bereaved's life

3. Actions with symbols evoke and shape new experiences

4. Body/mind congruency

(Cas & Coman, 2106; van Unden & Zondag, 2016)

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Therapeutic Bereavement Rituals

6. Increases sense of control of uncontrollable event

7. Experiences emotional shift

8. Movement towards integration

9. Enables closure

10. Cuts through intellectualization

11. Enables separation from loss

(Gillian, 1991; Rando, 1993; Sas & Camon, 2016; Wyrostok, 1995; van Der Har 1983)

Develop Your Own Nature-Based Bereavement Ritual

In your handouts, find the "Developing Your Own Nature-Based Ritual" worksheet.

After we discuss the steps, take 10 minutes to create a ritual for yourself.
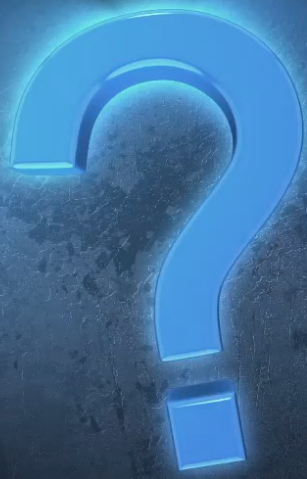
Questions?? Comments?

My emotional support dog after I tell him all my problems

Live like someone left the gate open!

Dr. Christina Zampitella, Psy.D., FT
Licensed Clinical Psychologist
Fellow of Thanatology
Founder/Owner
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Podcast: Phoenix Rising with Dr. Z

Center for Grief and Trauma Therapy

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Seven Domains of Grief Reactions

It is important to consider all reactions to grief with caution. These reactions are commonly found in the grieving process, but if they remain intense over a prolonged period of time, it may be an indicator that the person is not adapting to his or her loss. A mental health professional who specializes in grief (Thanatologist) should be consulted if the symptoms do not relent. Additionally, it is important to collaborate with other health care professionals to ensure there is not another reason for the symptom(s) (i.e., ulcer, ADHD, neurological problem, etc.). The following symptoms may not be the only ones present.

I.   Physical Reactions

- Headaches
- Nausea/fluttering in stomach
- Appetite disturbance
- Shortness of breath
- Heart palpitations/chest pain
- Vision problems
- Loss of motor skills
- Sweating
- Chills
- Bedwetting
- Dizziness
- Sleep difficulties
- Fatigue
- Choking sensation
- Muscle weakness
- Dry mouth
- Bodily pains
- Tremors
- Hyperactivity
- Increased risk of disease

II.   **Emotional Reactions**

- Sadness/Sorrow/Depression
- Fear
- Anxiety
- Guilt
- Anger/Fury/Rage
- Relief
- Uncertainty
- Grief
- Hopelessness
- Feeling lost
- Shame/Embarrassment
- Numbness
- Release
- Helplessness
- Listlessness
- Loneliness
- Longing
- Overwhelmed
- Feeling abandoned
- Worry
- Wanting to die
- Indifference

III.   **Psychological Reactions**

- Denial
- Repression
- Intellectualization
- Rationalization
- Projective identification
- Dissociation

IV.   **Cognitive Reactions**

- Memory problems
- Poor concentration
- Poor decision-making
- Confusion
- Auditory or visual hallucinations

- Poor attention
- Calculation difficulties
- Sensing the deceased
- Intrusive or obsessive thoughts
- Disbelief
- Poor sequential processing
- Disruption of logical thinking
- Seeing an event repeatedly

V.   **Behavioral Reactions**

- Regression
- Suspiciousness
- Crying
- Poor grades
- Carrying pictures/items
- Absentmindedness
- Loss of interest
- Retelling of events of loss
- Avoiding painful reminders
- Frequent sighing
- Intolerance of noise
- Appetite changes
- Hypervigilance/clinging
- Excessive humor
- Excessive silence
- Dreams/nightmares
- Reluctance to explore
- Excessive hugging/touching

VI.   **Interpersonal Reactions**

- Distancing from others
- Changes in communication
- Argumentative and rejecting
- Separation anxiety
- Blaming others
- Identification with the deceased
- Rejects old friends and seeks new ones
- Turning to social supports

VII.   **Spiritual Reactions**

- Inability to pray, meditate, etc. or change in the way prayer is used

- Belief system is no longer valid or sufficient
- Strengthening of spirituality
- Preoccupied with own death
- Rejection of higher power
- Loss of meaning
- Increase in meaning
- Loss of faith
- Anger towards higher power; feeling betrayed
- Not feeling "centered" or "balanced"
- Disappointment in belief system, clergy, or religious institution

Results from loss in infancy

- Wants to connect with others, but is unsure how
- Decreased frustration tolerance, impulse control, and attention span
- Cannot tolerate long periods of intense emotional pain – behavioral dysregulation
- Shifts between experiencing loss and engaging in activity
- Poor self-regulation
- May not seek stimulation
- Rapid emotion shifts
- Inability to self-soothe
- Uninhibited behavior
- Toilet training problems
- Reduced ability to become self-aware
- Attachment problems
- Delayed language development
- All or nothing thinking
- Inability to identify and empathize with others
- Oppositional behavior

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<u>Developing Your Own Nature-Based Rituals</u>

Please answer the following questions you might use in creating the ritual:

1.   What am I ritualizing (what ending, beginning, transformation, accomplishment, connection)? Is this ritual one of separation and saying "goodbye", trying to get "unstuck" in your grief in order to move forward, or focusing on putting the pieces of your life back together? Without a focused, meaningful intention, your ritual will not be impactful. Therefore, be sure to take time to identify what is important to you at this time in your life.

2.   Why do you want to do this ritual?

3.   What symbols will be best to bring? In other words, what meaningful items could I bring, create, or look for that would help me connect with my intention of the ritual I identified in item #1?

4.   What symbolic actions would express the intention of the ritual? For example, if you were intending of letting go of fear, maybe you would do something that would make you have to face that fear, or perhaps you "bury" something. Or maybe you wish to start a new beginning, and so jumping in a body of water may represent a "clean" start. You should make sure to incorporate your items from #3.

5.   Are there words that need to be spoken? What role will silence play? Where in the ritual will you speak and/or be in silence?

6.   What are the steps of the ritual? What items need to be included or what actions will you do to express the intention of the ritual. Make sure to start with creating your plan and provide all the details from start to finish, so that if you read this to another person, he or she could almost do the ritual the way you will do it.

7. Nature has healing qualities that help deepen the ritual experience. Nature is non-judgmental, is not distracting, provides a soothing feeling, and helps with feeling mindful. It also is an example of natural cycles of life and death, beginnings and endings. When is the right time and where is the right place for this ritual? Since this ritual is meant to be completed outdoors, where could you find a location that feels soothing, beautiful, and private, away from many manmade distractions. Why did you choose this place? Does it have meaning for you?

8. Any other thoughts, feelings, items, intentions, etc. that you would like to add?

Differential Diagnosis of prolonged grief disorder, major depressive disorder, and post-traumatic stress disorder			
Characteristic	**Prolonged Grief Disorder**	**Major Depressive Disorder**	**Post-Traumatic Stress Disorder**
Affective Symptoms			
Depressed mood	Prominent; focused on loss; diagnostic criterion	Prominent; diagnostic criterion	May be present
Disbelief about death	Prominent; focused on loss; diagnostic criterion	Not usually present	May be present
Anhedonia	Not usually present	Prominent and pervasive; diagnostic criterion	Prominent and pervasive; diagnostic criterion
Anxiety	May be present; focused on separation anxiety	May be present	Prominent and pervasive; diagnostic criterion; focused on fear of recurrent danger
Yearning and Longing	Prominent and pervasive; diagnostic criterion	Not usually present	Not usually present
Guilt	Common; diagnostic criterion; related to regrets with deceased	Usually present; related to feelings of being undeserving and worthless	Prominent and pervasive; diagnostic criterion; usually focused on event or aftermath
Cognitive and Behavioral Symptoms			
Difficulty concentrating	Not usually present	Common; diagnostic criterion	Common; diagnostic criterion
Preoccupying thoughts	Common; Focused on thoughts and memories of the deceased; diagnostic criterion	May be present, focused on negative thoughts about self, other, the world	Negative, exaggerated, distorted thoughts related to the event; diagnostic criterion
Recurrent preoccupying images or thoughts	Common; focused on thoughts/memories of deceased; diagnostic criterion	May be present	Common; focused on event; associated with fear; diagnostic criterion
Avoidance of reminders of loss	Common; focused on reminders of the finality if the death; diagnostic criterion	May be present, but usually focused on social withdrawal	Common; focused on loss of safety or reminders of the event; diagnostic criterion
Loss of meaningful life	May feel meaningless without deceased; diagnostic criterion	May be present	May be present
Seeking proximity to the deceased	Common; diagnostic criterion	Not usually present	Not usually present

Identity disruption	Common; Sense of something inside has died; diagnostic criterion	May be present	May be present
Suicidal thinking/behavior	May or may not be present; usually to reunite with deceased	SI is present; increased risk of suicide; diagnostic criterion	SI is present; increased risk of suicide; diagnostic criterion
Abnormal eating patterns	May avoid certain foods or mealtimes; eat certain food to feel close	Change in eating patterns (weight gain/loss); diagnostic criterion	Not usually present
Disturbed sleep	May avoid bed due to reminders of loss; rumination	Common; diagnostic criterion	Sleep disturbance due to anxiety; diagnostic criterion
Nightmares	Not usually present	May be present	Related to traumatic event; diagnostic criterion

Rando, T. A. (1993). *Treatment of complicated mourning* (pp. 665-682). Champaign, IL: Research Press. (Website: www.thereserando.com)

APPENDIX

Grief and Mourning Status Interview and Inventory (GAMSII)

PART I: DEMOGRAPHIC INFORMATION

Name _____ Sex _____

Date of birth _____ Age _____

Address _____

_____

Where mourner calls home _____

Residence history _____

_____

_____

Social/cultural/ethnic/religious background _____

_____

_____

Marital status _____ Year of current marriage _____

Dates, durations, and outcomes of previous marriages _____

_____

_____

Highest level of formal education _____

Military history _____

_____

Occupation _____

Occupational/work history _____

_____

_____

Income level and degree of financial security _____

_____

Religion and extent of practice _____

Number of pregnancies _____

Number of live births _____

Number of live-birth children who died _____

Names, sexes, and circumstances _____

_____

_____

Number and dates of abortions _____

_____

Number and dates of miscarriages _____

_____

Number, dates, sexes, gestational ages, and postdeath rituals for stillbirths

_____

_____

Surviving children (names, sexes, ages, occupations, family status, health, locations)

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Family-of-origin members (names, sexes, ages, occupations, family status, health, locations)

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Close relatives, friends, and other supports (names, sexes, ages, occupations, family status, health, locations)

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Prior losses (physical and psychosocial)

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Date of identified current loss(es) _____

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PART II: COMPREHENSIVE EVALUATION OF HISTORY, MENTAL STATUS, AND SELECTED PREMORBID PERSONALITY CHARACTERISTICS

The caregiver must obtain the following information according to the standard practices of the discipline to which he or she belongs.

Comprehensive Psychosocial/Medical History

- Presenting problem
- History of presenting problem
- Past personal history and current psychological functioning

    Psychosocial history and current functioning
    Occupational history and current functioning
    Past psychiatric history and current status
    Substance use history and current status
    Medical history and current status
    Financial history and current status

- Family history (psychosocial, psychiatric, medical, financial) and current status
- Concurrent stresses or crises

Mental Status Examination

In the modified mental status examination suggested here, the following areas must be evaluated.

- Appearance
- Behavior and psychomotor activity
- Speech and language
- Mood and affect
- Thought process and content
- Perceptual disturbances
- Sensorium functions
- Insight and judgment
- Symptoms of depression

- Symptoms of anxiety and post-traumatic stress disorder (PTSD)
- Suicide and homicide risk

Selected Premorbid Personality Characteristics

- Ego functioning and strength
- Coping and defense mechanisms, styles, and abilities (specifically when dealing with stress, anxiety, threat, and feelings)
- Frustration tolerance
- Personality dynamics and conflicts
- Characterological scripts
- Sense of self, self-concept, and self-esteem
- Internal versus external locus of control and processing
- Cognitive style and biases
- Problem-solving skills
- Maturity
- Assumptive world components
- Sense of personal meaning and fulfillment in life
- Philosophy of life and values
- Spirituality
- Communication style
- Relationship patterns
- Characteristic ways of managing psychosocial transitions
- Specific strengths, skills, and assets
- Specific vulnerabilities and liabilities

DIAGNOSTIC/CLINICAL IMPRESSIONS
BASED ON DATA FROM PARTS I AND II

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PART III: STRUCTURED INTERVIEW SCHEDULE

Topic Area A: Circumstances of the death; events that led up to and followed it

A-1. Tell me about the death and what led up to it.

    a. If _____'s death followed an illness, please answer the following:

        (1) What was _____'s experience during his/her illness?

        (2) What was your experience during _____'s illness?

        (3) What was the length and course of the illness?

        (4) What, if any, was the nature of your participation in _____'s care during the illness?

        (5) Did you ever discuss _____'s dying with him/her? If so, what was this like?

        (6) What, if anything, was the nature of your anticipatory grief during _____'s illness?

        (7) What were the hardest parts for you in _____'s illness?

        (8) Do you have any unfinished business or unresolved conflicts about anything that happened or didn't happen during _____'s illness? If so, please explain.

        (9) What would you change, if anything, if you could about the illness experience for you? For _____?

      (10) Were you prepared when _____ died?

      (11) How could things have been better for you during _____'s illness? At his/her death?

      (12) What, if anything, do you feel good about regarding your interaction with _____ during his/her illness? Guilty about? Regretful about?

A-2. What happened immediately after the death and in the few days thereafter?

    a. What kind of funeral activities or rituals took place?

        (1) How were they for you?

        (2) What kind of impact have they had on you?

Topic Area B: Nature and meaning of what has been lost

B–1. Tell me about _____.

   a. Help me to know him/her as a person.

   b. What was he/she like?

B–2. What type of relationship did the two of you have?

   a. How did you get along?

   b. How did your relationship start and what course did it take?

B–3. You've told me a great deal about what was positive in the relationship. Could you tell me a little about the aspects that were not so positive?

B–4. Exactly what did _____ and the relationship with him/her mean to you and give to you in your life?

   a. In what ways (positive and negative) did _____ help you or cause you to be the person that you are/were?

B–5. Specifically, what have you lost in your life physically or symbolically with _____'s death?

   a. What has/have been the impact(s) on you of this/these secondary loss(es)?

B–6. Do you have any unfinished business with _____? Anything you would have wanted to say or do that would have made you more comfortable with ending the relationship but that you never said or did and therefore lack closure on?

   a. What do you think you need to do to finish this business?

Topic Area C: Mourner's reactions to the death and coping attempts

C–1. Please describe for me the type, quality, extent, and intensity of all the various reactions you have had since _____'s death.

   a. What specific kinds of responses did you find yourself having and what particular kinds of behaviors did you witness in yourself?

   b. Did you have any reactions and/or behaviors that were unexpected or that frightened you? If so, what were they?

   c. Have you experienced any changes in your self-esteem, self-image, or sense of self? If so, what?

C–2. Tell me what you have done to cope with _____'s death.

   a. How do you cope on an everyday basis?

   b. Over the long haul?

   c. Do you have what you personally require to cope with this loss? If not, why do you think that you do not?

   d. If and when you feel pain over this loss, how do you deal with/defend against/protect yourself from it?

C–3. Please complete this sentence: "I feel that I am coping/have coped with this death . . ."

   a. Rate your coping on a scale of 1 (worst possible coping) to 10 (best possible coping).

C–4. How would you complete these sentences?

   a. "The things that I do/did that help/helped me the most are/were . . ."

   b. "If I have/had problems related to this loss, they seem/seemed to be in the areas of . . ."

   c. "The most difficult parts of this for me are/have been . . ."

   d. "My most major concerns in all of this are . . ."

   e. "What I have specifically done to try and help myself is . . ."

Topic Area D: Reactions of others in the mourner's world and perceived degree of support

D–1. How have others reacted to _____'s death?

D–2. How have they reacted to your reactions?

   a. How have their reactions affected you?

D–3. Have your relationships with others changed since _____'s death?

   a. If so, with whom, how, and why?

   b. How do you feel about these changes?

   c. Have these changes caused you any specific problems?

D–4. What types of support have you received from others to help you cope with _____'s death?

    a. Who gave it and what did they do?

    b. What was helpful? Not helpful?

    c. Do you have some person(s) you can confide in? If so, who?

D–5. Were there any types of support or recognition you required but did not receive or any specific persons from whom you needed support or recognition but did not receive it?

    a. Why do you think this happened?

D–6. How did the support or recognition you did and did not receive affect you and your grief and mourning?

D–7. What needs for support or recognition remain unmet?

    a. From whom in particular?

Topic Area E: Changes in the mourner and the mourner's life since the death

E–1. Please describe what has happened to you in the time since _____ died. For example, what changes (either gains or losses; internal or external; physical or psychosocial; psychological, behavioral, social, physical, spiritual, occupational, or financial), if any, have occurred to you, in you, and in your life since _____'s death?

E–2. Do you feel changed by this death?

    a. If so, in what ways are you different (positively and negatively)?

    b. In what ways are you the same as before?

    c. What percentage of your old self are you back to?

    d. Do you feel, think, or act any differently than before? If so, how?

    e. What is the current impact, if any, of grief and mourning on your ability to function normally (psychologically, behaviorally, socially, physically, spiritually, occupationally, financially)?

    f. Have you blocked off any corners of the world since the death?

g. Have you experienced any changes in habits, activities, pleasures?

h. Have any new problems developed since _____'s death?

E–3. If this death has affected the way you look at and live life, how has it done so?

a. How has the death affected your assumptive world (i.e., your assumptions, expectations, and beliefs about and view of the world), religion, or philosophy of life?

E–4. What, if anything, have you learned (positively or negatively) from this loss?

Topic Area F: Mourner's relationship to the deceased and stimuli associated with the deceased

F–1. How would you describe _____'s role, if any, in your life at this time? In other words, do you have an ongoing sense of connection to _____ or does _____ play an active part in your ongoing life?

a. Do you think about _____?

b. Talk to _____?

c. Have you found yourself acting, thinking, or feeling in any ways _____ used to act, think, or feel? If so, how?

d. How do you relate to _____ at this time, if you do?

e. What types of things do you do to keep _____ "alive" to yourself and others or to maintain a sense of connection with _____?

f. What, if anything, do you do to memorialize _____?

g. What is it like for you to have this type of relationship or sense of connection with _____?

h. How do you feel about the ways in which you relate to, maintain a sense of connection to, or keep _____ "alive"?

i. What is the meaning in your life today of your current relationship with _____?

j. What about you today is influenced (positively or negatively) by your current relationship with _____?

k. What is your current image of yourself with regard to _____ (e.g., dependent child, adult)?

1. Was there anything in _____ that you would choose to develop in yourself? If so, what?

F–2. Many times after a person loses a loved one, he or she has some experiences in which there is a sense of the presence of the loved one. Sometimes the mourner takes these experiences as a "sign" or as some form of communication from the loved one. Sometimes there are vivid dreams, or the mourner has an experience of seeing the image of the deceased or hearing that person's voice. Sometimes mourners are reluctant to talk about this because they think it makes them sound crazy, even though they are not. I know that this happens with many mourners, and I am wondering if anything like this has ever happened to you. Have you ever had any of these types of experiences or anything like them?

   a. What was it like for you to have this happen?

   b. How did you respond?

   c. What was the nature of the experience for you? Did you view it as positive (as comforting or something that made you feel good) or was it more negative (something frightening that you would not want to have happen again)?

F–3. How are you choosing to deal with _____'s room? Clothing? Other possessions?

   a. What is this like for you?

   b. Have you saved any special items?

      (1) What do you do with it/them?

      (2) Where do you keep it/them?

      (3) What made you choose it/them?

      (4) What does/do it/they represent to you?

      (5) How does/do it/they make you feel when you encounter it/them?

F–4. At this point, how is it for you when you come across things that remind you of _____ or bring back memories of him/her? For example, how may you react when you see pictures of him/her, suddenly remember a special time you shared, or go to an event and wish he/she would be there with you, such as a wedding or holiday gathering?

    a. How do you tend to handle these things?

    b. Are there some things that are more difficult than others?

    c. What kind of reactions, if any, do you have?

    d. What types of memories tend to come back to you?

    e. What characteristics do your memories have and what types of reactions do they precipitate in you?

    f. Do you talk about your memories to anyone? If so, who?

    g. Is it comfortable or uncomfortable to remember _____? Under what conditions?

F–5. Have you noticed any responses on your part around the anniversary of the death, during other occasions, or under other circumstances (i.e., STUG reactions)?

    a. If so, what are they like?

    b. How intense are they?

    c. How do you cope with them?

F–6. How do you think _____ would want you to respond in your grief and mourning over him/her?

    a. What would he/she want of you as you live without him/her?

    b. Did you and _____ ever discuss how he/she wanted you to go on? If so, what was said?

    c. Even if you two never discussed this topic, what do you think _____ would expect you to do?

    d. Is there anything from your relationship with _____ that guides you in your going on without him/her? If so, what?

Topic Area G: History, status, and influence of prior loss experiences, including mourner's methods of coping

G–1. What other difficult physical or psychosocial losses have you experienced in your life?

G–2. What types of things did you do to cope with each loss?

    a. How effective were you in coping?

    b. In what ways did the loss affect you then?

c. How does the loss affect you now, if it still does?

d. Did you learn anything in particular from the loss?

e. Was that loss different for you from this one? If so, in what ways?

Topic Area H: Mourner's self-assessment of healthy accommodation of the loss now and in the future

H–1. Compared to how you coped with and functioned in life in general prior to the death, how do you think you are doing now?

    a. Rate your previous and present general coping on a scale of 1 (worst possible coping) to 10 (best possible coping).

H–2. How do you think you are coping/have coped with this specific loss?

    a. Rate your coping on a scale of 1 (worst possible coping) to 10 (best possible coping).

H–3. To what extent, if any, has the loss been integrated into your life?

H–4. How do you view the future?

H–5. How do you think you will ultimately do in your grief and mourning, and in learning to live without _____?

    a. Rate how you think you will ultimately do on a scale of 1 (worst possible outcome) to 10 (best possible outcome).

H–6. What remains for you to do or change in your grief and mourning and in your life to reach the point where you will be doing the best you can in coping with this loss and living without _____?

H–7. Have you made a decision to "make it"?

H–8. In what areas is/will it be the hardest to rebuild your life and/or to reinvest in it?

    a. The easiest?

H–9. How do you, if you do, make sense out of this loss and its having occurred in your life?

H–10. In retrospect thus far, is there anything you would do differently in your grief and mourning?

Topic Area I: Mourner's degree of realistic comprehension of and expectations for grief and mourning

I–1. What do you think is necessary to cope with or survive a loss like this?

I–2. In your estimation, what is normal to experience after this kind of death?

I–3. In what ways do you think you have been a healthy and successful mourner?

    a. In what ways do you think you have been unhealthy or unsuccessful?

I–4. How do you anticipate the rest of your mourning will go?

I–5. What will indicate to you when you have achieved the best possible accommodation of this loss or are coping the very best you ever will be able to with _____'s death?

Topic Area J: Open topic

J–1. Are there any areas pertinent to your grief and mourning that we have not examined?

J–2. Are there any topics we have discussed that you feel we should consider further?

J–3. What do you feel is the most important piece of information about your grief and mourning?

DIAGNOSTIC/CLINICAL IMPRESSIONS
BASED ON DATA FROM PART III

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**SUMMARY: DIAGNOSTIC/CLINICAL IMPRESSIONS
BASED ON SYNTHESIS OF PARTS I, II, and III**

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Center for Grief and Trauma Therapy

We often try to say things to support and help people we care about after they have experienced a loss. However, some things that are often said can lead the person feeling alone, shut down, or feel like he or she is grieving "wrong." Below are examples of some things that are helpful and not helpful when reaching out to help a friend or loved one.

Helpful Things to Say to Someone Who is Grieving

1. I am so sorry for your loss.
2. I wish I had the right words, just know I care.
3. I don't know how you feel, but I am here to help in any way I can.
4. You and your loved one will be in my thoughts and prayers.
5. My favorite memory of your loved one is…
6. I am always just a phone call away
7. Give a hug instead of saying something
8. We all need help at times like this, I am here for you
9. I am usually up early or late if you need anything
10. Saying nothing, just be with the person
11. I know it's hard to be strong right now
12. There was no good reason for this to happen
13. It's OK to feel this way

Unhelpful Things to Say to Someone Who is Grieving

1. At least she lived a long life, many people die young
2. He is in a better place
3. She brought this on herself
4. There is a reason for everything
5. Aren't you over him yet, he has been dead for a while now
6. You can have another child still
7. She was such a good person God wanted her to be with him
8. I know how you feel
9. She did what she came here to do, and it was her time to go
10. Be strong
11. It's good she is no longer suffering. Now she is at peace
12. Maybe if you started dating again?
13. I know it's tough, but he wouldn't want you to suffer like this
14. You have to remember the good times. Those are what matters

Inventory of Complicated Spiritual Grief 2.0 (ICSG 2.0): Validation of a revised measure of spiritual distress in bereavement

Laurie A. Burke, A. Elizabeth Crunk, Robert A. Neimeyer & Haiyan Bai

Routledge
Taylor & Francis Group

Inventory of Complicated Spiritual Grief 2.0 (ICSG 2.0): Validation of a revised measure of spiritual distress in bereavement

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ABSTRACT

Spirituality has long served as a source of solace for many grievers following a loss. For other mourners, whose bereavement experience has been significantly challenged by struggles in their relationship with God and/or their faith community, the opposite is true. Complicated spiritual grief (CSG) is a spiritual crisis following the loss of a loved one. To assess CSG in samples of bereaved adults, a simple-to-use, multidimensional measure of spiritual crisis following loss called the Inventory of Complicated Spiritual Grief (ICSG) was previously developed and validated. However, subsequent research providing greater clarity about the construct of CSG supported the need to revise and update the ICSG. The goal of the present study was to establish the psychometric validity of a revised measure of CSG, called the Inventory of Complicated Spiritual Grief 2.0 (ICSG 2.0), with a large, diverse cohort of bereaved Christian adults ($N = 440$). Analyses of the bifurcated sample supported a three-factor model measuring insecurity with God, estrangement from the spiritual community, and disruption in religious practices. Further analyses supported the convergent and incremental validity of a 28-item scale relative to other theoretically similar instruments and measures of poor bereavement outcome, indicating the instrument's research and clinical usefulness.

Introduction

Of all distressing human experiences, grief is one of the most ubiquitous. Individuals express a variety of reactions to loss ranging from resilient to complicated (Galatzer-Levy & Bonanno, 2012). and cope in myriad ways (Meichenbaum & Myers, 2016). Religion and spirituality are among the most important means by which bereaved individuals cope with crises (Hill & Pargament, 2008), and particularly the death of a loved one (Wortmann & Park, 2008). Many people experience spirituality in bereavement as a comfort; however, increasingly, research shows that a significant subset of grievers finds the opposite to be true (e.g. Burke, Neimeyer, McDevitt-Murphy, Ippolito, & Roberts, 2011). Anger, distrust, and other negative sentiments toward God – who once was viewed as "good," – are relatively common among spiritually inclined grievers, especially when the unbearably painful reality of the death is inconsistent with their prior spiritual beliefs, practices, or experiences (Burke et al., 2011). Specifically, a crisis of faith occurs when

grievers, who once perceived God as providing care and comfort, now perceive that they are being punished or abandoned by a distant, controlling, or authoritative deity (e.g. Burke & Neimeyer, 2014).

Within the context of bereavement, this phenomenon is known as complicated spiritual grief (CSG; Burke & Neimeyer, 2014) – the collapse or erosion of the bereaved individual's sense of relationship to God, which is often accompanied by discord with and/or a distancing from his or her faith community. CSG has been associated contemporaneously and prospectively with other forms of bereavement distress, including anticipatory grief, complicated grief (CG), depression, and post-traumatic stress disorder (PTSD; Burke et al., 2015; Burke & Neimeyer, 2014; Burke et al., 2011). Longitudinal studies indicate that spiritually inclined grievers who struggle in terms of their lost relationship with the deceased also tend to struggle spiritually over time in relation to God and/or their spiritual community (Burke et al., 2011). Studies also show that survivors of violent death loss (e.g. suicide,

homicide, fatal accident) have higher levels of CSG than do survivors of natural death loss (e.g. old age; Burke & Neimeyer, 2014).

Until recently, measurement of CSG was conducted using instruments that were not specifically designed for use with bereaved samples. To address this critical gap, Burke, Neimeyer, Holland, et al. (2014) validated a measure of CSG, called the Inventory of Complicated Spiritual Grief (ICSG). However, subsequent qualitative research (Burke, Neimeyer, Young, Piazza Bonin, & Davis, 2014) not only provided greater clarity about the construct of CSG but also highlighted numerous themes that suggested the need to revise the original measure. Thus, the current study sought to modify, expand, and improve the ICSG to accommodate these new data.

Complicated spiritual grief

Complicated spiritual grief (CSG) is a spiritual crisis during bereavement that compromises the griever's sense of relationship to God and/or the faith community, such that he or she struggles to reestablish spiritual equilibrium following the loss (Burke & Neimeyer, 2014). Findings from a diverse sample of bereaved Christian adults showed that 43% of participants endorsed CSG (Burke, Neimeyer, Young, et al., 2014). This is consistent with other samples, including homicide survivors who reported feeling distant from and angry toward God and fellow church members (Burke et al., 2011) or who pled unsuccessfully to God for a miracle (Thompson & Vardaman, 1997), and spiritually inclined bereaved parents who questioned God's role in the death of their child (Lichtenthal, Currier, Neimeyer, & Keesee, 2010). Intense fury toward God (Burke, Neimeyer, Young, et al., 2014), an inability to trust God's goodness in the face of indescribable anguish (Burke & Neimeyer, 2014), and an existential crisis that makes or breaks ones' faith (Hill & Pargament, 2008) all describe how some mourners experience CSG. Notably, CSG increasingly has been associated with other deleterious forms of bereavement distress and is prevalent at high levels in violently bereaved adults (e.g. Burke & Neimeyer, 2014).

The Inventory of Complicated Spiritual Grief (ICSG)

To assess CSG, Burke et al. (2014) validated a novel, easy-to-use measure called the Inventory of Complicated Spiritual Grief (ICSG). The ICSG systematically evaluates CSG using 18 items and two subscales (Insecurity with God and Disruption in Religious Practice) to capture spiritual reactions to loss beyond that of generic, non-grief-specific measures of spiritual struggle (e.g. the Spiritual Assessment Inventory (Hall & Edwards, 2002); the Brief RCOPE (Pargament, Smith, Koenig, & Perez, 1998); the Attitudes Toward God Scale-9 (Wood, et al., 2010)) designed for use with samples of adults experiencing a range of life stressors. However, Burke, Neimeyer, Young, et al.'s (2014) study revealed additional information about the construct of CSG not found on the original scale.

Need for a revised measure of spiritual crisis in bereavement

Research consistently suggests that CSG represents a compromised spiritual system wherein the bereaved struggle both vertically in terms of their relationship with God and also horizontally in their relationship with their spiritual community. However, Burke et al. (2014) gleaned narrative data from 84 grievers, which, when coupled with focus group data, revealed 17 CSG themes that were not found on the original ICSG. Specifically, focus group members' overarching narrative was one of resentment and doubt toward God, dissatisfaction with the spiritual support received, and substantial changes in their spiritual beliefs and behaviors following the loss. Together, this new information (Burke et al., 2014), CSG's relation to CG, PTSD, and depression (e.g. Burke & Neimeyer, 2014), and the role of traumatic death loss in the development of CSG (e.g. Burke et al., 2011) indicated that developing a modified, expanded instrument to measure CSG was clinically and scientifically warranted. The current study thus sought to revise and expand the ICSG to accommodate new data, to test the scale's psychometric properties using exploratory factor analysis (EFA) and confirmatory factor analysis (CFA), and to evaluate its internal consistency and test–retest reliability, and convergent and discriminant validity with a large, diverse sample of bereaved Christian adults.

Method

Participants

Two groups of participants were recruited for the qualitative and quantitative phases of the study, respectively. In the first case, the lead investigator (LAB) invited 10 Christian grievers who had received grief psychotherapy through her private practice in

Portland, OR to assist in the pilot testing of the ICSG 2.0. Eight clients agreed to participate in a focus group, including five women and three men, all of whom were Caucasian, and had lost a loved one to either natural- (e.g. cancer) or violent causes (e.g. fatal accident). In the second instance, study participants were recruited from Amazon's Mechanical Turk (MTurk), a web-based recruitment and data collection site with an international reach, to ensure a diverse sample of bereaved participants (e.g. varying in ethnicity, age, gender, type of loss).

In both instances, participants (1) were 18 years old or older, (2) endorsed the Christian faith tradition, (3) had been bereaved at least 6 months but no more than 5 years, (4) did not belong to a vulnerable population (e.g. pregnant women), (5) could read English fluently, (6) could operate a computer, and (7) had access to the internet while completing the questionnaires. Of the 1472 individuals who registered for the validation study, we removed those participants with extensive missing data (i.e. missing more than 50% of the total assessment battery; $n = 291$), who did not complete the measures of convergent and discriminant validity ($n = 13$), who did not meet inclusion criteria ($n = 652$), or who had random responding to two out of three validation items ($n = 36$). Finally, we generated boxplots for each item and removed univariate outliers ($n = 40$). Cleaning and vetting of the data yielded a final sample of $N = 440$ usable cases, which was bifurcated into subsamples prior to conducting further analyses.

In terms of demographics, our subsamples were quite similar. Participants were mostly Caucasian (74%), women (64%), between 25–44 years old (64%), who were employed full-time (66%), living in North America (93%), had completed university or trade school (41%), made at least $50,000/year (54%), and had lost a parent or grandparent (48%) to a natural anticipated (e.g. cancer) or natural sudden (e.g. heart attack) death (74%) approximately 2.6 years prior (see Table 1).

Procedure

The development and testing of the proposed new scale included pilot testing through the use of the focus group and validation testing through the use of the large, diverse, online sample.

Scale development

Using all 18 items from the ICSG as its basis, the ICSG 2.0 was developed by using previous focus group members' narratives and other qualitative data (Burke, Neimeyer, Young, et al., 2014) to formulate candidate items for the revised scale. This beta version was critically examined by grief experts with knowledge and experience in assessing and treating CSG, who added additional items based on their clinical experience. Prior to validation, a focus group was conducted to pilot test the new measure to establish its face validity with a sample of spiritually inclined bereaved adults.

Focus group recruitment and data collection

Our goal in conducting a focus group was to gain insight regarding grievers' understanding, attitudes, perceptions, and ideas about CSG (Plummer-D'Amato, 2008). Eight grievers participated in a one-time focus group session that lasted 60 min, and each received a $10 gift card for their time and contribution to this study.

First, focus group participants completed pencil/paper versions of the Background Information and ICSG 2.0. Next, they met together with the focus group leader (a clinical psychologist who did not know them), who answered their study questions prior to their signing the informed consent form. During the audiotaped session, the facilitator asked participants semi-structured questions, allowing time for spontaneous responses and/or prompting them to respond if they wished.

Focus group members addressed issues related to: instruction clarity, response option formatting, item understandability (e.g. confusing wording), particularly relevant/irrelevant items (to self and others), whether they could easily keep in mind that the scale assessed CSG since the loss, other examples of CSG experienced by self or others, and what we might have missed. Finally, we asked "If you could tell us only one thing about your experience of spiritual struggle following loss, what would that be?" Next, the initial pool of ICSG 2.0 candidate items was again reviewed by the team of CSG experts, who used the focus group's feedback and suggested items as a basis for further modification and expansion prior to validity testing of an enlarged 55-item beta version of the scale.

Validation study recruitment and data collection

Participant recruitment and data collection were conducted through MTurk, an online survey system. MTurk has been validated as an efficient and inexpensive means of gathering good quality data for psychological studies (e.g. Berinsky, Huber, & Lenz, 2012),

Table 1. Participant demographic and loss-related information for EFA and CFA samples.

	EFA Sample (n = 220)		CFA Sample (n = 220)	
	Total (n)	%	Total (n)	%
Age	(Range: 19–78 years; M = 38.3 years; SD = 12.1)		(Range: 20–76 years; M = 37.3 years; SD = 12.5)	
18–24	18	8.2	29	13.2
25–34	92	41.8	88	40.0
35–44	49	22.3	45	20.5
45–54	24	10.9	31	14.1
55–64	27	12.3	18	8.2
65+	10	4.5	9	4.1
Gender				
Female	149	67.7	131	59.5
Male	70	31.8	88	40.0
Other	1	<1	1	<1
Race/Ethnicity (if American)				
African American	14	6.4	15	6.8
Asian American	25	11.4	15	6.8
Hispanic/Latino/Latina	12	5.5	17	7.7
Native American	7	3.2	7	3.2
White	158	71.8	168	76.4
Other	1	<1	1	<1
Not American	12	5.5	6	2.7
Continent of Residence				
Asia	13	5.9	5	2.3
Australia/Oceania	1	<1	0	0
Europe	2	<1	5	2.3
North America	201	91.4	209	95.0
South America	3	1.4	1	<1
Employment Status				
Employed full-time	139	63.2	150	68.2
Employed part-time	36	16.4	31	14.1
Not currently employed, looking	12	5.5	16	7.3
Not currently employed, not looking	18	8.2	16	7.3
Full-time student	5	2.3	4	1.8
Other (e.g. retired)	10	<1	9	4.1
Educational Level (Years of education)				
Middle school (8)	0	<1	1	<1
Some high school (<12)	3	1.4	0	<1
High school graduate or GED (12)	17	7.7	24	10.9
Some university or trade school	45	20.5	52	23.6

	n	%	n	%
Completion of university or trade school	97	44.1	84	38.2
Some post-graduate or professional school	17	7.7	20	9.1
Completed post-graduate or professional degree	41	18.6	39	17.7
Household Income				
Less than $10,000	10	4.5	8	3.6
$10,000 to less than $20,000	23	10.5	18	8.2
$20,000 to less than $30,000	21	9.5	25	11.4
$30,000 to less than $40,000	26	11.8	27	12.3
$40,000 to less than $50,000	20	9.1	23	10.5
$50,000 to less than $75,000	58	26.4	57	25.9
$75,000 to less than $100,000	35	15.9	27	12.3
$100,000 to less than $150,000	21	9.5	26	11.8
$150,000 or more	6	2.7	9	4.1
Participant Relationship to the Deceased				
Aunt or uncle	2	<1.0	5	2.3
Cousin	7	3.2	6	2.7
Daughter or son	51	23.2	50	22.7
Friend	14	6.4	13	5.9
Granddaughter or grandson	57	25.9	55	25.0
Grandparent	3	1.4	2	<1.0
Niece or nephew	13	5.9	14	6.4
Parent	9	4.1	14	6.4
Intimate partner/fiancé(e)	25	11.4	29	13.2
Sibling	16	7.3	16	7.3
Spouse	7	3.2	6	2.7
Other (e.g. co-worker)	16	7.3	9	4.1
Cause of Death				
Natural anticipated	95	43.2	111	50.5
Natural sudden	69	31.4	49	22.3
Accident	26	11.8	31	14.1
Violent or traumatic (e.g. homicide, suicide, terrorism, natural disaster)	11	5.0	13	5.9
Other (e.g. medical malpractice)	19	8.6	11	5.0
Years Since Loss	(M = 2.4 years; SD = 1.4)		(M = 2.8 years; SD = 5.6)	

and used successfully by this research team across several studies. Specifically, we recruited participants to "answer a survey about how your spirituality relates to your grief following the death of a loved one," and used the keywords: survey, questionnaires, grief, bereavement, death, loss, faith, religion, and spirituality. MTurk workers received our study's task description, eligibility criteria, anticipated completion time, task instructions, and compensation rate.

Measures

In addition to the Inventory of Complicated Spiritual Grief 2.0 (see Appendix A), to assess background information, convergent and discriminant validity, and to conduct factor analyses, we also administered a total of seven measures, including:

Demographic information

We garnered information about both the deceased and the bereaved participant, such as age, religious affiliation, type of death, and time since loss.

Complicated grief

Two instruments were used to measure complicated grief:

The Persistent Complex Bereavement Inventory (PCBI). The PCBI (Lee, 2015) is a 16-item instrument that measures persistent complex bereavement disorder (PCBD), using three factors that correspond with DSM-5 criteria for PCBD, by assessing symptom frequency using a Likert scale ranging between not at all (no symptomatology) to nearly every day (severe symptomatology). An example item includes: Found it extremely difficult to accept the death. The PCBI yielded strong internal consistency in two samples of bereaved college students ($\alpha = .95$; Lee, 2015). In the present study, the PCBI demonstrated high internal consistency ($\alpha = .95$ for both EFA and CFA subsamples).

The Inventory of Complicated Grief-Revised (ICG-R). The ICG-R (Prigerson & Jacobs, 2001) is a 30-item scale that uses 5-point Likert-style ratings (almost never to always) to measure the frequency of grief symptoms indicative of long-term dysfunction. A representative item is: Memories of _____ upset me. The scale achieved high internal consistency in a sample of homicidally bereft African Americans ($\alpha = .95$; Burke, Neimeyer, & McDevitt-Murphy, 2010). In the

present sample, the ICG-R had very high internal consistency ($\alpha = .97$ in both subsamples).

Convergent validity

Two instruments were used to measure convergent validity:

The Religious and Spiritual Struggles Scale (RSS). The RSS (Exline, Pargament, Grubbs, & Yali, 2014) has 26 items measuring general spiritual/religious struggle using six domains: Divine, moral, doubt, ultimate meaning, demonic, and interpersonal. A sample item includes: Felt hurt, mistreated, or offended by religious/spiritual people. The RSS and its subscales achieved high internal consistency in adult and undergraduate samples ($\alpha = .85$ to .93; Exline et al., 2014). The RSS in the present samples showed very high internal consistency ($\alpha = .97$, EFA; $\alpha = .96$, CFA).

The Negative Religious Coping (NRC) subscale of the Brief RCOPE. The NRC (Pargament et al., 1998) subscale uses seven items to measure negative religious coping. An example item is: Wondered whether God had abandoned me. The NRC subscale has shown good reliability in a sample of family members bereaved of a terminally ill Veteran ($\alpha = .84$; Burke, Neimeyer, Bottomley, & Smigelsky, 2017). Likewise, the NRC subscale achieved good reliability in this study ($\alpha = .90$ and .89 for EFA and CFA subsamples, respectively).

Discriminant validity

Two instruments were used to measure discriminant validity:

The Positive Religious Coping (PRC) subscale of the Brief RCOPE. The PRC (Pargament et al., 1998) subscale uses seven items to measure positive religious coping. An example item includes: Tried to see how God might be trying to strengthen me in this situation. In a sample of violently bereaved African Americans, the PRC subscale showed good internal reliability ($\alpha = .88$; Burke et al., 2011). In this sample, the PRC subscale achieved high internal consistency reliability ($\alpha = .93$ and .94 for EFA and CFA, respectively).

The Inventory of Stressful Life Events Scale-Short Form (ISLES-SF). The ISLES-SF (Holland, Currier, & Neimeyer, 2014) assesses meaning made of stressful life experiences, using a six-item scale and Likert response options ranging from strongly agree to

strongly disagree. A representative item is: This event is incomprehensible to me. In the present sample, the ISLES-SF had high internal consistency reliability ($\alpha = .92$, EFA; $\alpha = .91$, CFA).

Data analysis plan

Data cleaning and exploratory factor analyses were conducted using SPSS (Mac and Windows Version 24.0). Kolmogorov–Smirnov value of $p < .001$ (Pallant, 2013) indicated that the data were not normally distributed. Bartlett's test of sphericity yielded a significant value of χ^2 (1485) = 10105.730 ($p < .001$) and the Kaiser-Meyer-Olkin (Kaiser, 1974) measure of sampling adequacy was .958 for the original 55-item scale, indicating that the data were appropriate for EFA (Pallant, 2013). We split the dataset in half for EFA ($n = 220$) and CFA ($n = 220$), rendering an adequate sample size for EFA (Hair, Black, Babin, & Anderson, 2010) and yielding a participant-to-item ratio ($N{:}p$; Hair, Black, Babin, Anderson, & Tatham, 2006) of 4:1 (i.e. 4 subjects for each of the 55 items).

We used the principal axis factoring method to analyze only the common variance and an oblique (i.e. direct oblimin) rotation method, which assumes that factors are correlated (Mvududu & Sink, 2013). Our criteria for item selection were: (a) items with communalities $> .50$ (Kline, 1994), (b) the Guttman-Kaiser criterion of eigenvalues > 1.00, (c) items with factor loadings of .30 or higher, and (d) factors with 3 or more items (Costello & Osborne, 2005). Items with cross-loadings $>.30$ were removed, and we examined the scree plot for factor selection.

We used EFA to obtain optimal item pool and factor structure, and CFA to cross-validate the construct validity of the instrument. CFA was performed using SPSS Amos (Windows Version 24.0). The CFA model was tested using chi-square goodness-of-fit, Root Mean Square Residual, Normed Fit, Comparative Fit, and Root Mean Square Error of Approximation (Mvududu & Sink, 2013).

With the EFA and CFA subsamples, we examined bivariate correlations between the ICSG 2.0 and the NRC subscale and the RSS, and the PRC subscale and the ISLES-SF to test convergent and discriminant validity, respectively. We examined differences between demographic factors and ICSG 2.0 total and subscale scores using nonparametric equivalent tests when necessary to correct for heterogeneous variances (Pallant, 2013). Incremental validity was assessed using multiple regression analyses in both subsamples to test the association between ICSG 2.0 and ICG-R

scores after variance associated with the NRC measure was accounted for. We also examined the internal consistency reliability of the total scale, as well as for the three factors extricated through factor analysis. Finally, Pearson correlations assessed test-retest reliability at 10–14 weeks with a subset of participants.

Results

Exploratory factor analysis

The EFA subsample ($n = 220$) yielded a parsimonious three-factor, 28-item factor structure representing the best performing items based on our preestablished item retention criteria. Bartlett's test of sphericity remained favorable, with a significant value of χ^2 (378) = 4815.251 ($p < .001$) and a KMO value of .954. Each of the three factors had eigenvalues greater than 1.00 and all items possessed communalities greater than .50, with the exception of two items with communalities of .43 and .47. EFA resulted in three factors that we named based on content of item clusters: (a) Estrangement from Spiritual Community, (b) Insecurity with God, (c) Disruption in Religious Practices (see Tables 2 and 3). Moderate correlations (i.e. .55–.67) indicated that relations between factors were high enough to support CSG as the structure's overarching construct, but low enough to indicate distinctness between factors.

Confirmatory factor analysis

With the CFA subsample ($n = 220$), we tested the three-factor exploratory structure for item selection. The CFA model demonstrated adequate model fit after model specification, χ^2 (341) = 817.404, $p < .001$; RMR = .069; NFI = .822; CFI = .887; RMSEA = .080, 90% confidence interval (CI) = .073–.087). Although chi-square fit indices should be nonsignificant ($p > .05$), significant chi-square is common with large samples and data from Likert scales. CFA supported a three-factor, 28-item scale, with each item loading above .60 (see Figure 1).

Internal consistency reliability

The total 28-item ICSG 2.0 demonstrated high internal consistency reliability ($\alpha = .96$ for both subsamples). Good internal consistency also was found for the 11-item Estrangement from Spiritual Community subscale ($\alpha = .94$ and .93 for EFA and CFA, respectively), the 11-item Insecurity with God subscale ($\alpha = .94$ and .93 for EFA and CFA,

Table 2. Factor loadings for exploratory factor analysis of the ICSG 2.0.

Item		Factor	
	1	2	3
43. People in my spiritual community don't want me to express my grief much or at all.	.914		
38. My spiritual community thinks I've been grieving for too long.	.821		
14. My spiritual community appears to care more about their own comfort than my pain.	.793		
52. Sharing my spiritual struggle with my spiritual community seems to complicate our relationship.	.775		
19. My spiritual community places unrealistic expectations on my grieving process (e.g. suggesting I should "get over it").	.743		
34. People in my spiritual community act as if my loved one's death didn't happen.	.689		
46. My grief responses often contradict my spiritual community's spiritual beliefs.	.607		
47. Since my loss, my spiritual beliefs are overshadowed by the beliefs of my spiritual community.	.567		
48. My spiritual community might reject me because of the way that my loss has re-shaped my spiritual beliefs.	.543		
29. My spiritual community criticizes my anger toward God.	.525		
44. It is challenging to find a spiritual leader to discuss difficult spiritual issues with.	.436		
7. I feel it is unfair that God took my loved one.		.868	
26. I'm confused as to why God would let this happen.		.855	
11. I struggle with accepting how a good God allowed bad things to happen.		.745	
36. I am a faithful believer, so I don't understand why God didn't protect me.		.734	
2. I feel angry at God.		.729	
17. I sometimes feel like God is punishing me.		.708	
32. I sometimes feel disappointed with God.		.671	
27. I sometimes feel abandoned by God.		.642	
35. My doubts about my spiritual beliefs trouble me.		.566	
41. I feel like I have been robbed of the future God had planned for me.		.533	
6. I no longer feel safe and protected by God, knowing that anything can happen to anyone.		.514	
13. I find that spiritual/religious activities (e.g. prayer, worship, Bible reading) are no longer fulfilling.			.907
28. I have lost the desire to worship.			.849
8. I go out of my way to avoid spiritual/religious activities (e.g. prayer, worship, Bible reading).			.667
18. I find it difficult to pray.			.658
37. I have walked away from my faith.			.591
3. I have withdrawn from my spiritual community.			.471

Note: Factor 1: Estrangement from Spiritual Community; Factor 2: Insecurity with God; Factor 3: Disruption in Religious Practice.

Table 3. ICSG 2.0 descriptive statistics of the EFA subsample.

| Item		Factor	Scores M	SD
43.	People in my spiritual community don't want me to express my grief much or at all.	1	1.64	1.10
38.	My spiritual community thinks I've been grieving for too long.	1	1.62	1.05
14.	My spiritual community appears to care more about their own comfort than my pain.	1	1.88	1.16
52.	Sharing my spiritual struggle with my spiritual community seems to complicate our relationship.	1	1.83	1.21
19.	My spiritual community places unrealistic expectations on my grieving process (e.g. suggesting I should "get over it").	1	1.77	1.12
34.	People in my spiritual community act as if my loved one's death didn't happen.	1	1.65	1.10
46.	My grief responses often contradict my spiritual community's spiritual beliefs.	1	1.79	1.10
47.	Since my loss, my spiritual beliefs are overshadowed by the beliefs of my spiritual community.	1	1.65	1.03
48.	My spiritual community might reject me because of the way that my loss has re-shaped my spiritual beliefs.	1	1.72	1.14
29.	My spiritual community criticizes my anger toward God.	1	1.54	1.02
44.	It is challenging to find a spiritual leader to discuss difficult spiritual issues with.	1	2.06	1.26
7.	I feel it is unfair that God took my loved one.	2	2.42	1.36
26.	I'm confused as to why God would let this happen.	2	2.14	1.28
11.	I struggle with accepting how a good God allowed bad things to happen.	2	2.25	1.27
36.	I am a faithful believer, so I don't understand why God didn't protect me.	2	1.80	1.74
2.	I feel angry at God.	2	1.85	1.15
17.	I sometimes feel like God is punishing me.	2	1.95	1.23
32.	I sometimes feel disappointed with God.	2	1.89	1.10
27.	I sometimes feel abandoned by God.	2	1.90	1.16
35.	My doubts about my spiritual beliefs trouble me.	2	1.91	1.10
41.	I feel like I have been robbed of the future God had planned for me.	2	1.66	1.10
6.	I no longer feel safe and protected by God, knowing that anything can happen to anyone.	2	1.74	1.12
13.	I find that spiritual/religious activities (e.g. prayer, worship, Bible reading) are no longer fulfilling.	3	1.65	1.04
28.	I have lost the desire to worship.	3	1.88	1.26
8.	I go out of my way to avoid spiritual/religious activities (e.g. prayer, worship, Bible reading).	3	1.64	1.10
18.	I find it difficult to pray.	3	1.94	1.17
37.	I have walked away from my faith.	3	1.63	1.08
3.	I have withdrawn from my spiritual community.	3	1.57	0.98
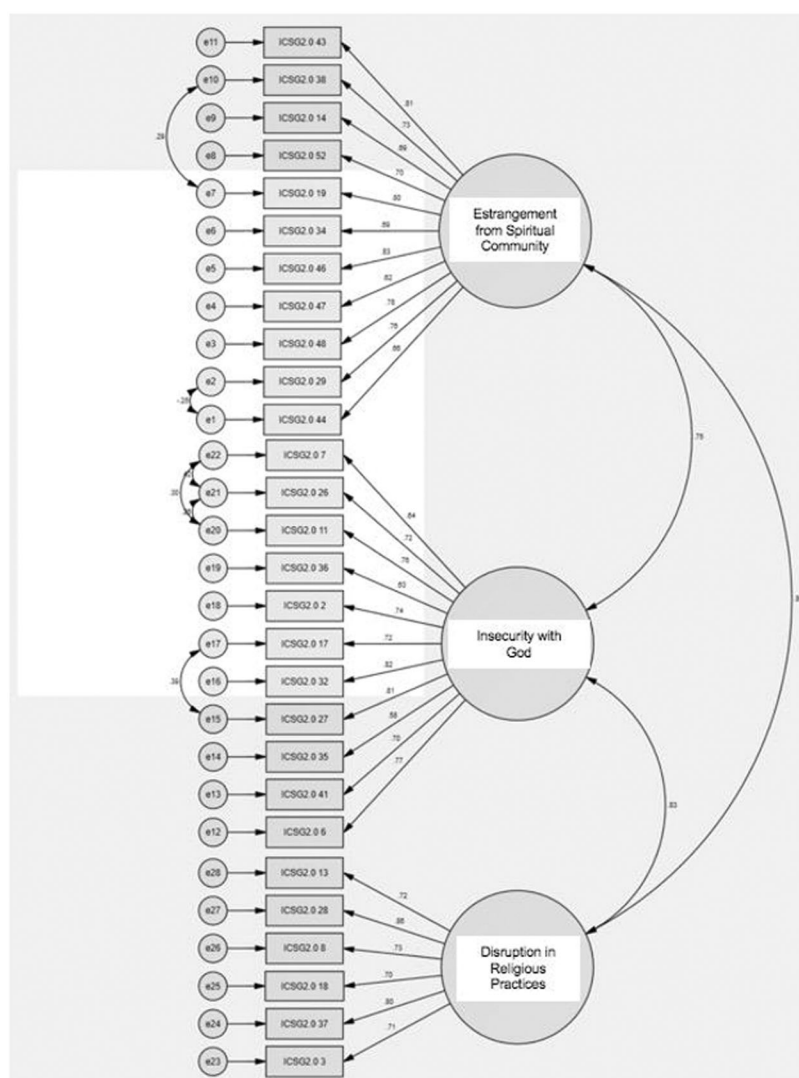
Figure 1. Three-factor confirmatory factor analysis for the 28-item ICSG 2.0.

respectively), and the 6-item Disruption in Religious Practices subscale ($\alpha = .90$ and .89 for EFA and CFA, respectively).

Overall, adequate test-retest correlations over a period of 10-14 weeks were obtained with a subset of 28 participants for the total ICSG 2.0 ($r = .82$, $p < .001$), for the Estrangement from Spiritual Community subscale ($r = .84$, $p < .001$), and the Insecurity with God subscale ($r = .72$, $p < .001$); however, the Disruption in Religious Practices subscale showed a weaker association ($r = .63$, $p < .001$).

Validity

Convergent validity

ICSG 2.0 total- and subscale scores were significantly associated with each measure in the anticipated directions. Specifically, high ICSG 2.0 scores correlated with high negative religious coping and spiritual struggle scores (see Table 4).

Discriminant validity

High ICSG 2.0 total- and subscale scores correlated with lower PRC scores and meaning making scores. Small effect sizes (i.e. $r < .30$) provided evidence of discriminant validity between the ICSG 2.0 and the PRC subscale of the Brief RCOPE, but not for the ICSG 2.0 and the ISLES, which yielded higher effect sizes. The correlation of the PRC subscale and the *Insecurity with God* subscale of the ICSG 2.0, which was nonsignificant in the EFA subsample (see Table 4), provided further support for discriminant validity, and consistent with research showing no relation between PRC and spiritual- or grief distress (e.g. Burke & Neimeyer, 2014).

Table 4. Correlations between the ICSG 2.0 and measures of related constructs in the EFA and CFA subsamples.

Measure	EFA Subsample				CFA Subsample			
	Total	Factor 1	Factor 2	Factor 3	Total	Factor 1	Factor 2	Factor 3
Inventory of Complicated Grief – Revised	.642**	.550**	.669**	.442**	.621**	.547**	.645**	.418**
Persistent Complex Bereavement Inventory	.619**	.516**	.650**	.441**	.627**	.570**	.626**	.437**
Brief RCOPE: Negative	.720**	.621**	.713**	.555**	.762**	.677**	.734**	.608**
Brief RCOPE: Positive	−.184**	−.13**	−.129**	−.288**	−.270**	−.176**	−.240**	−.362**
RSS Total	.807**	.677**	.797**	.662**	.841**	.720**	.790**	.664**
RSS F1: Divine Struggles	.778**	.595**	.848**	.591**	.791**	.614**	.854**	.605**
RSS F2: Demonic Struggles	.645**	.574**	.598**	.546**	.620**	.587**	.557**	.500**
RSS F3: Interpersonal Struggles	.796**	.736**	.703**	.689**	.801**	.771**	.689**	.679**
RSS F4: Moral Struggles	.647**	.536**	.644**	.532**	.625**	.564**	.589**	.499**
RSS F5: Doubt Struggles	.679**	.546**	.701**	.540**	.698**	.858**	.692**	.572**
RSS F6: Ultimate Meaning Struggles	.782**	.638**	.773**	.669**	.786**	.673**	.769**	.640**
Integration of Stressful Life Experiences Scale – Short Form (ISLES-SF)	−.538**	−.408**	−.621**	−.349**	−.526**	−.424**	−.591**	−.332**
ISLES-SF F1 Comprehensibility	−.454**	−.311**	−.571**	−.265**	−.431**	−.317**	−.535**	−.232**
ISLES-SF F2 Footing in the World	−.539**	−.442**	−.576**	−.378**	−.540**	−.465**	−.558**	−.380**

*Correlation is significant at the 0.05 level (2-tailed)
**Correlation is significant at the 0.01 level (2-tailed)
Note: Factor 1: Estrangement from Spiritual Community; Factor 2: Insecurity with God; Factor 3: Disruption in Religious Practices.

Demographic and loss-related analyses

Table 5 shows demographic and loss-related comparisons. Age was negatively associated with CSG in both the EFA and CFA subsamples, with younger adults endorsing higher levels of CSG on total ICSG 2.0 ($r = −.35$, $p < .001$), Estrangement from Spiritual Community ($r = −.28$, $p < .001$), Insecurity with God ($r = −.33$, $p < .001$), and Disruption in Religious Practices ($r = −.32$, $p < .001$) in the EFA subsample, as well as in the CFA subsample on the total ICSG 2.0 ($r = −.17$, $p = .01$) and on the Insecurity with God subscale ($r = −.175$, $p = .009$). However, age was not significantly associated with CSG on the Estrangement from Spiritual Community and Disruption in Religious Practices subscales in the CFA subsample.

No significant differences between ICSG 2.0 total- or subscale scores for income level were found in either subsample. In terms of gender comparisons, men generally had significantly higher CSG than women in both subsamples (total scores, EFA, $U = 4394.5$, $z = −2.03$, $p = .04$; CFA, $U = 4793.5$, $z = −2.24$, $p = .03$; Estrangement from Spiritual Community, EFA, $U = 4303.5$, $z = −2.261$, $p = .02$; CFA, $U = 4470.5$, $z = −2.95$, $p < .01$; Disruption in Religious Practices, EFA, ns; CFA, $U = 4748.0$, $z = −2.38$, $p = .02$). As the single exception, significant gender differences were not found for the Insecurity with God subscale in either subsample.

Except for Insecurity with God, racial/ethnic minorities had significantly higher CSG than Whites within the American sample (total scores; EFA, ns; CFA, $U = 3698.0$, $z = −2.41$, $p = .02$; Estrangement from Spiritual Community, EFA, $U = 4035.0$, $z = −2.50$, $p = .01$; CFA, $U = 3343.0$, $z = −3.30$, $p = .001$; Disruption in Religious Practices, EFA, ns; CFA, $U = 3803.5$, $z = −2.19$, $p = .03$).

Fine-grained examination of loss-related factors also revealed some intriguing patterns. For example, significant differences between kinship and CSG emerged (total score, EFA, $F(4, 215) = 3.68$, $p = .006$; CFA, ns; Estrangement from Spiritual Community, EFA, $F(4, 215) = 2.53$, $p = .04$; CFA, ns; Insecurity with God, EFA, $F(4, 215) = 4.32$, $p = .002$; Disruption in Religious Practices, EFA, ns; CFA, ns). Interestingly, Tukey's post hoc tests with the EFA subsample revealed that grievers who lost an intimate partner had significantly higher CSG than those bereaved of all other relationships (e.g. child, co-worker). Mean scores of EFA and CFA groups were similar, with participants bereaved of an intimate partner endorsing higher levels CSG.

Table 5. Descriptive statistics of demographic and loss-related factors.

| | | EFA subsample | | | | | | CFA Subsample | | | |
Variable	n	Total M (SD)	Factor 1 M (SD)	Factor 2 M (SD)	Factor 3 M (SD)	n	Total M (SD)	Factor 1 M (SD)	Factor 2 M (SD)	Factor 3 M (SD)
Income										
< $10,000–19,999	33	56.55 (22.19)	22.55 (10.38)	22.88 (9.86)	11.12 (4.99)	26	59.58 (23.18)	22.00 (8.81)	24.00 (10.61)	13.58 (5.74)
$20,000–29,000	21	52.14 (28.74)	20.05 (12.30)	21.86 (11.96)	10.24 (5.78)	25	55.68 (24.29)	21.76 (9.86)	22.12 (12.15)	11.80 (6.13)
$30,000–39,000	26	53.35 (25.78)	20.35 (10.33)	22.96 (12.00)	10.04 (5.81)	27	51.15 (20.43)	19.96 (9.54)	20.59 (8.42)	10.59 (5.35)
$40,000–49,000	20	50.35 (25.08)	19.15 (10.32)	20.85 (10.38)	10.35 (5.65)	23	53.61 (20.94)	22.39 (8.70)	20.48 (8.62)	10.74 (4.82)
$50,000–74,000	58	50.16 (21.09)	17.67 (8.04)	21.88 (10.50)	10.60 (5.90)	57	49.49 (19.02)	18.40 (8.37)	21.63 (8.65)	9.46 (4.25)
$75,000–99,000	35	45.71 (19.79)	16.86 (8.34)	19.94 (9.34)	8.91 (4.66)	27	51.41 (23.62)	19.15 (8.69)	21.70 (10.41)	10.56 (5.67)
$100,000 to >150,000	27	50.00 (21.26)	19.41 (10.01)	19.89 (8.81)	10.70 (5.55)	35	45.34 (19.75)	16.20 (8.92)	19.31 (9.35)	9.83 (5.10)
Gender										
Female	149	48.36 (20.61)	18.19 (9.20)	20.36 (9.21)	9.80 (4.98)	131	48.31 (18.66)	17.92 (7.72)	20.54 (9.03)	9.85 (4.54)
Male	71	56.46 (26.04)	21.20 (10.43)	23.92 (11.96)	11.35 (6.27)	89	56.44 (24.11)	21.98 (10.00)	22.56 (10.32)	11.90 (6.00)
Race/Ethnicity (if American)										
White	153	48.95 (21.57)	18.05 (8.95)	20.73 (10.02)	10.18 (5.43)	162	49.22 (19.92)	18.31 (8.23)	20.82 (9.46)	10.09 (4.83)
Racial/ethnic minority	67	55.58 (24.85)	21.72 (10.84)	23.30 (10.73)	10.57 (5.57)	58	58.22 (23.91)	23.03 (9.86)	22.86 (9.92)	12.33 (6.10)
Participant relationship to deceased										
Immediate family	133	47.68 (22.22)	18.08 (9.62)	19.83 (9.82)	9.77 (5.26)	138	49.69 (19.92)	19.17 (8.68)	20.14 (8.85)	10.37 (5.08)
Extended family	30	53.70 (19.42)	19.40 (9.11)	23.47 (9.58)	10.83 (5.19)	33	52.45 (24.10)	18.27 (9.47)	23.85 (11.85)	10.33 (5.55)
Friend	14	56.07 (24.68)	22.29 (11.68)	23.21 (9.91)	10.57 (4.89)	13	50.92 (20.88)	20.54 (9.02)	20.38 (8.05)	10.00 (4.51)
Romantic partner or fiancé(e)	31	63.10 (24.51)	23.29 (9.60)	27.35 (11.27)	12.45 (6.68)	29	59.52 (24.08)	22.69 (9.47)	24.21 (9.73)	12.62 (6.10)
Other	12	43.42 (19.57)	16.25 (6.62)	18.17 (9.43)	9.00 (4.75)	7	53.57 (22.72)	18.43 (7.68)	23.57 (11.87)	11.57 (4.76)
Cause of death										
Nonviolent	164	48.59 (22.35)	18.47 (9.33)	20.07 (9.99)	10.05 (5.48)	160	50.06 (20.93)	18.86 (8.48)	20.61 (9.58)	10.59 (5.25)
Violent	37	61.03 (22.95)	22.65 (10.67)	27.24 (10.32)	11.14 (5.37)	44	58.27 (23.16)	22.50 (9.79)	24.43 (9.48)	11.34 (5.75)
Other	19	52.00 (21.67)	18.37 (9.81)	22.79 (9.05)	10.84 (5.59)	16	48.63 (17.78)	18.50 (9.57)	20.38 (8.99)	9.75 (3.94)

Note: Factor 1: Estrangement from Spiritual Community; Factor 2: Insecurity with God; Factor 3: Disruption in Religious Practices.

Violent death loss (e.g. suicide, homicide, or accident) was associated with significantly higher CSG on two dimensions of the construct than nonviolent death loss (e.g. cancer; total scores, EFA, $F(2, 217) = 4.70$, $p = .01$; CFA, ns; Estrangement from Spiritual Community, EFA, $F(2, 217) = 2.92$, $p = .056$; CFA, $F(2, 217) = 3.06$, $p = .05$; Insecurity with God, EFA, $F(2, 217) = 8.00$, $p < .001$; CFA, $F(2, 217) = 2.90$, $p = .059$). However, this difference was not evident on Disruption in Religious Practices (EFA, ns; CFA, ns).

Incremental validity

Finally, higher ICSG 2.0 scores were associated with higher CG scores, even after controlling for NRC scores in both subsamples (EFA, $\beta = .32$, $p < .001$; CFA, $\beta = .35$, $p < .001$), supporting the new measure's incremental validity over a validated general purpose measure of spiritual struggle.

Discussion

Conducting an earlier qualitative inquiry with a diverse sample of spiritually distressed survivors (Burke, Neimeyer, Young, et al., 2014) enabled us to garner data to bolster our existing measure, the ICSG (Burke, Neimeyer, Holland, et al., 2014). Fine-grained analyses of participant narratives suggested candidate items for a revised scale – the ICSG 2.0 – with apparent face validity and clinical utility. Thus, developing the ICSG 2.0 and testing its psychometric properties was the focus of our study.

This study provides initial evidence for a 3-factor, 28-item revised measure of spiritual distress in bereavement demonstrating good psychometric properties, including replication with CFA. Specifically, testing of the ICSG 2.0 with a diverse sample of Christian bereaved adults revealed that the instrument performed well in terms of high internal consistency reliability, adequate test-retest reliability, and evidence of convergent, discriminant, and incremental validity with other established instruments. However, Disruption in Religious Practices revealed more modest test-retest reliability across a period of several weeks. While this could reflect lower stability for this dimension of CSG, it is also possible that participants' behavioral engagement with their faith was actually more variable across time than the attitudinal dimensions of their spiritual struggle, as might be expected if they were to experience ongoing disenchantment with God or members of their spiritual communities, while continuing to join sporadically in worship services and rituals. A more substantial longitudinal study could shed light on temporal shifts in the expression of spiritual struggle in bereavement.

With regard to CG, our results are consistent with Burke, Neimeyer, Holland et al. (2014) study, such that grievers in our sample with high levels of CSG on generic instruments like the R-COPE or high levels of CG also had high ICSG 2.0 scores. Likewise, participants with high CSG reported lower levels of sense-making and higher ultimate meaning struggles. In fact, grievers with high ICSG 2.0 scores not only scored high on all aspects of CSG (e.g. NRC, interpersonal-, doubt-, and ultimate meaning struggles), but also on divine- and demonic struggles as measured by the RSS, suggesting that CSG is experienced by spiritually inclined grievers in multiple clinically significant domains (Burke et al., 2011).

Exploration of demographic factors revealed interesting variations in ICSG 2.0 scores. For example, in contrast to Burke et al. (2014) who found no differences on the original ICSG in terms of gender, age, and specific relationship category, we found that being younger, male, and losing an intimate partner exacerbated participants' spiritual reactions to the death as assessed by the ICSG 2.0, especially in terms of relating to one's spiritual community – a dimension of spiritual distress addressed more explicitly on the revised measure. Our finding that CSG is more pronounced in younger mourners might be explained by the evolving spiritual identity and religious practices of emerging adults/Millennials. Although men and women did not differ in terms of their level of discontent with God, males struggled more in terms of engagement with their religious relationships and practices, which might reflect men's generally lower interest and participation in religion (Pew Research Center, 2018, "The Gender Gap in Religion," para. 2), especially when faith is further compromised by loss. Our finding that loss of an intimate partner was uniquely associated with CSG relative to other relationship types is surprising, especially in light of studies showing that being either the parent or spouse/partner of the deceased is a risk factor for poor bereavement outcome (Burke & Neimeyer, 2013). Perhaps grievers made single by a loss have a more difficult time re-engaging in their spiritual community and/or feel more lost in terms of knowing God's plan for their life in their partner's absence. Follow-up studies are needed to determine if spiritual distress, per se, has an especially negative effect on specific types of relationship loss.

Likewise, in contrast to Burke et al. (2014) who found that Caucasians completing the original ISCG had higher spiritual distress, this same demographic group displayed less distress on the ICSG 2.0, particularly with regard to their spiritual community and religious practices. Such divergent findings suggest that further research with diverse samples is needed to understand the role of race/ethnicity in CSG. In contrast, violent death loss proved to be a robust risk factor for CSG in both previous research (Burke et al., 2011; Burke, Neimeyer, Holland, et al., 2014; Burke & Neimeyer, 2014) and in the present study. Unsurprisingly, our violently bereaved mourners experienced both more global spiritual distress and more discontent in their relationships with God and their spiritual community. Grievers' lived experiences (Burke et al., 2014) help explain the "why" of this, such that, on one hand, everything about the nature of violent death is incongruent with a loving God, and, on the other hand, stigmatization and ostracism by one's spiritual family can be unbearably painful and isolating.

Limitations and future directions

The present study provides substantial evidence for the validity, factorial structure, and reliability of the ICSG 2.0, suggesting that this improved measure should prove useful in both research and clinical settings ongoing. However, the ICSG 2.0 is not without limitations. For instance, expanding beyond MTurk as a sampling source would be valuable in future studies in order to more confidently generalize to other populations (e.g. clinical samples, grievers without Internet access).

Still, although a majority of our participants were 25–44 years old ($M = 37$ years), studies using non-web data collection means often attract mostly similarly aged adults (e.g. 20–33 years; Burke et al., 2014). Additionally, unlike grievers who were recruited using more traditional means (e.g. through churches), or who contribute without being compensated, MTurk workers participate primarily to be monetarily compensated, which may have affected participants' responses. Our cross-sectional, correlational study also meant that possible causal relations between variables could not be inferred.

Future studies should include mourners who endorse other monotheistic traditions such as Judaism or Islam, or other faith traditions such as Buddhism, which emphasizes impermanence and encourages meaning-making in the face of suffering. That said,

the development of a one-size-fits-all scale is unlikely, especially given that CSG is experienced differently by grievers regardless of one's particular faith tradition (Burke, Neimeyer, Young, et al., 2014). Thus, although spiritual struggle might be expressed in terms of disruptions of spiritual communities and practices across different religions, "insecurity with God," understood in terms of compromised attachment to what was once a security enhancing being, may be irrelevant for traditions that do not conceive the divine in these terms. Thus, these differences warrant further exploration, as does the role of attachment style as a predisposing factor for spiritual struggle in general, and security with God in particular. In fact, even grievers who do not endorse a faith tradition *per se* – who rely instead on naturalistic, practical, or philosophic worldviews to make sense of the world – likely would benefit from research exploring ways to understand and capture the existential challenges inherent in life and loss.

In conclusion, the ICSG 2.0 shows potential as a valid and multidimensional tool for researchers, mental health professionals, and clergy alike to understand, assess, and document grief-related spiritual crisis to facilitate healing in bereavement for grievers and their spiritual communities.

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Appendix A

Inventory of Complicated Spiritual Grief—2.0 (ICSG 2.0)
  Important points to underline read before completing this questionnaire:

- During bereavement, many people experience struggles, concerns, or doubts regarding spiritual or religious issues.
- The purpose of this scale is to understand how you have been coping spiritually since your loss.
- On the list of items below there are no right or wrong answers. The best answer is the one that most accurately reflects your experience. If a statement does not apply to you or your situation, simply mark N/A (not applicable).
- When items refer to your "spiritual community," please allow that to represent whatever *spiritual community* means to you. It's meant to include all spiritually inclined individuals in your social network, for instance, fellow believers, members of your church, spiritually like-minded friends or family, etc.
- Please read each statement with the loss you are currently grieving in mind.
- We want you to respond based on how you *actually* feel, not how you believe you *should* feel.
- Please think about your loss of _____, and then read each statement carefully.
- Choose the answer that best describes how you have been feeling *about your loss* during the **past month** including today.

Since the death of _____	Not at all true/ NA	A little true	Somewhat true	Mostly true	Very definitely true
1. People in my spiritual community don't want me to express my grief much or at all.	0	1	2	3	4
2. I feel it is unfair that God took [LOVED ONE].	0	1	2	3	4
3. My spiritual community appears to care more about their own comfort than my pain.	0	1	2	3	4
4. I struggle with accepting how a good God allows bad things to happen.	0	1	2	3	4
5. My spiritual community places unrealistic expectations on my grieving process (e.g. suggesting I should "get over it").	0	1	2	3	4
6. I feel angry at God.	0	1	2	3	4
7. My grief responses often contradict my spiritual community's spiritual beliefs.	0	1	2	3	4
8. I sometimes feel disappointed by God.	0	1	2	3	4
9. I find that spiritual/religious activities (e.g. prayer, worship, Bible reading) are no longer fulfilling.	0	1	2	3	4
10. People in my spiritual community act as if [LOVED ONE]'s death didn't happen.	0	1	2	3	4
11. It is challenging to find a spiritual leader to discuss difficult spiritual issues with.	0	1	2	3	4
12. I sometimes feel like God is punishing me.	0	1	2	3	4
13. I'm confused as to why God would let this happen.	0	1	2	3	4
14. My spiritual community criticizes my anger toward God.	0	1	2	3	4
15. I am a faithful believer, so I don't understand why God didn't protect me.	0	1	2	3	4
16. My spiritual community thinks I've been grieving for too long.	0	1	2	3	4
17. Since my loss, my spiritual beliefs are overshadowed by the beliefs of my spiritual community.	0	1	2	3	4
18. Sharing my spiritual struggle with my spiritual community seems to complicate our relationship.	0	1	2	3	4
19. I sometimes feel abandoned by God.	0	1	2	3	4
20. My doubts about my spiritual beliefs trouble me.	0	1	2	3	4
21. I have lost my desire to worship	0	1	2	3	4
22. I no longer feel safe and protected by God, knowing that anything can happen to anyone.	0	1	2	3	4
23. My spiritual community might reject me because of the way that my loss has re-shaped my spiritual beliefs.	0	1	2	3	4
24. I feel like I have been robbed of the future God had planned for me.	0	1	2	3	4
25. I go out of my way to avoid spiritual/religious activities (e.g. prayer, worship, Bible reading).	0	1	2	3	4
26. I have walked away from my faith.	0	1	2	3	4
27. I find it difficult to pray.	0	1	2	3	4
28. I have withdrawn from my spiritual community.	0	1	2	3	4

OPEN-ENDED ITEMS
If your spiritual struggle has been experienced in ways not covered by the items above, please add your statements below:

	0	1	2	3	4
1._____	0	1	2	3	4
2._____	0	1	2	3	4
3._____	0	1	2	3	4
4._____	0	1	2	3	4
5._____	0	1	2	3	4

Note:.
The ICSG 2.0 is placed in the public domain to encourage its use in clinical assessment and research. No formal permission is therefore required for its reproduction and use by others, beyond appropriate citation of the present article.

Scoring Instructions:
A total ICSG 2.0 score can be calculated by summing all 28 items and dividing that sum by 28.
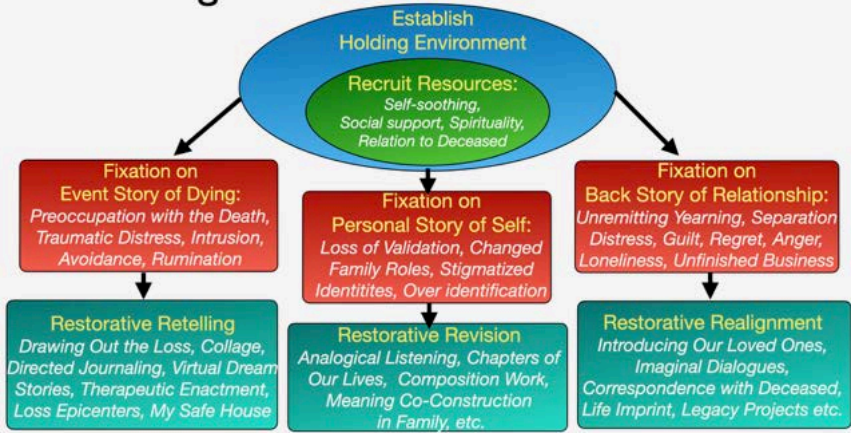Subscales by item #
(calculated by summing the items and dividing by the number of items in parentheses):
Insecurity with God (13): 2, 4, 6, 8, 11, 12, 13, 14, 15, 19, 20, 22, 24
Estrangement from Spiritual Community (9): 1, 3, 5, 7, 10, 16, 17, 18, 23
Disruption in Religious Practices (6): 9, 21, 25, 26, 27, 28

Meaning Reconstruction in Suicide Loss

Establish Holding Environment

Recruit Resources:
Self-soothing, Social support, Spirituality, Relation to Deceased

Fixation on Event Story of Dying:
Preoccupation with the Death, Traumatic Distress, Intrusion, Avoidance, Rumination

Fixation on Personal Story of Self:
Loss of Validation, Changed Family Roles, Stigmatized Identities, Over identification

Fixation on Back Story of Relationship:
Unremitting Yearning, Separation Distress, Guilt, Regret, Anger, Loneliness, Unfinished Business

Restorative Retelling
Drawing Out the Loss, Collage, Directed Journaling, Virtual Dream Stories, Therapeutic Enactment, Loss Epicenters, My Safe House

Restorative Revision
Analogical Listening, Chapters of Our Lives, Composition Work, Meaning Co-Construction in Family, etc.

Restorative Realignment
Introducing Our Loved Ones, Imaginal Dialogues, Correspondence with Deceased, Life Imprint, Legacy Projects etc.

Adult Surviving Siblings:
The Disenfranchised Grievers

Christina Zampitella[1]

Adult siblings have a relationship unique to all others. They share not only 50% of their biological composition but a familial story. They expect to outlive their parents, but this expected trajectory of life and loss is not followed when one sibling dies, leaving behind an adult surviving sibling. These survivors compose a group of disenfranchised grievers, complicating an already painful grieving process. For clinicians, it is essential not only that the bereavement process for these specific grievers be understood but also that they know the most effective interventions to ensure an uncomplicated grieving process. This article will explore adult sibling loss and the familial changes that occur as a result and will suggest specific considerations in group therapy.

KEYWORDS: Siblings; adult sibling; disenfranchised; grief; grief group; bereavement.

The sibling relationship is distinctive in comparison to all other human relationships. Siblings share personal and familial history, experiences, values, and traditions; are often each other's first playmates and confidants; and even share 50% of their genetic composition. They can spend 80%–100% of their lifetimes with each other, with the feeling of affection and closeness often increasing with age (Davies, 2003). It is the most equal of all familial relationships. Siblings expect to outlive their parents and grow old together in what may be one of the most intimate relationships of their lives. However, the death of a sibling signals the end to such promise and marks the beginning of a unique and intense loss experience. Unfortunately, a review of the literature in the field of psychology (and in other fields such as thanatology and medicine) reveals only a handful of studies that focus attention on this group of

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unique grievers. In fact, one need only review the books and journals that address death, dying, and grief to recognize that most studies, even in this specialized field, focus on children and adolescent loss of siblings. This article will focus on adult surviving siblings as a distinctive subgroup of the bereaved and will examine the effects of disenfranchisement from individual and larger systems viewpoints. Finally, *the clinical implications for psychological treatment will be considered.*

LACK OF RESEARCH IN EDUCATIONAL SYSTEMS

Despite the universal nature of death, dying, and grief, how people experience their grieving processes and construct their awareness of death has been, in general, omitted from the educational, clinical training, and professional experiences of the mental health and medical practitioner (Dickinson & Leming, 2007; Leviton, 1977; Mallory, 2003). Even the basics of thanatology (death, dying, and grief) are rarely covered in graduate school programs that train clinicians. Furthermore, a review of the literature regarding adult surviving siblings as a group reveals a significant dearth of research (Godfrey, 2002; Zampitella-Freese, 2005).

Comparatively few researchers have broached this topic, so psychologists, researchers, and others in the mental health and medical fields are poorly prepared to identify an adult surviving sibling's idiosyncratic understanding and expression of death, dying, and grief. Furthermore, they are unprepared to understand the effects of such a loss on the familial system. Without foundational knowledge and training, the practitioner may be unable to create an integrally informed individualized treatment plan for a bereaved sibling and his or her family, inadvertently pathologizing and disenfranchising the client's grieving process by confusing uncomplicated and complicated grief responses with mental health disorders.

THE RISK OF PATHOLOGIZING GRIEF

Owing to the lack of education and clinical training regarding death, loss, and grief, a clinician may not be aware that the well-known Kübler-Ross (1969) stage model of the grieving process is outdated and unsupported. If he or she treats bereaved clients with this model in mind, the result may be to pathologize a client's grieving process as a mental health disorder, such as adjustment or major depressive disorder, when it may in fact be an uncomplicated, or even complicated, grieving process. In the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM–IV–TR*; American Psychiatric Association, 2000), bereavement may only be diagnosed for two months following the loss, at which point, the clinician must identify a different diagnosis (i.e., acute stress disorder, major depressive disorder, etc.) to apply to the client and inform the treatment plan. Specific diagnostic criteria allow a clinician to make a differential diagnosis between complicated and uncomplicated grief, major depressive disorder, and posttraumatic stress disorder (Zampitella, 2009a).

However, this is not identified in psychology's classification system or in educational and training programs.

It is just recently that researchers who have been actively involved in the identification of pathological bereavement reactions are now campaigning for the inclusion of prolonged grief disorder (Prigerson, Vanderwerker, & Maciejewski, 2008) in the upcoming *DSM–V*, scheduled for release in 2013. The development of complicated grief criteria is being clarified in the hope of depathologizing normal and uncomplicated bereavement and correctly identifying complicated bereavement so that appropriate and effective treatment may ensue. However, this inclusion is meeting some significant barriers by the psychiatric board involved in developing current and future *DSM* editions.

SOCIOCULTURAL INFLUENCES

Thanatology is often relegated to a quiet corner in the fields of psychology, social work, counseling, and nursing. Ours is often a death-denying culture, so facing our mortality in scholarship, interpersonal communications, and public practices goes against the prevailing attitudes of "don't ask, don't tell." In a culture that emphasizes youth and vitality, Americans continue to push their own mortality out of their awareness, embracing death denial (Becker, 1973). The elderly are placed into nursing homes, are rarely seen in vibrant roles in the media, and are not considered useful contributors to society because of their decreased earning potential in a materialistic society. Death is, in American society, a threatening inevitability that remains hidden in the value system of industry and technology (Marrone, 1997).

The populations that are studied extensively in regard to sibling loss are those who are under the age of 18 years or over the age of 65 years (Balk, 1990; Batten & Oltjenbruns, 1999; Davies, 1995, 1998; Fanos & Nickerson, 1991; Moyer, 1992; Robinson & Mahon, 1997). Studies rarely focus on the experience of sibling loss when the individual is adult (aged 18–64 years) and still has one or both parents surviving (Birenbaum, 2000; Davies, 1988; McCown & Davies, 1995; Moyer, 1992; Worden, Davies, & McCown, 1999). This unexplored population faces a unique experience when one or both parents are surviving and an adult-aged person has lost an adult sibling.

DISENFRANCHISED GRIEVERS

Another essential topic is that of disenfranchised grieving. This occurs when a person experiences a loss that is not openly acknowledged, publicly mourned, or socially supported. The relationship is deemed unimportant, replaceable, or even stigmatized. As a result, the bereaved are not given full permission to grieve the loss publicly. They are denied the social support essential to overcoming their loss and the social validation needed to heal (Doka, 2002). The bereaved person is

expected to resume his or her life as though nothing has happened. The adult sibling relationship is one that is overlooked not only by society but also in the fields of psychology and medicine.

What we do know is that unsupportive, disenfranchised social interactions greatly increase avoidant coping, which in turn can result in complications as the individual is adjusting to the loss. According to Doka (1989), responses from others can be (a) avoiding contact, (b) discouraging communication or expressing feelings, (c) giving unsolicited advice, (d) making rude or insensitive comments, or (e) expressing inappropriate expectations about the person's grief responses.

The responses of the bereaved following the death of a sibling when his or her social support is not available, or when he or she is experiencing a disenfranchised loss, may therefore be complicated, resulting in the surviving sibling acting or feeling in maladjusted ways. Doka (1989) states that the following reactions are common to disenfranchised grievers:

1. not recognizing that they have the right to grieve
2. anger
3. guilt
4. desperation
5. loneliness
6. hopelessness
7. numbness
8. repression and denial
9. depression
10. isolation
11. preoccupation with the deceased
12. searching behavior
13. use of avoidant strategies (e.g., drugs)

MODELS OF THE GRIEVING PROCESS

A comprehensive exploration of all the models of the grieving process can be found in many books and journals (i.e., *Handbook of Bereavement Research,* 2001; *Handbook of Thanatology,* 2007). This article has space only to indicate the main models to ensure a general understanding of the current state of research and literature in the field of thanatology.

Stage Models

In the United States, practitioners and mainstream culture (pop culture) embraced the original stage model developed by Kübler-Ross (1969), despite its lack of empirical validation or evidence of corresponding subjective experiences of grief. It was

originally used to conceptualize the *dying,* rather than the *grieving,* process. Kübler-Ross stated later in her career that her model was not intended for the bereaved and was not as linear as many believed it to be. Some argue that stage models are too linear and simplified to embrace all the facets of the grieving process. They may suggest that if the griever does not experience a stage, perhaps his or her adjustment is maladaptive.

Task Models

Task models, such as Worden's (2008) four-task model, suggest that there are tasks that need to be worked through and completed for the resolution of grief and the formation of new relationships. This model stresses the active, individualistic nature of grieving, but it underestimates the cultural influences and the passive aspects of grieving. Stroebe, Hansson, Stroebe, and Schut (2001) state that

> it is clear that not all grievers undertake these tasks . . . [and] this formulation incorporates an implicit "time" dimension . . . which is a useful consideration in making predictions about adaptive coping. . . . Nevertheless, in our view, additional tasks need to be performed, such as working towards acceptance of the changed world, *not just the reality of the loss. . . . The subjective environment itself (not just adjustment to the environment) needs to be reconstructed.* Finally, we need to specify that bereaved people work toward developing new roles, identities and relationships, not just relocating the deceased and "moving on." (p. 388)

Phase Models

Phase models, such as those proposed by Marrone (1997) and Bowlby (1973), suggest a more flexible bereavement process. In Marrone's (1997) model, the bereaved moves back and forth among the phases (i.e., cognitive restructuring, emotional expression), depending on multiple individualistic factors and issues in his or her life. Adjustment of the family to a loss, for example, is addressed in this model. Bowlby (1973), and later, Parkes (1998), identified four phases, including numbness and shock, searching and yearning, despair and disorganization, and reorganization and recovery. However, this model does not address the systems that affect the griever, such as the family, in enough detail to be comprehensive.

Cognitive Process Models

In cognitive process models, coping with loss requires positive and negative appraisal of the loss and includes approach and avoidance of the feelings and reconstructions associated with adjustment. Rumination is one style of coping in which the individual focuses more on the "distressing aspects and the meanings in a repetitive and

passive manner . . . [which] was associated with higher depression levels months later" (Stroebe & Schut, 2001, p. 388). This style of coping is connected to more complicated grief outcomes. Confronting more positive aspects of the loss results in healthier adjustment, which is identified as "positive psychological states" (p. 389). This is associated with meaning making. However, these models focus on coping *and are not a theory of treatment of the grieving process as it relates to therapy.*

Social Construction Models

Social construction models have roots in family systems theory (Rosenblatt, 1983). The bereaved must reconstruct meaning between family members, understanding that this process continues as the course of the familial system shifts and develops. A narrative is developed regarding the nature of the deceased's life and death, and the construction around the narrative affects the outcome of the grief. The assumptions about the dynamic relationship are actively explored and adjusted (Stroebe & Schut, 2001). This model is also associated with meaning making, but within a familial system (Neimeyer, 2001).

Family Systems

The focus of the family systems approach is on impact and reorganization of roles, rules, and boundaries as they relate to the reconstruction of meaning (Nadeau, 2001). Multigenerational effects are revealed, and the adjustments of family and processes within are identified. In this model, the family is the first unit that tries to understand the loss, often developing co-constructed conclusions (something Nadeau calls *family meanings*). The role of an individual includes the expectations that individual holds within the family system (e.g., sibling). These roles are read-justed after a loss. Rules refer to how a family is expected to react to a loss; the wider the range of rules is, the better is the adaptation.

Integrative Models

Integrative models, such as Zampitella's (2009b) integral model of bereavement and Bonanno and Kaltman's (1999) four-component model, consider bereavement more comprehensively. Bonanno and Kaltman's model has four components: the context of the loss, the continuum of the meanings that the griever associates with the loss, the changing representations of the lost relationship over time, and the role of coping and emotional regulation processes, which include the griever's strategies. Zampitella's (2009b) integrative model is conceptualized in terms of Wilber's (2000) integral model of human experience and functioning. It includes assessment and treatment from four perspectives: individual subjective experience and influences,

individual objective experience and influences, collective internal experience and influences, and collective objective experience and influences. Not only the four quadrants but also how they influence one another are considered. If one of the quadrants is crippled, then the others suffer as well.

Fortunately, thanatologists who work with the dying and bereaved are starting to respond to the need for a more individualized, but systems-based, approach to evaluation and treatment (Doka, 2007) because the traditional views of bereavement are being challenged by those in the field (Jordan & Neimeyer, 2007). Regardless of the type of grief experience model, movement through the grieving process is seldom without challenges and very rarely—if at all—experienced in a strict linear progression.

Case Example

A clinical case study will be used to illustrate the impact of the death of an adult sibling on the family system. Throughout the subsequent sections of this article, it will be used to demonstrate the concepts introduced.

Sara is a 26-year-old, African-American, single, heterosexual, Christian female *who resides with her family of origin, which consists of her mother, her father,* and her two siblings: a 15-year-old sister and a 20-year-old brother. Late in the evening in December, the family received a call from the police informing them that there had been an incident with her brother, Michael, and that they should go to the emergency room immediately. On arrival, they were informed that Michael, who had struggled with substance abuse for many years, had overdosed on heroin. Her parents decompensated in the emergency room, her sister withdrew, and Sara, as was often the pattern, became the "strong one" by interacting with the police and hospital staff. She felt sadness over the loss of her brother but also guilt because of the ambivalence she felt toward her relationship with him.

The subsequent months following Michael's death proved to be very hard for the family. Her parents pulled back from both Sara and her younger sister, immersed in their own grief. She found herself taking care of her younger sister with little social support and/or direction from her immediate and extended family. At times, she was approached by others, who would ask, "That's horrible! How are your parents holding up?" Sara found herself becoming ignored and resentful, and she felt as though others did not recognize that she was missing work, that her grades were falling, that she had broken up with her boyfriend, *that she was emotionally reactive, and that she refused to go to church,* once an important part of her life. At the age of 30, Sara presented to therapy with symptoms of depression and anxiety.

SHIFTS IN THE FAMILIAL SYSTEM AND LOSS
OF ADULT SURVIVING SIBLINGS

The internal balance of the familial structure after the death of an adult child can be significantly altered, shifting family dynamics and disrupting the stability of inter-related emotional roles for surviving members. Surviving siblings are in a position not only to carry unmet psychological needs from the parents but also to be person-ally susceptible to various psychological disturbances as adults, as in schizophrenia (Fanos, 1996) and depression. According to Lamers (2003),

> *the death of a sibling may be a double loss to the surviving siblings. Their parents may become so involved in their own grief that they withdraw from the surviving children. Survivors may feel that they cannot show their grief because it will make their parents feel sadder.* (p. 275)

Expectations for the care of surviving parents and even for the deceased's chil-dren will need to be addressed. Often one sibling was assumed to perhaps provide (or was actively providing) care for elderly parents and/or children. Therefore the surviving sibling will not only grieve but may also need to make significant shifts in his or her responsibilities. This was the case for Sara, whose role of the eldest child shifted into a parental role.

CLINICAL IMPLICATIONS

Because of the lack of research with this population, many of the clinical implications for adult surviving siblings and their families must be gleaned from the research on loss of less specific and unique relationships in adulthood, while considering the research gathered from child and adolescent sibling loss. Multiple studies suggest that ongoing bereavement counseling for surviving siblings is neglected (Arnold & Gemma, 1994; Fanos, 1996; McCown & Davies, 1995). Though a full review of how to conduct grief-specific therapy is beyond the scope of this article, considerations for grief groups for adult survivors of sibling loss will be presented later.

Thanatology as a Specialty

Clinicians need to become more aware that thanatology is an area of clinical special-ization. In fact, several organizations, such as the Association of Death Education and Counseling, provide certification for those who wish to specialize. To receive certification or fellowship, one must pass a national test, meet educational and practice-level requirements, and maintain active thanatological continued education.

Adult Surviving Siblings

An area that clinicians serving this population may find helpful to appreciate is the unique experience that adult surviving siblings have in their grieving process. Adult sibling death is a disenfranchised loss that receives little, if any, research. However, according to Walter and McCoyd (2009), "this is a loss most adults face . . . and as they continue to live, one's siblings are [usually] a part of an adult's life longer than anyone else, making their eventual loss all the more significant" (p. 221). The therapist needs to understand that sibling relationships fall on a continuum from very little interaction to close and supportive relationships (Robinson & Mahon, 1997). In Sara's case, the ambivalence in her relationship with her brother and the embarrassment about how he died resulted in significant guilt, fear, anger, and confusion, which has complicated her grieving process and resulted in masked grief—she presented for depression and anxiety attacks, but she did not recognize these as connected to the grief she was unable to process in a healthy manner.

Additionally, those in the adult surviving sibling's social network "may be unaware of the special bond that may have continued for years [between adult siblings]. In mobile societies people may not live where they were born; thus present friends and potential support systems may not know what to say or do" (Humphrey & Zimpfer, 2008, p. 75). This can increase a sense of isolation. Therefore recognizing adult sibling loss as a unique loss will help validate the individual's experience and provide opportunities for healing and empowerment. Additionally, the clinician needs to help the bereaved sibling develop an ability to identify and communicate his or her feelings when others disenfranchise him or her and develop a support network of people who validate his or her loss.

In our case example, Sara's therapist educated her about disenfranchised grief and complicated grief responses, normalized her paradoxical feelings, worked on developing ways for Sara to assert herself when she felt unsupported, and connected her to a grief group specifically designed for adult surviving siblings so that she could feel less socially isolated. Specific grief group considerations will be addressed after family therapy is discussed.

Family Therapy

Family therapy could certainly help to address the specific roles, rules, and boundaries that have shifted as a result of the sibling's death. Because of the nature of the loss, it is essential that family members share and validate their experiences of loss and the changes in the family system. Robinson and Mahon (1997) state that the surviving sibling is often overlooked as a griever because the majority of support and attention focuses more on the parents, as was the case in our vignette. Sara's

parents' disengagement created a sense of resentment and made her feel jealous of her brother, who received more attention than she did after he died. Her therapist asked for her parents and sister to come to a conjoint session so that she could socialize them to the changes that occur at the family system level and begin to open up a dialogue between the family members. Although this was a painful session, it provided them with an opportunity to share their loss experiences with one another.

Researchers (Beavers & Hampson, 2003; Cook, 2007; Cook & Oltjenbruns, 1998) have documented the importance of families learning how to share the loss (i.e., postdeath rituals, reminiscence, etc.) to the degree of cultural acceptance. Families need to maintain open communication, which will allow for the development of *shared meanings and perhaps even stronger bonds. They must also learn to* "clearly identify and express emotions associated with the [loss] . . . and to verbalize their commitment to one another throughout the recovery process" (Barnes & Figley, 2005, p. 311). The focus shifts from the identified patient to how the family must face the loss together. Not only does the family need to adapt to the shifts of emotions, attitudes, beliefs, and loss or changes in roles, but it may need to deal with mundane changes such as who will care for elderly parents. The therapist also must investigate each family member's understanding of the loss and what the impact was for each person. Sara's therapist helped her sister share how she felt smothered by the increased attention of her parents, who attempted to avoid yet another loss via their overprotection. Her mother discussed how she felt sad, guilty, and angry toward her husband for what, she felt, was a lack of attention to her son's drug addiction. Sara's father explored his feelings of incompetence, failure, and fear of the increasing distance between him and his wife. As a result, Sara's understanding of the parental role she had to assume was clarified, and she felt less disenfranchised in the conflictual nature of her grief when her parents validated her loss of the adult sibling role. As a result, the family began to shift from a fatalistic frame of reference to a mastery orientation (Barnes & Figley, 2005).

Multicultural counseling competence is also important because relationships between family members are often prescribed by cultural and ethnic expectations (Shapiro, 2008). For example, perhaps there are traditional ancestral beliefs, expectations, and rituals that should be considered, but without knowledge of these, the clinician runs the risk of making assumptions counterproductive to the healing process. In our vignette, Sara's therapist was Caucasian, and owing to the history of turbulence between the Caucasian and African-American cultures, she was cautious about taking on too much of an expert role and shifted into a more egalitarian position to reduce the amount of inequality of power in the therapeutic setting.

Group Therapy

Support groups have been proven to be helpful to the bereaved. This is especially true when they are offered through the formal human service system and when there

is a "failure of existing family and other supports to give the help that is needed" (Parkes, 1998, p. 161). In our vignette, Sara's family did not offer the support needed for uncomplicated grief, and her counselor's suggestion of a grief group was then clinically indicated.

However, Corey and Corey (1997) state that "the training standards make it clear that mastery of the core competencies does not qualify a group worker to independently practice in any group work specifically. Practitioners must possess advanced competencies relevant to a particular area of group work" (pp. 8–9). This takes us to the previously mentioned need for clinicians to be trained specifically in thanatology, while also being well versed in group therapy skills. Too often do grieving individuals attend a linear and manualized grief support group that is informed by inaccurate, stagelike grief models.

Even the members may believe that grief is a linear process with a specific time trajectory. Therefore grief groups must also have a thorough psychoeducational component so that myths and misconceptions can be dispelled. A clinician running an adult surviving sibling support group needs to be versed not only in grief-focused group work and thanatology but also in the unique effects and experiences of loss of adult surviving siblings.

Regarding the question of having a closed or open-ended support group for the bereaved, Corey and Corey (1997) state that "hospices typically offer both closed and time-limited groups" (p. 431). Other researchers (Meert, Thurston, & Briller, 2005) agree that bereavement groups should be time limited: "Bereavement focus groups should not be too long and should have finite and predicable end points" (p. 264). As mentioned previously, grieving is nonlinear, and therefore "attention to time is particularly challenging. . . . For bereaved people who come together because of their losses, the ending of the focus group is an especially sensitive time" (Briller, Schim, Meert, Thurston, 2007–2008, p. 266). Therefore, because all members of the group must face the same end date, the shared experience of the ending of yet another important relationship (e.g., to the group and its members) could be a therapeutic opportunity. Groups that have flexible attendance could bring up painful thoughts and emotions that complicate an already difficult experience. For adult surviving siblings, the prospect of leaving the group after finally receiving the support needed to heal a specific loss may be especially daunting.

Also important is the need for those participating in a grief group to hold more egalitarian positions within the group. Briller and colleagues (2007–2008) state that "when starting the group, the facilitator needs to encourage an open and frank discussion of death-related experiences and prevent a hierarchical dynamic from developing between the bereaved participants" (p. 262). This is especially important with adult surviving siblings because many have taken on parental roles or have become invisible in the family system. The probability that bereaved siblings will reenact these dynamics within a heterogeneous group (i.e., a group of bereaved parents, among friends, etc.) is high, which could create difficulties because the

group is intended to be a counseling rather than a psychotherapy group. If a parent who lost a child were included in the support group, Sara might disenfranchise her loss by trying to be sensitive to a parent in the group who would never see his or her child meet adult developmental milestones. As a result, she might shut her grieving process down yet again or have a negative transference–related reaction that thwarts her healing process.

Furthermore, the use of specific terms must be considered. Because we are in a death-denying culture, finding terms to use in the group that are not calloused, inappropriate, or negative could be challenging and create additional disenfranchisement. This may be essential to a successful support group for bereaved adult siblings because their level of disenfranchisement is both familial and social. Pacing should also be carefully considered (Meert et al., 2005). For adult surviving siblings, discussing the loss and grief may have been disenfranchised for prolonged periods of time. Therefore finding words to express the complex emotions or to focus the attention of grief on themselves could take longer. There needs to be consideration for space in sharing their grief stories without unneeded interruption.

CONCLUSION

The loss of an adult surviving sibling is a unique, and often disenfranchised, loss. Not only must one consider the individualistic implications of this type of loss but one must also assess the impact of the loss on the family system in which the griever is embedded. It is important for the clinician to have specialized training in thanatology for successful individual and family therapy, and support groups, owing to the unique nature of the loss and the need to understand the cyclic, integrative, and distinctive experience of adult surviving siblings. Gaining knowledge and training in thanatology will help a clinician provide ethically sound and clinically accurate interventions.

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Restorative Retelling

Preparatory Entry

- Would it be a good time to talk about [loss incident] now?
- Supposed we start talking about [loss incident/the deceased], how would that be for you?
- You may share about the part that you are ready to, and pause at any point you need.
- If you want, you may close your eyes (with possible breathing/relaxation exercises as warm-up)… and slowly bring yourself back to that scene now.

Narrative Processes

1) External narrative – The objective or factual story of 'what happened?

- When you're ready, you may tell me where you were and what you're doing at that point.
- How did you get the death news? How did you react at that moment then?
- Who else was with you at that time?
- What did you do/what happened afterward?
- How did you deal with the necessary arrangements thereafter?

2) Internal narrative – The emotion-focused story of 'what am I feeling?

During the loss event

- What do you recall about your body sensations/feelings when you received the news?
- Suppose I took a picture of you during the incident, what do you think we would see in this photo? How would that reflect on your inner state at that moment?
- If your body could say a word to describe how it was for you at that point, what would it say?

During the retelling process

- Now that you're in touch with that feeling again, how is it for you?
- Now that you're recalling and telling this story again, how have your feelings changed, if at all?
- How have you been getting along with your grief thus far?
- If there's still a difficult feeling lingering in you, what could that be? How come it's difficult?
- In which part of your body do you think that painful feeling resides? How would you describe it?

3) Reflexive narrative – The meaning-oriented story of 'what does this mean to me now?'

- Which part of this story was the most painful for you to recall and share? Why? How have you been managing it then?
- How did you make sense of the death now? As compared with the initial phase, has there been any shift in your perspectives?
- How has this loss experience made a difference to your life?
- Having gone through such a loss experience, and arriving at where you are now, what did you discover/learn about yourself? What does it say about you as a person?
- If there is anything that could bring you comfort from this loss experience, what would that be?
- "How did this incident change your priority and values in life and life outlook?

Appendix

<u>Integration of Stressful Life Experiences Scale – Short Form (ISLES-SF)</u>

Please indicate the extent to which you agree or disagree with the following statements with regard to [the stressful life event]. Read each statement carefully and please note that for these statements, a response of 1 indicates that you "strongly agree" and a response of 5 indicates that you "strongly disagree."

		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1.	I have difficulty integrating this event into my understanding about the world.	1	2	3	4	5
2.	This event is incomprehensible to me.	1	2	3	4	5
3.	I am perplexed by what happened.	1	2	3	4	5
4.	Since this event happened, I don't know where to go next in my life.	1	2	3	4	5
5.	I don't understand myself anymore since this event.	1	2	3	4	5
6.	This event has made me feel less purposeful.	1	2	3	4	5

Note: A sum of all items can be taken to compute a total Integration of Stressful Life Experiences Scale-Short Form (ISLES-SF) score. Likewise, Items 1, 2, and 3 can be summed to compute the Comprehensibility-SF subscale, and Items 4, 5, and 6 can be summed to compute the Footing in the World-SF subscale. The portion of the instructions in parentheses may be altered to make the measure applicable to different groups of interest. The numbering of items here does not correspond to the numbering used for the full version of the ISLES (Holland et al., 2010).

Reference:
Holland, J. M., Currier, J. M., & Neimeyer, R. A. (2014). Validation of the Integration of Stressful Life Experiences Scale-Short Form in a bereaved sample. *Death Studies*, *38*, 234-238.

The Sudden Bereavement Needs Inventory (SBNI)
(Bottomley & Smigelsky, 2022)

Instructions: Below you will find a generic list of grief-specific needs that individuals bereaved by the death of a loved one commonly express. We would like to know the role these needs play in your life _at this current time_. Please read each statement and select the response to indicate how important this need is to you.

	Not at all important	Somewhat important	Moderately important	Very important	Extremely important
1. To eat well	1	2	3	4	5
2. To sleep well	1	2	3	4	5
3. To exercise regularly	1	2	3	4	5
4. To successfully complete the task(s) of the day	1	2	3	4	5
5. To maintain financial balance	1	2	3	4	5
6. To receive valuable information and/or advice from professionals	1	2	3	4	5
7. To be walked through/introduced to various support resources	1	2	3	4	5
8. To better understand the grief journey following this type of loss	1	2	3	4	5
9. To have time to reflect on life	1	2	3	4	5
10. To have an ongoing connection with God	1	2	3	4	5
11. To have an ongoing connection with my spiritual self	1	2	3	4	5
12. To be with those who experienced a similar loss	1	2	3	4	5
13. To receive valuable information and/or advice from others who have experienced a similar loss	1	2	3	4	5
14. To express my thoughts and feelings regarding the loss with those who experienced a similar loss	1	2	3	4	5
15. To find some sort of benefit in the loss	1	2	3	4	5
16. To make sense of the loss	1	2	3	4	5
17. To understand who I am after the loss	1	2	3	4	5
18. To express my thoughts and feelings about the loss with those I love	1	2	3	4	5
19. To have my grief witnessed (acknowledged, respected, appreciated) by others	1	2	3	4	5
20. To be emotionally supported	1	2	3	4	5

All items should be summed within their respective factor.

Factor:
1. Pragmatic Needs
2. Informational Needs
3. Spiritual Needs
4. Relational Needs
5. Meaning Needs
6. Emotional Needs

Items:
1, 2, 3, 4, 5
6, 7, 8
9, 10, 11
12, 13, 14
15, 16, 17
18, 19, 20

Citation:
Bottomley, J. S., & Smigelsky, M. A.. (2022). Bereavement in the Aftermath of Suicide, Overdose, and Sudden-Natural Death: Evaluating a New Measure of Needs. _Assessment_, 107319112210811. https://doi.org/10.1177/10731911221081139