A Clinician’s View of Complicated Spiritual Grief

Bridging Research and Clinical Practice
Covenant Health Research Day
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An Unexpected Journey

• My Clinical Practice and Research: Why am I here today?
• Overview of Grief and Grieving: Understanding the Landscape
• Reviewing a Research Focus: Complicated Spiritual Grief
• Reflect on the opportunities from a chaplain’s perspective
Clinical Context

• Chaplain at University of Alberta Hospital
  – Acute Care Hospital: tragic loss
  – Chronic Care: Kidney Failure and Renal Replacement Therapy
  – Dialysis Mortality rate high; adjusted all cause mortality rate 6-8 times greater
    than general population, risk increases with age (USRD Annual Report 2012 p. 262)
  – Meet many people who are grieving, experiencing loss
  – Research and evidence based practice

“Grief, perhaps the most inevitable of all human emotions, given the unalterable fact of mortality, is seen as an illness if it goes on too long” Miriam Greenspan
Research Focus

CASC Competency # 10: Sees research as integral to professional functioning and in keeping with one’s area of expertise.

- **Reads research articles** as continuing education pertinent to one’s area of practice.
- Asks researchable questions as these arise from practice.
- Participates in and/or promotes research.
- Uses appropriate methodologies and established ethical protocols (if/when conducting research).
- Subjects one’s findings as required and appropriate to professional peer review (if/when conducting research).
- Disseminates research information.

Improving the Quality of Spiritual Care as a Dimension of Palliative Care

Quality Improvement: Recommendation # 5

Research that will contribute to improving spiritual care outcomes to palliative care patients should be supported. Recognizing the **complex definition of spirituality and its difficult measurement**, studies should use multiple **quantitative and qualitative methods** for evaluation.

Pulchalski et al (2009)
Reading Research

Research in Spirituality “partners” with other disciplines

- Palliative Care
- Psychology
- Mental Health
- Bereavement, Grief and Loss
- Culture/Religion
- Nursing/Healthcare

- Spirituality(religion) is significant, yet slippery/elusive
- Few spiritual clinicians in the lead role
- Requires a bridging of two different cultures, types of Clinicians
Learning Opportunities

• Oct 2013, Good Samaritan Workshop, Edmonton
  – Grief and the Spiritual Quest for Meaning: The Spiritual Arc of Tragic Loss, Robert Neimeyer

• April 2014 ~ ADEC Conference Baltimore MD
  – Reconstructing the Continuing Bond: Accessing the Back Story, Dr. Robert Neimeyer
  – Complicated Spiritual Grief Mixed Method Study, Qualitative and Quantitative, Laurie Burke, University of Memphis

• Sept 2014 Spiritual Care Journal Club Presentation: Complicated Spiritual Grief
  – Telehealth session for chaplains and other interested HCP
“Grief is not a disorder, a disease or a sign of weakness. It is an emotional, physical and spiritual necessity, the price you pay for love. The only cure for grief…is to grieve.”

Earl Grollman, Rabbi

Types of Grief: Adaptive, Ambiguous Loss, Disenfranchised Grief, Complicated/Prolonged

Trajectories of Grief

Adaptive Grief:
1. (40-45%) “Resilient” = few weeks (Bonnano & Kaltaman, 2001)
2. 1-2 years (Bonnano and Mancini 2006)

Complicated Grief:
1. 10%-20% of population,
2. Higher in violent, traumatic death
Pathways of Grief: Adaptive/Resilient, Complicated & Complicated Spiritual Grief

Adaptive Grief: Majority, few weeks to 1-2 year grieving period, typically draw on internal and external supports; including meaning making and spiritual beliefs both (PRC/NRC) as appropriate to individual and circumstances

Complicated Grief (CG): 10-20%, impacted by type of death; violent death, suicide, murdered, fatal accident,

Complicated Spiritual Grief (CSG):
- Negative Religious Coping (NRC) and challenges making meaning;
- Discontent (anger/abandonment) with God/faith, and/or faith community
- CG a high predictor of CSG six months later, difficulty making meaning of the event impacts CSG.

Death shakes the assumptive world of griever

Complicated Grief (CG) Symptoms
- Protracted grieving
- Profound separation distress
- Emotionally disconnecting and invasive memories
- Emptiness and meaninglessness
- An inability to accept the loss
- Difficulty living without loved one.

Negative Religious Coping:
- Spiritual discontent
- Punishing God appraisals
- Interpersonal religious discontent
- Demonic reappraisals
- (attributing the event to the work of the devil)
- Reappraisals of God’s power

Pargament, et al. 1998 p. 71
Research Focus: Complicated Spiritual Grief (CSG)


“Diagnosis should facilitate the process of patient evaluation and treatment rather than hinder it” (Stein, 2010)

Goal of studying CSG: is “to alleviate distress, believe this to be best aided by empirically supported assessment and accomplished through psycho spiritual intervention.” (Burke 2014, )
Historical Context (2 Studies)

- Pilot study, church based grief intervention with grieving congregants.
- 31 African American worshipers, impact natural loss had on their faith
- Most bereaved by natural vs. violent causes of death
- Range: “Stronger than ever \(\leftrightarrow\) faith seriously shaken.” -
- resilient to highly complicated
- 19% faith negatively impacted.

- Longitudinal study of 46 African American Homicide survivors
- Purpose: relationship of psychological distress (CG, PTSD and depression) predict religious coping
- NRC associated consistently with CG symptoms
- PRC unrelated to bereavement outcome (counterintuitive finding) those who depend on religion will cope better when experiencing violent death.
- **Inability to make sense of loss**, prologues intense distress over a period of years = CSG which is “a deeper spiritual crisis over time versus a slower recovery.”
- Suggest development of a new assessment tool to supplement BRCOPE
Complicated Spiritual Grief (CSG)

“A spiritual crisis following loss such that he or she struggles to reestablish spiritual equilibrium following loss, often accompanied by the disruption of spiritual religious activities and experience, a sense of discord, conflict, and distance from God and at times with members of or from his/her faith community.”


1. **Spiritual Crisis**: Fury towards God, an inability to trust God’s goodness in the face of unspeakable grief (Batten and Oltenburns, 1999)

2. **Spiritual Grief (SG)** marked by a temporary confusion, anger, despair and attempts to grasp God’s will

3. **Complicated Spiritual Grief (CSG)** more prolonged and intense, fostering a crisis of faith and alienation from faith community
“Inventory of Complicated Spiritual Grief” (ICSG)

Assessment Tool: Burke, Neimeyer, Holland, Dennard, Oliver, Shear (2014)

- A scale specifically designed to capture the range of experiences of spiritually inclined bereaved individuals whose faith has been compromised by loss.
- Similar to ranges of other generic measures: Brief RCOPE, Pargament 1998, Exline and Martin (2005)
- Easy to use, multidimensional, validated measure of spiritual struggle
- Measured on college and community samples (150 grievers)
- Structure of Scale focuses on time honored tradition of vertical and horizontal dimensions for faith and faith community
- Limitations:
  - Needs a broader sampling, use multi-site or multi region sampling
  - Christian based, “One scale is unlikely to fit all”
Complicated Spiritual Grief I: Quantitative study of symptomatology  CG/CSG

**Purpose:** Investigate the deleterious(harmful) outcomes in the context of violent, as opposed to natural death, bereavement in a diverse sample of mourners, ethnically diverse, 18+ and Christian faith tradition

**In general:**
- Spiritual beliefs and religious practices can be significant coping with losses.
- “God functions psychologically as an “attachment figure”, Kirkpatrick (1995) safe haven, secure base
- Religiously inclined mourners, with protracted anger was indicative of poor adaption (Exline and Rose 2005)

Paper and Pencil or online survey completed by participants (diverse sample 150 mourners)
- Inventory of Complicated Grief -Revised(ICG-R) Prigerson and Jacobs 2001
- Brief RCOPE (Pargament, Smith, Koening, and Perez (1998)
- Religious Coping Activities Discontent Subscale (Pargament, Ensin, Falgout and Olsen, 1990)
Complicated Spiritual Grief I: Quantitative study of symptomatology CG/CSG

- **Results/Discussion:** Spiritual struggle commonly experienced by Christians in study
  - 58% endorsed CSG in terms of NRC and 44% in terms of discontent scores
  - Attempting to cope with loss through positive recourse to one's religious belief does little to blunt the sharp pain of grief. (p.264)

- Grievers who struggled with the loss of their loved one, also *simultaneously struggled* with feeling angry with or distant from God and from members of their church, felt punished by God for a lack of devotion, wondered whether God had abandoned them.

- Cause of death: (violence) suicide, murder, fatal accident greatest difficulty accommodating loss emotionally and spiritually, CG and CSG is a greater risk than when natural death occurs.

- **Need exists for spiritually sensitive clinicians and clergy to work together** to develop informed and culturally appropriate interventions for spiritually inclined bereaved clients, especially for those losses are sudden, unexpected and violent. p. 266

- More work on assessment of spiritual struggle in bereavement; systematic qualitative research
Complicated Spiritual Grief II: Qualitative and Quantitative Components

- Little research knowledge about relationship between CG and CSG (spiritual crisis = sense of discord, conflict and distance from God.)
- Aim: to understand the experience of spiritual crisis in the lives of grievers.
- One of the first studies to report narrative response of individuals who suffer from CSC.

Value of Qualitative Inquiry in Bereavement
- Straightforward meaningful interviews
- Critical to understanding individuals grievers experience
- Listening to bereaved individuals share their loss narrative.
- Looking for themes of CSG

Process – 2 Steps
- Used 4 Open Ended Questions for 84 individuals, highlighted and coded text for spiritual crisis
- Followed up by a Focus Group for 5 participants
Complicated Spiritual Grief II: Results

Step One Results:
Spiritual struggle was fairly common among church goers in this study
- 43% (36/84) endorse CSG on qualitative questionnaire
- 56% (20/36) endorsed CSG at least once in relation to both God and spiritual community
- 26% (10/36) endorsed CSG in 3 of four questions
- 11% (9/84) endorsed CSG in both qualitative and quantitative assessments

Step Two: Focus Group Development
- 5 of 15 invited candidates participated; Others too busy, too ill, or unavailable
- 3 African American and 2 Caucasian women
- Focus Group Questions
  - Spiritual struggle in relation to God (6)
  - Spiritual struggle in relation to spiritual community (6)
  - Perception of “Why some bereaved people walk away from God?” (1)
Questioning God’s Character:
  “How could that be good for me?”
  “I questioned God’s intentions”

Negative Feelings towards God:
  “I was mad at God”
  “I’m not angry…I’m devastated”

Lack of Spiritual Sense Making:
  “It still doesn’t make sense and I’m still struggling with that”

Misunderstood by spiritual community:
  “O Just depend on the Lord and He’ll send you a husband”

Negative feelings about spiritual community:
  “Some friends would look at me weird if I told them I cussed God out.”

Selective about sharing feelings:
  “It’s not comforting and you don’t really want to say, well that’s not helpful, so please stop talking.”
CSG: Salient Themes (stood out as unique)

1. Spiritual crisis coupled with strong faith
2. Betrayed and robbed
3. Questioning what they did to cause death?
4. Desire to hurt God in return
5. Abandoned by spiritual community
6. Silent silencers
7. Faith related changes
8. Understanding not pity
9. Avoided spiritual community
10. Afterlife concerns
11. Lapse of faith
CSG: Overarching Narrative

1. Resentment and doubt toward God
2. Dissatisfaction with spiritual support received from faith community: “emotionally neglected” ~ “abandoned”
3. Substantial changes in spiritual beliefs/behaviors
   - Spiritual Anguish: a residual sense of anger and bewilderment in relation to God
   - Felt punished, as if they or their deceased loved one did something that warranted death.
   - Feeling misunderstood when like minded supporters responded with invalidating platitudes, truisms, and banalities. Felt judgment from the people they looked to for support.
   - Grievers seek a fresh start, safety and anonymity in a new church.
   - Silent silencers – a) remain silent about death b) unrealistic expectations c) not let griever express how they felt - “get over it”
Concluding Thoughts, Implications,

- “Creatively educate parishioners, … that spiritually inclined grievers do not want to be felt sorry for, but instead crave likeminded others who will try to understand their pain.” p. 277

- Faced with bereavement-related spiritual crisis, even people with a strong belief system sometimes find themselves questioning foundational doctrines such as heaven, hell and their loved one’s eternal salvation.

- Spiritual crisis does not necessarily indicate weak or immature faith

- Value of a scale to measure range of experiences of spiritually inclined whose faith has been compromised (Clinically and for Research):
  – Inventory of Complicated Spiritual Grief (ICSG)

- Goal is to alleviate distress, believing this to be best aided by empirically supported assessment, and accompanied through a targeted psycho-spiritual intervention.

- Increase understanding of the nature of spiritual crisis following loss

- Target psycho-spiritual interventions for believers who struggle spiritually in grief.
Limitations

- Study in a cultural context of American Protestantism.
- Requires testing with other monotheistic (Judaism, Islam) and other spiritual frameworks (Buddhism, Hinduism)
- Lack of male representation

Resource
Creative writing in partnership with Buddhist teaching on suffering and renewal.

What is in my Clinician Tool Box?

- Look and Listen attentively for narrative threads of spiritual struggle following various types of loss; attuned to the potential for CSG where violent loss occurs
- Encourage retelling with a goal to reframe and search for meaning, become “unstuck”
  
  Meaning Making: “the quest for meaning is the key to mental health and human flourishing

- Patient Centered Work: journey with and allow for self discovery

Narrative processes (Levitt and Angus) – York University

1. **External narrative**: objective or factual story
2. **Internal narrative**: emotion focused story.
3. **Reflexive narrative**: meaning-orientated story

Foster narrative elaboration by “tacking” between three stories

“When you braid three elements of narrative together,
It results in an ability to go deeper”
Reflections/ Opportunities: An Unexpected Journey

- “More Research required”- looking for learning and research opportunities
- Greater education/awareness on the landscape of grief and CG and CSG
- Researchers required, clinical background
- More Partnerships
  - Interdisciplinary, HCP, SCP, Researchers
  - Organizational, Clinical, Academic, Funders
  - Clinical and Community Settings

  - Continue to integrate spirituality into whole person care through both research and clinical practice.
Questions Discussion