Life After Death: Bereavement and Complicated Grief

James Downar, MDCM, MHSc (Bioethics)
Critical Care and Palliative Care, UHN
Assistant Professor, Dept. of Medicine, University of Toronto

james.downar@utoronto.ca
Case

• 62M- Severe CAP
  - Transferred for ECLS
  - Initial improvement, but pontine hemorrhage
  - Discussion with family- WDLS

• You are alone with patient and wife
  - Crying, burying face in sheets
  - Daughter leaves room, unable to contact
  - Sunday 11pm
Objectives

• Understand grief and complicated grief
• Appreciate the challenges and potential benefits involved in identifying and treating complicated grief
• Explore the desirability and feasibility of a screening and support program for bereaved relatives of ICU decedents
Definitions

• Loss
  • Losing someone/something that is valued
  • Bereaved: the condition of having lost something

• Grief
  • Emotional response to the loss
  • Normal grief
    – Life holds meaning
    – Sense of self, self-efficacy
    – Trust in others, ability to invest in new relationships
Course of “Normal” Grief

• Many published
• Early phases marked by disruption, emotion
• Late phases marked by adjustment to new reality, reinvestment, reorganization
• Variable by individual
  • Timing
  • Situation
  • Culture
Timing of Grief

DEATH

GRIEF

DEATH

GRIEF

DEATH

GRIEF

DEATH

GRIEF
Complicated Grief

- 2-3% of population
  - Parents or life partner
  - Sudden, violent death
  - Women >60

- Social dysfunction

- Sleep disorder, substance abuse

- Increased use of health resources

- Risk of cancer, cardiovascular disease

Prigerson et al. JAMA 2001;286:1369-76.
Shear. NEJM 2015;372:153-60.
Complicated Grief - Features

- Intense, persistent yearning, sadness
- Rumination
- Avoidance, disturbing emotional reactivity to reminders of loss
- Diminished sense of self, meaning
- Mistrustful
- >6 months

Shear. NEJM 2015;372:153-60.
Diagnosis

- Controversial addition to DSM-V
  - Pathologizing a condition
- Inventory of Complicated Grief
- Brief Grief Questionnaire
- Overlap with other conditions

Shear. NEJM 2015;372:153-60.
MDD vs. Complicated Grief

**Major Depression**
- Pervasive sadness
- Loss of interest/pleasure
- Pervasive guilt
- Rumination about failures

**Complicated Grief**
- Sadness due to loss
- Yearning, memories
- Guilt related to deceased
- Preoccupation with positive thoughts of deceased
- Intrusive thoughts of deceased
- Avoidance of reminders

Shear. JAMA 2005;293.
PTSD vs. Complicated Grief

**PTSD**
- Triggered by threat
- Primary emotion is fear
- Nightmares
- Painful reminders of event – specific to event

**Complicated Grief**
- Triggered by loss
- Primary emotion is sadness
- Nightmares rare
- Painful reminders pervasive
- Yearning and longing
- Pleasurable reveries

Shear. JAMA 2005;293.
Diagnosis – Brief Grief Questionnaire

1. How much are you having trouble accepting the death of ________________?
2. How much does your grief still interfere with your life?
3. How much are you having images or thoughts of ________________ when s/he died or other thoughts about the death that really bother you?
4. Are there things you used to do when ________ was alive that you don’t feel comfortable doing anymore, that you avoid? How much are you avoiding these things?
5. How much are you feeling cut off or distant from other people since ____________ died, even people you used to be close to like family or friends?

Shear and Essock 2002.
Treatment – Prior to Death

- Advance Care Planning (?)
- Avoidance of Aggressive Life-Sustaining Measures (?)

(Depression and Anxiety)

Wright et al. JAMA 2008;300:1665-73.
Treatment – At Time of Death

A Communication Strategy and Brochure for Relatives of Patients Dying in the ICU

Alexandre Lautrette, M.D., Michael Darmon, M.D., Bruno Megarbane, M.D., Ph.D., Luc Marie Joly, M.D., Sylvie Chevret, M.D., Ph.D., Christophe Adrie, M.D., Ph.D.,

• 25% ARR in Depression, PTSD, Anxiety

Treatment - Bereavement

• “Complicated Grief Treatment”
  – Focused, Structured Psychotherapy
  – Restoration of function
    • Enthusiasm for future, making plans
  – Loss
    • Think about death without intense anger, guilt, anxiety
  – Superior to interpersonal psychotherapy
    • 51-69% vs. 28-32%

Shear. NEJM 2015;372:153-60.
Treatment - Bereavement

- Group/Internet-based therapy
- Pharmacotherapy poorly studied
  - Antidepressants
    - Adherence to psychotherapy
    - Response to psychotherapy
  - Benzodiazepines
    - No evidence of response
- Prevention ineffective

Bui et al. Dialogues Clin Neurosci 2012;14:149-57
Complicated Grief in ICU deaths

• Large proportion lost to follow-up

• Single-centre studies (30-40 relatives)
  • Complicated Grief 3-5%
  • CG symptoms (subthreshold) 22-25%
  • Low rate of dissatisfaction with care

• Multicentre study (282 relatives)
  • CG symptoms 52%
  • Large overlap with PTSD, Major Depression

Downar et al. JCC 2014;29:311e9-e16.
Complicated Grief in ICU deaths

Significantly associated with both outcomes
- Patient died while intubated
- Relative did not say goodbye to the patient
- Relative witnessed the death
- Relative of female sex
- Relative living alone

Significantly associated with one outcome
- Intensivist board certification before 2009
- Communication with intensivist was unsatisfactory
- Patient refused treatments
- Patient could not breath peacefully

Other issues in bereavement...

- Financial/social difficulties (7%)
  - Most ICU staff unable to help
- High desire for support (68%)
- Informational needs (55%)
- Strong desire for follow-up (58%)
  - Stressful (32%) but not unhelpful (10%)
- Outreach vs. Inreach

Downar et al. JCC 2014;29:311e9-e16.
Death → 3 months → 6 months

Early Bereavement

Prolonged/Complicated Grief?

Screen

Tailored Intervention
- Emotional Support
- +/- Psychiatric Referral
- +/- Cognitive Behavioral Therapy
- +/- Group Therapy
- +/- Social Work Referral

Follow-up
How can we detect and treat CG?

- 240000 Canadians died in 2009
  - 1/5 after ICU admission
- Limited resources to screen/support
- What would bereaved FMs need?
- Would they want support?
- Can we find a way to provide it?
  - If someone asked you to refer them to a support service, would you be able to do so?
Survey of ICU Staff

- 85% willing to receive support training
- 73% willing to participate in support program
- 98% willing to participate in support program or cover a colleague who is providing support

Barriers

- “Not knowing what to say”, dealing with emotion
- Lack of knowledge about support services
- High workload

Downar et al. JCC 2014;29:311e9-e16.
Ongoing Research

• ICU BEREAVE
  • Multicentre mixed-methods trial (5 sites)
  • Assessed at 3-4 mo and again at 6-9 mo
  • Enrolled 69 patients (target 100)
  • Anticipated completion 2016

Ontario MOHLTC AFP Innovation Grant
Next Steps

- Education around bereavement support
- Pilot/expand support program
PROJECT LEAD
James Downar, MDCM, MHSc
james.downar@uhn.ca

CO-INVESTIGATORS
Tasnim Sinuff, MD, PhD
Sarah Hales, MD, FRCPC
Derek Strachan, MDiv
Klara Siber, MDiv, MHSc
Orla Smith, MN
Deborah Cook, MD, MSc
Amanda Roze des Ordons, MD, MEd,

RESEARCH COORDINATOR/ASSOCIATE
Ellen Koo, MSc
Csilla Kalocsai, PhD

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References

- Shear. NEJM 2015;372:153-60.