Bereavement

St George Hospital Renal Supportive Care Psychosocial Day, 10th August 2017

Michael Noel, Supportive and Palliative Care Physician, Nepean Hospital

Michael.Noel@health.nsw.gov.au

Hannah Burgess, Renal Supportive Care Social Worker, St George Hospital

Hannah.Burgess@health.nsw.gov.au

What will be covered

- Dr Michael Noel:
  - What is Grief?
  - What is Bereavement?
  - Identification of Depression vs Grief, or Complicated Grief
  - Experiences for the Bereaved
  - Screening Tools and their application

- Hannah Burgess:
  - ‘On the Ground’ Bereavement follow up frameworks
  - Communication in Bereavement

“Grief 1.01”

Dr Michael Noel
Palliative Care Physician
Nepean Hospital

Learning Objectives

- What is grief?
- What does it look like?
- What is complicated grief?
- Causative factors for complicated grief
- Does our duty of care include grief management?
- Are there tools to help us?

What is Grief?

- Reaction to loss
- Normal
- Usually a response to bereavement
- Often associated with emotional and physical distress
- Can precipitate or worsen mental disorders
- Can become intense, prolonged, debilitating
  - “Complicated Grief”

Bereavement

- The loss of a person who is loved

- One of the most stressful experiences of a lifetime
  - redefine goals and plans
  - new responsibilities

What does Grief look like?

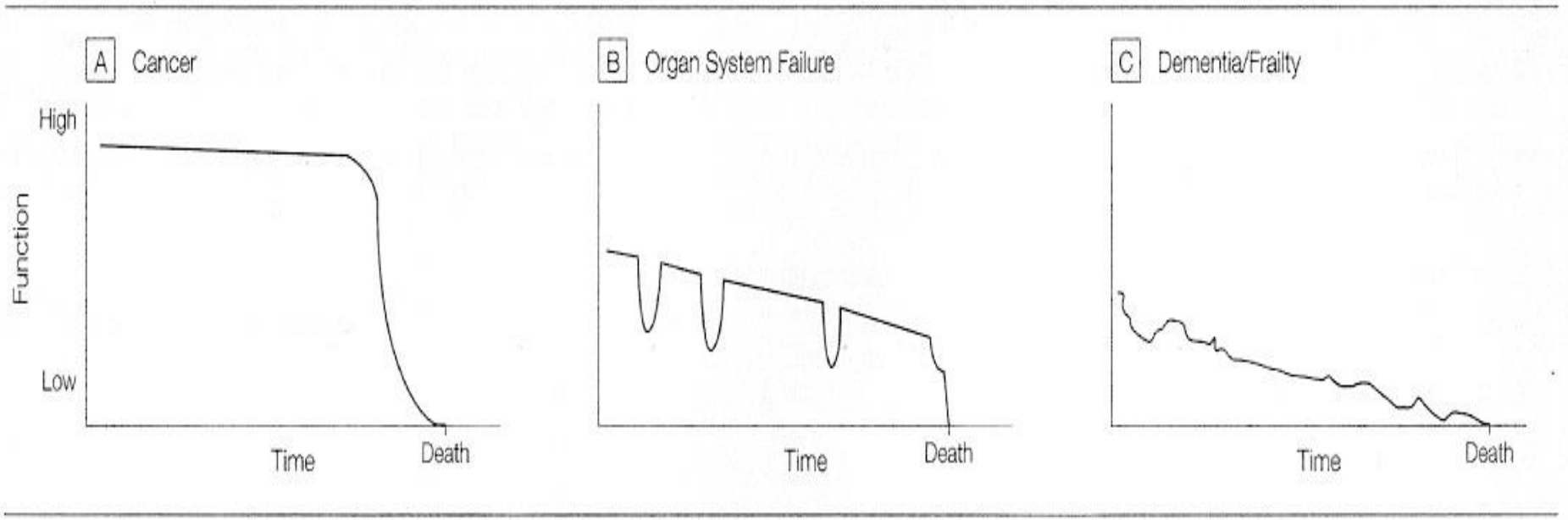
- Kübler-Ross model
  - Denial
  - Anger
  - Bargaining
  - Depression
- Extended models
  - Low mood
  - Anxiety
  - Guilt
  - Loneliness
  - Shock
  - Numbness
  - Loss of pleasure
  - Physical illness
  - Thinking about the person constantly
  - Sense of the deceased still being present
  - Pseudo-hallucinations
  - Over or under activity
  - Social withdrawal
  - Loss of appetite
  - Sleep disruption
  - Fatigue

Attachment

- Attachment theory
  - Person you love reciprocates your love
  - Want to be with the person you love
  - Safe haven at times of stress
  - Loved ones contribute to a sense of belonging and a sense of identity

- Bereavement ➔ acute attachment insecurity
  - Want to find the person who has died
  - Preoccupied with thoughts of the person
  - Sense of identity disrupted

Disease Trajectories



Lynn, J. *Serving Patients Who May Die Soon and Their Families* JAMA 2001; 285(7):925-932

Adverse Medical Outcomes of Grief

- Mortality
  - risk is 11-12% greater for bereaved spouses relative to married spouses

- Morbidity
  - somatic symptoms
  - deteriorating health behaviours
  - myocardial infarction
  - psychopathology
    - complicated grief
    - unipolar or bipolar depression
    - anxiety disorders
    - PTSD
    - substance abuse

What is Complicated Grief?

- Prolonged acute grief lasting over **at least** 6 to 12 months
  - Sorrow, emotional pain, frustration, anxiety, guilt
  - Loss of interest, difficulty envisioning a meaningful life, feeling estranged from others
  - Disbelief, difficulty accepting the death, stunned, dazed, lost, unfocussed, intrusive thoughts or images of the death

- Complicating features
  - Guilt, self blame
  - Increased physical symptoms and/or insomnia when thinking of the loss
  - Avoiding reminders of the loss

- Impaired functioning
  - Difficulty trusting or caring for others
  - Impaired concentration
  - Difficulty performing ADLs

Major Risk Factors for Complicated Grief

- Significant death
  - child
  - spouse
  - parent
- Unexpected or violent death
- Prior psychiatric history

Is Grief a Psychiatric Disorder?

- No but yes
- Normal grief is not a psychiatric disorder

BUT

DSM 5

- **Persistent complex bereavement disorder**
  - The individual experienced the death of someone with whom he or she had a close relationship

AND

  - Since the death, at least one of the following symptoms is experienced on more days than not and to a clinically significant degree and has persisted for at least 12 months after the death in the case of bereaved adults and 6 months for bereaved children

Other mental disorders can be precipitated or worsened

Depression or Grief?

Depression

- Pervasive sad mood
- Loss of interest or pleasure
- Pervasive sense of guilt
- Rumination about past failures or misdeeds

Grief

- Sadness related to missing the deceased
- Interest in memories of the deceased maintained; longing and yearning for contact; pleasurable reveries
- Guilt focused on interactions with the deceased
- Preoccupation with positive thoughts of the deceased
- Intrusive images of the person dying
- Avoidance of situations and people related to reminders of the loss

Shear et al JAMA 2005 293:2601

PTSD or Grief?

PTSD:

- Triggered by physical threat
- Primary emotion is fear
- Nightmares are very common
- Painful reminders linked to the traumatic event usually specific to the event

Shear et al JAMA 2005 293:2601

Grief:

- Triggered by loss
- Primary emotion is sadness
- Nightmares are rare
- Painful reminders more pervasive and unexpected
- Yearning and longing for the person who died
- Pleasurable reveries

Screening Tools

- Brief Grief Questionnaire
  - 5 item self report questionnaire
- Inventory of Complicated Grief
  - 19 item self report questionnaire
  - Takes about 5 minutes to complete

BUT

- It is unlikely that screening alone improves patient outcomes
- What are our responsibilities?
- What do we do if we find someone with a positive Brief Grief Questionnaire?

‘On the Ground’

The numbers

Local example: StGH experiences approximately 60 deaths per month.

The Renal Unit at StGH has experiences roughly 7 deaths per month

What is a ‘usual’ Bereavement Service in the hospitals?

Practical

‘Emotional first aid’

Supported Viewings

Follow up emotional support & information

Immediate: phone call, letter/card

RMS

Bereavement info/support packs
~ 6 weeks post death

The Renal Memorial Service

Communication in Bereavement

- Whose job is it?
- How does the evidence guide us?
- What do Bereaved Persons need from us?
- When should we encourage specialised Bereavement Counselling?

What not to do

Dr Alan Wolfelt. *Companioning the Bereaved* (2005).

Case Study 1 – Mrs F

The patient: an elderly husband, long-term in-centre dialysis patient.

The Bereaved Person: Wife, younger, very dedicated Carer. Appeared as very loving and mutually supportive couple, even though the patient's physical support needs were obviously greater. Cultural background emphasising family care shown through action and 'holding on'.

Over course of months patient asking to cease dialysis in context of multiple comorbidities, significant functional deterioration. Patient also telling ward SW privately of wishes to cease, but concerned as felt it would 'hurt' wife.

Wife tried many ways to counter his requests to withdraw. Sometimes this included accusations to MDT of 'not wanting to help him', or 'doing the wrong thing' by entertaining his request. Multiple family meetings both as inpatient and outpatient with RSC.

Husband RIP. Wife still in two minds about it.

Q: *What will bereavement communication with her be like?*
Q: *What stages might we find her in if we call at different times?*
Q: *Are there evidentially-supported 'time points' to contact her?*

Case Study – Daughter J

The patient: a well-loved father of two middle-aged daughters. All 3 live together.

The Bereaved Person: One daughter, primary carer. Had left work to care for father around 5 years prior, as care needs increased. Reported feeling very glad to do so.

Initial impressions: Daughter verbalised capability, not too fazed about the 24/7 nature of her caring role. However: flat affect, appeared fatigued.

SW decided to see Carer alone. Open-ended question: What's it like for you?

SW built initial rapport then dug deeper into social isolation: identified Suicidal Ideation(SI), Anxiety, Depression. Suicide risk screening – low risk.

Ongoing SI throughout multiple phone calls and clinic visits. Primary source of this were her concerns about her own future after her Caring role has ended.
A common concern for Carers of all ages.

Worked with Carer to communicate stressors of caring role to her sister.

Carer commences seeing private Psychologist, feels it is helping a lot.

SW Liaised with Renal Psychiatrist. Agreed on action plan. Concern remains.

Father RIP early 2016. Bereavement support in initial weeks-months. Carer continues to see Psychologist.

Q: *What stands out in this story?*

Q: *What might have triggered you to be concerned for the Carer?*

Q: *How would you feel being the clinician to whom she disclosed?*

Q: *Do you know your local processes for an action plan?*

Q: *How is she now?*

Takeaways

- Grief is normal
- Grief lasts as long as it lasts
- Complicated Grief usually needs Specialist attention
- Bereavement Care can start long before the patient passes away
- Bereavement is everybody’s business
- Allow room for the Bereaved Person to express themselves - ‘Companioning’
- Most bereavement communications will be ‘normal’

References

- Lynn, J. *Serving Patients Who May Die Soon and Their Families* JAMA 2001; 285(7):925-932
- Shear et al JAMA 2005 293:2601
- Shear MK, Simon N, Wall M, et al. Complicated grief and related bereavement issues for DSM-5. *Depression and Anxiety*, 2011 February ; 28(2): 103–117. doi:10.1002/da.20780.
- Tranter, S., Anastasiou, A., Bazzi, H., Burgess, H., & Josland, E. (2013). The renal memorial service: an important component of renal supportive care. *Renal Society of Australasia Journal* 9(2), 80-82, 84.
- Wolfelt AD. Companioning the Bereaved: a soulful guide for Counselors & Caregivers. Companion Press; 2005.
- http://www.thegroundswellproject.com/