Life After Death: Bereavement and Support

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Disclosure

• I have received speaker fees/honoraria from:
  – Boehringer Ingelheim (Canada) Inc.
  – Medtronic Inc.
  – Novartis

• I will not be discussing any of their products in this talk
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
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
  - Complicated Grief
  - Prolonged Grief Disorder
  - Persistent Complex Bereavement-Related Disorder (DSM-V)
  - ICG “Score” >25
- Brief Grief Questionnaire
- Overlap with other conditions

Shear. NEJM 2015;372:153-60.
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

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.
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.
Rationale/Research Questions

• 240,000 Canadians died in 2009
  • 1/5 after ICU admission
  • Limited resources to screen/support

• Questions
  • What is the burden of CG, psychiatric morbidity?
    – Simple screening tests to identify those at risk?
  • Would FMs want support?
  • Can we find a way to provide it with existing staff?
Conceptual Model

Death

3 months

Early Bereavement

Screen

Tailored Intervention

Emotional Support

+/- Psychiatric Referral

+/- Cognitive Behavioral Therapy

+/- Group Therapy

+/- Social Work Referral

6 months

Prolonged/Complicated Grief?

Follow-up
Methodology

• National, multi-centre, mixed-methods study

<table>
<thead>
<tr>
<th>Domain</th>
<th>3M (Screen)</th>
<th>6M (Outcome)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complicated Grief</td>
<td>BGQ</td>
<td>ICG-r</td>
</tr>
<tr>
<td>PTSD</td>
<td>IES-r</td>
<td>IES-r</td>
</tr>
<tr>
<td>Depression</td>
<td>PHQ-9</td>
<td>PHQ-9</td>
</tr>
<tr>
<td>Social Distress</td>
<td>SDI</td>
<td>SDI</td>
</tr>
<tr>
<td>Qualitative</td>
<td>+</td>
<td>+</td>
</tr>
</tbody>
</table>

• HCPs
  • Experience with bereavement support
  • Willingness to participate in screening/support program
Study Recruitment - FMs

ICU Deaths 860

- No response 366 (42%)
- Mail returned or phone disconnected 212 (25%)
- No family or next of kin 19 (2%)

Confirmed Contact 263 (31%)

- Not eligible:
  - Language barrier 11 (4%)
  - Did not have close relationship with patient 4 (2%)

Contacted and Eligible 248 (94%)

- Declined enrolment 141 (57%)
- Expired 1 (0.4%)

Enrolled 106 (43%)

- Withdrew or lost contact 23 (22%)

Completed 6M follow-up 83 (78%)
### Results - Patient Demographics

<table>
<thead>
<tr>
<th>ICU Data</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age</td>
<td>67</td>
</tr>
<tr>
<td>Male (%)</td>
<td>70  (66%)</td>
</tr>
<tr>
<td>Intubated at time of death</td>
<td>21  (20%)</td>
</tr>
<tr>
<td>Mean ICU LOS</td>
<td>12d.</td>
</tr>
<tr>
<td>Median ICU LOS</td>
<td>5d.</td>
</tr>
<tr>
<td>Mode ICU LOS</td>
<td>1d.</td>
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</tbody>
</table>
## Results - Patient Demographics

<table>
<thead>
<tr>
<th>ICU admitting diagnosis / reason for death</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>29%</td>
</tr>
<tr>
<td>End-organ disease</td>
<td>50%</td>
</tr>
<tr>
<td>Neurological disease</td>
<td>19%</td>
</tr>
<tr>
<td>Trauma</td>
<td>6%</td>
</tr>
<tr>
<td>Suicide</td>
<td>2%</td>
</tr>
<tr>
<td>Infection</td>
<td>50%</td>
</tr>
</tbody>
</table>
Results - FM Demographics

- 106 participants
  - Median age: 59 years, 75% Female
- 30% Previous depression or anxiety
- 75% Very/somewhat religious or spiritual
- 87% satisfied with the quality of care received by their loved one
- 57% made a decision to withdraw life support on behalf of loved one
## Results - Symptoms

<table>
<thead>
<tr>
<th>Domain</th>
<th>3M (Screen)</th>
<th>6M (Outcome)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complicated Grief</td>
<td>38% (BGQ &gt;4)</td>
<td>19% (ICG &gt;25)</td>
</tr>
<tr>
<td>PTSD (IES-r &gt;32)</td>
<td>23%</td>
<td>20%</td>
</tr>
<tr>
<td>Depression (PHQ-9 &gt;9)</td>
<td>19%</td>
<td>21%</td>
</tr>
<tr>
<td>Social Distress (SDI &gt;9)</td>
<td>17%</td>
<td>15%</td>
</tr>
</tbody>
</table>

- ICG Score at 6M most correlated with 3M (p<0.0001):
  - Univariate
    - IES Score
    - Brief Grief Score
    - PHQ-9
    - SDI Score
Table 24: Predicted probabilities of ICG > 25 for combinations of values of these two predictors (10th, 25th, 50th, 75th and 90th percentiles). Note that the overall probability is 18%.

<table>
<thead>
<tr>
<th>IES</th>
<th>BG=1</th>
<th>BG=2</th>
<th>BG=4</th>
<th>BG=5</th>
<th>BG=7</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>1.2</td>
<td>1.9</td>
<td>4.2</td>
<td>6.3</td>
<td>13.5</td>
</tr>
<tr>
<td>14.5</td>
<td>2.1</td>
<td>3.2</td>
<td>7.2</td>
<td>10.6</td>
<td>21.6</td>
</tr>
<tr>
<td>21</td>
<td>3.1</td>
<td>4.7</td>
<td>10.3</td>
<td>14.9</td>
<td>28.8</td>
</tr>
<tr>
<td>30</td>
<td>5.2</td>
<td>7.8</td>
<td>16.4</td>
<td>23.0</td>
<td>40.9</td>
</tr>
<tr>
<td>42.8</td>
<td>10.6</td>
<td>15.3</td>
<td>29.5</td>
<td>39.0</td>
<td>59.7</td>
</tr>
<tr>
<td>Criteria</td>
<td>Shear</td>
<td>Prigerson</td>
<td>PCBRD</td>
<td>ICG &gt; 25</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-------------</td>
<td>------------</td>
<td>-------------</td>
<td>----------</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>16 (19%)</td>
<td></td>
</tr>
<tr>
<td>Bereavement (death of a loved one)</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Separation distress</td>
<td>39/83 (47%)</td>
<td>28/83 (34%)</td>
<td>35/83 (42%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive, emotional, behavioural symptoms</td>
<td>21/83 (25%)</td>
<td>3/83 (4%)</td>
<td>3/83 (4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration of symptoms and impairment</td>
<td>75/83 (90%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time (≥6 months) elapsed since death</td>
<td></td>
<td>+</td>
<td>+</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impairments in social, occupational or other areas of functioning</td>
<td>2/83 (2%)</td>
<td>2/83 (2%)</td>
<td>2/83 (2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All of the above criteria</td>
<td>1/83 (1%)</td>
<td>1/83 (1%)</td>
<td>1/83 (1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All criteria excluding impairments in social, occupational or other areas of functioning</td>
<td>17/83 (20%)</td>
<td>3/83 (4%)</td>
<td>3/83 (4%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
FM Desire for Support

• 66% wanted a follow-up phone call
• 55% willing to receive formal support for depression/anxiety at 6M

• **BUT** … desire for follow-up and/or support not associated with presence of CG symptoms (p=0.09)
FM Results - Summary

• Relatively high prevalence of symptoms of complicated grief, PTSD and depression
• Prevalence of complicated grief depends on definition, social dysfunction
• Strong desire for support and follow-up
  • IES-r and Brief Grief Score at 3m are best predictors of CG symptoms at 6m
  • Desire for support not correlated with morbidity
ICU Staff Survey

• 332 / 778 completed, 42% response rate

• 87% RN

• 69% spend 75-100% of time providing direct patient care

<table>
<thead>
<tr>
<th>Years of experience</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;10</td>
<td>47%</td>
</tr>
<tr>
<td>10-19</td>
<td>28%</td>
</tr>
<tr>
<td>20-29</td>
<td>17%</td>
</tr>
<tr>
<td>30-39</td>
<td>8%</td>
</tr>
</tbody>
</table>
ICU Staff Survey

• 51% *comfortable* providing or arranging support for a FM
• 81% willing to receive training
• 68% would provide FM support as part of a program
• Barriers
  • “Not knowing what to say”, dealing with emotion
  • Lack of knowledge about support services
  • High workload and time constraints
Qualitative Methodology

• Narrative interviews with FMs to understand their bereavement experiences and needs

• Semi-structured interviews with HCPs to further explore their bereavement support experiences and needs
  – 34 HCP interviews (13 physicians and 21 nurses)
ICU Impact on Bereavement – HCP Perspective

“I think we can have an impact on bereavement indirectly as well by doing our job properly, by consenting people properly for surgery, consenting people for a therapeutic plan, by giving people information about their disease and giving them realistic expectations. I think that can have a huge impact on bereavement.”
ICU Impact on Bereavement – Family Perspective

“I think there were a lot of things that I didn’t understand. And then they asked if we wanted an autopsy, and because of what my uncle said, I said yes. He wanted to know why he was dying. Well, I want to know why he died, but we have still not been given the results to this, which makes it even harder, because I feel like it’s left unfinished.”
Discussion – Main Findings

• Bereaved FMs have a high prevalence of psychiatric morbidity, complicated grief
• Screening at 3M can predict those who need support, but they may not want it
• ICU-based HCPs are willing to screen and provide support given adequate training
• Complicated grief definitions affect prevalence - important for future studies
Next Steps

• Education around bereavement support
• Pilot screening and support program
  – Expand to multi-site prospective study
• Combining with other interventions
  – Protocolized WDLS/EOL care
  – Communication/family support pre-death
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FUNDING
Ontario Ministry of Health and Long-Term Care
UHN/MSH AMO Innovation Fund