Screening for Complicated Grief in Palliative Care: Evidence and Implications for Practice

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Psychological, Social and Spiritual Special Interest Group
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Overview

- Complicated Grief

- Tools
  - Screening for Complicated Grief
  - Bereavement Risk Assessment

- Bereavement Practice Guidelines

- Current Australian Practice
• **Complicated Grief** (Kristjanson, Lobb, Aoun & Monterosso 2006)
  – need to use consistent definition  
    (as specified by Prigerson and colleagues)

• **Prolonged Grief Disorder (PG – 13)**
  – inclusion in DSM-V (Prigerson and colleagues)

• **Intervention efficacy**
  – well designed Complicated Grief RCT (Shear, Frank, Houck & Reynolds 2005)
    – 16 sessions (Intervention & Control of psychotherapy)  
    – response rate greater & time to respond shorter  
  – “provides solid-evidence for guiding clinical intervention”
    (Zhang, El-Jawahri & Prigerson 2006:1200)
PART I:
For each question, put an [X] to indicate your answer.

1. In the past month, how often have you felt yourself longing or yearning for the person you lost?
   - 1 Not at all
   - 2 At least once
   - 3 At least once a week
   - 4 At least once a day
   - 5 Several times a day

2. In the past month, how often have you had intense feelings of emotional pain, sorrow, or pangs of grief related to the lost relationship?
   - 1 Not at all
   - 2 At least once
   - 3 At least once a week
   - 4 At least once a day
   - 5 Several times a day

3. For questions 1 or 2 above, have you had the experience at least daily, for a period of at least 6 months?
   - 1 No
   - 2 Yes

4. In the past month, how often have you tried to avoid reminders that the person you lost is gone?
   - 1 Not at all
   - 2 At least once
   - 3 At least once a week
   - 4 At least once a day
   - 5 Several times a day

5. In the past month, how often have you felt stunned, shocked, or dazed by your loss?
   - 1 Not at all
   - 2 At least once
   - 3 At least once a week
   - 4 At least once a day
   - 5 Several times a day
### Prolonged Grief – 13 (con’t)

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>Slightly</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Overwhelmingly</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Do you feel confused about your role in life or feel like you don't know who you are (i.e., feeling that a part of yourself has died)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<tr>
<td>7. Have you had trouble accepting the loss?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<td>8. Has it been hard for you to trust others since your loss?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Do you feel bitter over your loss?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Do you feel that moving on (e.g., making new friends, pursuing new interests) would be difficult for you now?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Do you feel emotionally numb since your loss?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. Do you feel that life is unfulfilling, empty, or meaningless since your loss?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
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### PART III:

For this one question, put an [X] to indicate your answer.

13. **Have you experienced a significant reduction in social, occupational, or other important areas of functioning (e.g., domestic responsibilities)?**

- [ ] 1. No
- [x] 2. Yes
WHO definition of palliative care:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

• … offers a support system to help the family cope during the patients illness and in their own bereavement;

• uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; … ”
Palliative Care Australia (2005)

Standard 8

“Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services.”

Primary Care

“Information (both verbal and written) on loss and grief and the availability of bereavement support services is routinely provided to family members prior to and after the death of the patient. Bereavement risk for caregiver/s and family members is assessed during the patient’s illness and support is offered based on need.”
TOOLS
1. “Screening to Predict Complicated Grief in Spouses of Cancer Patients”

(Brintzen-hofeSzoc, Smith, Zabora 1999, USA)

- cross-sectional
- time since death ranged from 5 – 19 months
- retrospective reporting
- self-assessed by bereaved/client
- recommended 2 tools for screening (total of 73 items)
- TRIG used to measure complicated grief
Screening for Complicated Grief

2. Bereavement Risk Index (BRI)
   (Kristjanson, Cousins, Smith & Lewin 2005, Australia)

   - prospective (3 and 6 months post-death)
   - aim to test the BRI as a screening tool and protocol for use in home-based hospice program
   - nurse assessed at time of death
   - Core Bereavement Items (CBI – 17) used to measure complicated grief
   - modified 4-item BRI acceptable reliability, validity and feasibility
   - predictive validity based on CBI, SF-36 & FAD
3. “Screening for Complicated Grief: When Less May Provide More”  
(Piper, Ogrodniczuk & Weideman 2005, Canada)

- Aimed to discover screening questions for initial assessments of psychiatric outpatients to identify which patients are likely experiencing complicated grief (CG).
- Used TRIG and items that define CG

Found:

- “Items that reflected clinical beliefs about indicators and risk factors associated with CG did not perform well.”
- best performer – “pictures about it popped into my mind” and “I tried not to think about it”.
  - Sensitivity (88.6%) and Specificity (89.2%)
  - Nearly 90% of patients with and without CG were correctly identified
- Mean time since death was 10.4 years
1. Bereavement Risk Assessment Tool (BRAT)
   (Victoria Hospice Society 2008, Canada)
   - identifies risk and protective factors
   - not validated instrument
   - undergoing further development
   - has accompanying manual
     - for instrument (protocol?)
   - used internationally
2. Range of Response to Loss

(Relf, Machin & Archer 2008, UK)

- based on Machin’s (2001) self-assessment bereavement tool
- not yet adapted for pre-bereavement self-assessment
- ‘from risk factors to coping styles’
- 2 axis
  - ‘overwhelmed’ and ‘controlled’
  - ‘resilience’ and ‘vulnerability’
- has ‘guidance’ manual

“Assessment in relation to bereavement is no different from ongoing assessment of family need.” (p. 15)
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<tbody>
<tr>
<td>Family involved with BRA</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>BRA to be multidisciplinary</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>BRA done at:</td>
<td>✓</td>
<td></td>
<td></td>
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<tr>
<td>Referral</td>
<td>✓</td>
<td></td>
<td></td>
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<tr>
<td>Death</td>
<td>✓</td>
<td>✓</td>
<td></td>
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<tr>
<td>Throughout care</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Early bereavement</td>
<td>✓</td>
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1. All receive info on bereavement & how to seek help

2. 'Befriending' support that doesn’t need professional

3. Process to establish complex need & referral

Protocols in place for three (above) levels of support

Consent and data protection issues managed

Carers’ needs part of terminal care

Ensure organisation components in place
“The extent to which the instruments are able to predict complicated grief responses has not been well documented given the cross-sectional nature of the study designs.”

(Kristjanson, Lobb, Aoun & Monterosso 2006:100)

“With the exception of the recent work by Kristjanson and colleagues, little systematic empirical work had been undertaken to test a clinical bereavement assessment tool for use in a palliative care setting.”

(Kristjanson, Lobb, Aoun & Monterosso 2006:75)
“Individual clinical judgment is currently the most effective way of identifying those as [sic] risk, as risk assessment tools cannot be relied upon as a predictor of outcome.”

Australian Practice
Survey of Australian Palliative Care Services
(Mather, Good, Cavenagh & Ravenscroft 2008 MJA)

– Response rate 73% (n=236)
– 95% (of 236) have a bereavement support program
  » Phone call (86%)
  » Individual session/visit (84%)
  » Memorial service (66%)
  » Letter (55%)
  » Group session (31%)

– ‘formal bereavement risk assessment tool’ used by approx 66%
  » Formal risk assessment 57% (met) 68% (regional) (ns)
  » Multidisciplinary assess 69% (met) 44% (regional)
Australian Survey of Palliative Care and Hospice Services
(Abbot, O’Connor & Payne 2008)

- Response rate 28% (n=143)
- 94% (n=127) provide bereavement services to all bereaved
- 3 orgs provide bereavement services to high risk only
- 66% (n=93) use bereavement risk assessment process
  » 83% (n=75) use in-house tool
  » 16% (n=14) use formal assessment tool
They conclude:

“... our data suggest that many services struggle to provide what they would wish, because of the models of bereavement support used, the lack [of] formal assessment of risk, and personnel and funding constraints. Questions remain about the value of providing bereavement support to all, rather than allocating services based upon level of need.”

(Abbot, O’Connor & Payne, 2008:17)
“The ‘universalistic’ approach of offering bereavement support to all eligible adults reported in this paper is consistent with the general philosophy of UK hospices to care for patient and their family. However, it is inconsistent with NICE guidance to use ‘risk assessment’ to identify those people most likely to need support.”

(Field, Reid, Payne & Relf 2006:327)
“Is what is currently offered by SPCHS [specialized palliative care/hospice services] really specialist bereavement services or simply a ‘bereavement approach’ to people after they have experienced an expected death?”

(Currow, Allen, Plummer, Aoun, Hegarty & Abernethy 2008:4)
How do risk factors for complicated grief identified before death contribute to outcomes for the bereaved? An Update and Overview

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Psychological, Social and Spiritual Special Interest Group
20 May 2009
• Eastern Palliative Care

• Professor Sanchia Aranda

• The NHMRC Palliative Care Research Fellowship Award
  (GRANT# 466669)
Protective and Risk Factors
(Stroebe, Schut & Stroebe 2007)

**Intrapersonal risk or protective factors**
- Personality (e.g., optimism)
- Attachment style
- Previous bereavements
- Socio-demographic variables
- Pre-bereavement depression
- Religious beliefs

**Interpersonal or non-personal resources & protective factors**
- Social support
- Economic resources
- Professional intervention

**Situation & circumstances of death**
- Cause of death (sudden, untimely etc)
- Circumstances or place of death
- Type of lost relationship (child etc)
- Pre-bereavement caregiver strain
Risk Factor (Last 1988:115-6)

- is a loosely used term:

1. An attribute or exposure associated with an increased probability of a specific outcome (not necessarily a causal factor)

2. An attribute or exposure that increases the probability of a specific outcome (i.e., a ‘determinant’)

3. A determinant that can be modified by intervention to reduce the probability of occurrence of the outcome (a ‘modifiable risk factor’)

All three have been used in the bereavement literature
(Stroebe, Folkman, Hansson & Schut 2006)
Protective and Risk Factors

(Stroebe, Folkman, Hansson & Stroebe 2006)

Risk Factor
- is a variable, when present, increases the likelihood of poor outcome

Protective Factor
- is a variable, when present, increases the likelihood of good outcome

Protective and Risk Factors
- two ends of the same continuum or orthogonal forces?
Aim
To examine factors that impact on bereavement outcomes within the context of palliative care.

Research Questions:
1. Does the quality of the dying and death experience (as perceived by the bereaved individual, in this case, the family caregiver) mediate the impact of known risk factors for complicated grief?

2. How effective is a bereavement risk assessment in predicting complicated grief?
Three Components to the Study

1. Quantitative data obtained from carers (postal survey)
2. Qualitative interviews with carers
3. Screening data obtained from palliative care staff
Research Design

1. Quantitative

Longitudinal design with three time-points for data collection

Time 1 (admission to the palliative care service)

- Patient information (age, disease, symptoms etc)
- Caregiver demographic & prior bereavements
- Caregiver burden, anxiety/depression/stress, optimism, subjective health, relationship quality, prolonged grief disorder (caregiver version)
1. Quantitative (con’t)

**Time 2 (six-weeks post-death)**
- patient symptoms week before death, preparedness for the death, opportunity to farewell, bereavement support received

**Time 3 (six-months post-death)**
- Subjective health, anxiety/depression/stress (repeated from Time 1)
- Bereavement phenomena (Core Bereavement Items)
- Prolonged Grief Disorder
2. Qualitative interviews with carers
   - With sub-sample at Time1, Time 2 and Time 3
   - To explore individual meaning, context and religious/spiritual beliefs

3. Screening Data
   - Not available
Progress to date

**Recruitment** (13 Oct 08 – 15 May 09)

**Time 1 (admission)**
- 276 postal invitations with 56 responses (**20.3% response rate**)

**Time 2 (6 weeks post-death)**
- 20 (of 56 carers) eligible for T2 package to be posted
- 18 have been received to date (**90% response rate**)

**Time 3 (6 months post-death)**
- 1 (of 56 carers) eligible for T3 package to be posted
- 0 received to date (posted Friday 15 May)
Progress to date

Interviews

**Time 1 (admission)**
- 10 interviews

**Time 2 (6 weeks post-death)**
- 2 interviews

**Time 3 (6 months post-death)**
- nil interview to date
Where to from here?


Palliative Care Australia. (2005). *Standards for Providing Quality Palliative Care for all Australians*. Deakin West, ACT.


