Title

Bereavement Risk Screening and Management Guidelines

Keywords

Palliative Care, Grief, Loss, Bereavement, Complicated Bereavement

Ratified

GRPCC Clinical Practice Group

Effective Date

May 2020

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Purpose

The intent of this document is to assist nurses and other health professionals in gathering relevant and up to date clinical information to provide best practice bereavement support.

Enquiries can be directed to GRPCC by email enquiries@grpcc.com.au or phone 03 5623 0684.

Acknowledgements

Some of the information contained in this document is based on the: Melbourne City Mission Grief and Loss Screening Guidelines; La Trobe Community Health Service Ambulatory Care, Bereavement Risk Assessment tool; Central Gippsland Health Service Bereavement Assessment Tool and Peninsula Health Spiritual Assessment Bereavement Risk Assessment and Referral.
Disclaimer
The intent of the GRPCC Clinical Practice Guidelines is to assist clinical staff across the Gippsland to facilitate evidence-based practice in palliative care. These guidelines may be used to inform the development of protocols and procedures for health services tailored to the requirements of their individual service or facilities within Gippsland.

These clinical guidelines are intended to provide general advice to the medical, nursing, and allied health staff working with clients who have life limiting illness. They should never be relied upon as a substitute for proper assessment with respect to the particular circumstances of each case and the needs of each patient or organisation.

Whilst the GRPCC endeavours to ensure these clinical guidelines are accurate at the time of their preparation, it takes no responsibility for matters arising from changed circumstances or information or material that may have become available after the issued or reviewed date.

Outside of Gippsland, please contact the GRPCC if you wish to use or customise any of these documents

Guidelines are uncontrolled once downloaded.
1. Background

Bereavement Support Standards for Specialists Palliative Care Services were published by the Department of Health, Victoria (2012). The standards are intended for use by all Victorian government funded, adult, specialist palliative care services including community, inpatient, acute and consultancy services. Most Australian palliative care services offer bereavement support services, often regardless of risk or need. Providing bereavement support is an essential component of palliative care delivery, but there is little evidence-based guidance or consistency for health professionals and others providing this support.

While loss and grief are fundamental to human life the cause and consequences of bereavement will vary for each individual:

1. For highly resilient individuals, significant grief may be limited to a few weeks. The majority of bereaved people manage their grief with the support of family, friends and neighbours. For most people the acute experience of grief subsides over time;
2. Only a small proportion (10-20 percent) will experience persistent psychosocial difficulties, including Prolonged Grief Disorder (PGD) (previously known as Complicated Grief) and who will benefit from professional intervention.

2. Purpose

The purpose of this document is to:

- provide practical guidelines to clinicians for assessing and documenting bereavement risk from admission to palliative care services in the region
- provide timely and appropriate support in a sensitive manner.
- provide an example of contemporary assessment tools, support systems, and resources for a consistent approach to bereavement risk assessment and management in Gippsland

It must be noted that this guideline is for use by health professionals working with adults.
This document includes three recommended tools:

1. **Complicated Bereavement Risk Assessment Tool (CBRAT)** (Appendix 1). This tool is for use on admission to the palliative care service. It can be reviewed (or repeated) if factors change during the care trajectory, and can again be completed in the bereavement period, as a part of the bereavement follow up.

2. **Palliative Care Problem Severity Score (PCPSS) Carer Distress Assessment, PCOC** (Appendix 2). This clinician-assessed measure is part of the PCOC assessment tools package, that is completed at every contact with the carer (phone contact or in person). Assessment of a moderate or severe score would trigger follow up or referral to a specialist service, for the family/carer. This tool could also be used in the bereavement period.

3. **Genogram** (Appendix 3). This is a tool that can be used to provide a visual picture of the family structure and the support system of the person having palliative care. It can be completed or revisited in any part of the episode of care, including bereavement.

### 3. Policy

The GRPCC Clinical Practice Group membership recognises that grief is a normal response to loss and that most people are resilient and supported in their grief by family, friends and community.

Key principles for bereavement support delivery:

- a) Bereavement support covers pre death to several months after death
- b) There is no time limit to providing bereavement support
- c) Focus on the primary carer, but can include other carers/family if resources allow.
- d) Identify need through structured screening and assessment in order to target resources to those most in need
- e) Identify bereaved person’s own coping resources and capacity:
- f) The clinician conducting the bereavement assessment can obtain meaningful information regarding carer and family coping mechanisms when significant events happened if the right questions are asked.
4. Screening, assessment and documenting of bereavement risk

Screening, assessment, and monitoring for risk of PGD is a continuous process that commences from the time the client enters the palliative care service to many months after the client’s death.

1. Initial assessment
   a. A bereavement risk assessment should be included as a mandatory item in the client’s care plan under the heading CBRAT;
   b. The CBRAT care plan identifies potential risks and proposed strategies to manage risks; and
   c. If no bereavement risk factors are identified; this is clearly documented.

2. Assessment and follow up procedure - key nursing/allied health considerations (see appendix 2 - PCOC PCPSS Family/Carer Distress Assessment and recommendations)
   a. Observe the following from a psychosocial and spiritual context:
      i. characteristics of the dying person;
      ii. characteristics of the main carer and other family members pre and post death;
      iii. interpersonal; relationships dynamics and cultural context;
      iv. burden and/or stigma of illness and nature of the death; and
      v. history of loss.
   b. Other elements to be considered when conducting a bereavement risk assessment:
      i. family cohesion or lack of; and
      ii. communication pattern e.g. open/closed communication within the family that includes expression of cultural beliefs and attitudes.
   c. When risk is assessed as moderate or high, during assessment process or at any time through the client’s episode of care, a timely referral is required (or at least a conversation with a grief and loss counsellor);
      i. may also require discussion with GP (for access to a mental health plan) and referral to an external health agency if expertise not available within the palliative care service

3. Once a bereavement risk is identified, this must be included as a mandatory item in the care plan under ‘Bereavement Risk’ heading, noting the presence of any of the listed factors:
a. It must be completed by the health professional involved following the initial assessment.

b. Add to the care plan and progress notes, as appropriate, as issues may emerge after subsequent visits and/or throughout the episode of care;

c. Use the PCPSS results of family/carer distress to track the coping skills and resilience that the family/carer are displaying. If needed make succinct notes in the progress notes under the same heading;

d. If a carer is identified as at a medium-high risk of complicated bereavement or issues of concern, consider referral to the GRPCCS service (Specialist Grief Counsellors), and discuss at the MDT meeting; and

e. Remember that protective factors and resilience may outweigh apparent risk factors.6,7,8

4. If the caregiver and/or family are identified to benefit from Bereavement Risk resources either at initial assessment or through subsequent visits. These resources can be accessed for downloading and viewing through the GRPCC website: www.grpcc.com.au

5. Important elements for nursing staff and other health professionals to consider

**Typical grief**

Each person’s grief trajectory will be unique. For the majority, grief will involve intense longing, intrusive thoughts and images and emotional responses such as anxiety, unhappiness, uneasiness and unexpected desire to cry. These symptoms subside in a few months and eventually the person will be able to integrate the loss into their lives and regain interest and engagement with life.9 People experiencing typical grief begin to understand that bereavement can be an experience to be engaged in rather than a problem to be solved.10

**Complicated grief**

State of chronic grieving, outside the period expected in “acute grief” (4 to 6 months post death), is characterised by intense separation distress, intrusive and unwelcome thoughts about the deceased, a sense of meaningless, trouble accepting the reality of the loss, and various difficulties “moving on” with life following the loss.11
Low Bereavement Risk  58.4% (60%)
The majority of individuals deal with grief with support of family and friends.
No risk of complicated grief identified by CBRAT

Moderate Bereavement Risk  35.2% (30%)
Individuals in need of some additional support e.g. peer support/trained volunteer led group.
Minimal risk of complicated grief identified by CBRAT

High Bereavement Risk  6.4% (10%)
Individuals at multiple risks of complicated grief identified by CBRAT.
May need referral to specialist health professionals\textsuperscript{12}
Appendix 1

AT A GLANCE BEREAVEMENT RISK SCREENING GUIDELINES

Factors Enhancing Resilience in Bereavement

- Drawing upon past losses – i.e. how I survived
- Connecting with family & community of care
- Drawing on spiritual/religious beliefs and practices
- Identifying internal & external strengths and resources
- Reconstructing meaning and identity after the loss
- Drawing on experience and support of other bereaved people
- Having higher levels of practical support
- Holding a belief in a just world, and acceptance of death
- Gaining comfort from talking or thinking about the deceased

Evidence Based Practice Bereavement Support

- Identify and reinforce their coping and positive achievements
- Reinforce the importance of family and community as sources of social support
- Build on strengths and encourage their innate capacity to recover and cope with grief
- Intervention should be minimal

COMPLICATED BEREAVEMENT RISK ASSESSMENT TOOL (CBRAT)

(**it is acknowledged that protective factors and resilience may outweigh apparent risk factors)

<table>
<thead>
<tr>
<th>Client Characteristics (Bereaved client)</th>
<th>History of Loss (Bereaved Client)</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Under 18</td>
<td>□ Cumulative Multiple Losses</td>
</tr>
<tr>
<td>□ Was a twin</td>
<td>□ Previous Mental Health Illness</td>
</tr>
<tr>
<td>□ Young Spouse</td>
<td>□ Current Mental Health Illness</td>
</tr>
<tr>
<td>□ Elderly Spouse</td>
<td>□ Other Significant Health Issues</td>
</tr>
<tr>
<td>□ Isolated</td>
<td>□ Migrant/Refugee</td>
</tr>
<tr>
<td>□ Lacks Meaningful Social Support</td>
<td></td>
</tr>
<tr>
<td>□ Dissatisfied with help available during illness</td>
<td></td>
</tr>
<tr>
<td>□ New to Financial Independence</td>
<td></td>
</tr>
<tr>
<td>□ New to Decision Making</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Deceased Illness</th>
<th>Relationship with Deceased</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Inherited Disorder</td>
<td>□ Profound Lifelong Partner</td>
</tr>
<tr>
<td>□ Stigmatised Disease in the Family/Community</td>
<td>□ Highly Dependant</td>
</tr>
<tr>
<td>□ Lengthy and Burdensome</td>
<td>□ Antagonistic</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Death</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Sudden or Unexpected</td>
<td>□ Ambivalent</td>
</tr>
<tr>
<td>□ Traumatic Circumstances Associated with Death</td>
<td>□ Deeply Connected</td>
</tr>
<tr>
<td>□ Significant Cultural/Social Burden as a result of death</td>
<td>□ Culturally Defined</td>
</tr>
</tbody>
</table>

**Risk factors scores**

0-2 Low
3-5 Moderate
5+ High

All persons scoring moderate to high presume to be at risk**
Appendix 2

Carer Distress Assessment (Clinician-Assessed, as a part of PCPSS in PCOC)

Palliative Care Problem Severity Score (PCPSS)

The Palliative Care Problem Severity Score (PCPSS) is recommended as a clinical tool which can be used for initial screening and ongoing coordination of specialist palliative care (Bostanci, Hudson et al. 2012). Clinician rated, it facilitates the global assessment of four palliative care domains: pain, psychological/spiritual, other symptoms and family/carer. The family/carer domain measures problems associated with a patient’s condition or palliative care needs. Each domain is rated on a 4 point scale measuring the severity of the symptoms: 0 = absent, 1 = mild, 2 = moderate and 3 = severe. The domain scores are used as triggers for referral, intervention or further assessment (Smith and Firns 1994, Eagar, Gordon et al. 2004). Further information and videos on the PCPSS is available on the PCOC website.

<table>
<thead>
<tr>
<th>The PCPSS domains</th>
<th>The PCPSS score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>0 Absent</td>
</tr>
<tr>
<td>Other symptoms</td>
<td>1 Mild</td>
</tr>
<tr>
<td>Psychological/spiritual</td>
<td>2 Moderate</td>
</tr>
<tr>
<td>Family/carer</td>
<td>3 Severe</td>
</tr>
</tbody>
</table>

See PCOC Clinical Manual for further details

Appendix 3

The genogram

One method of pictorially representing key findings of a family risk assessment is the genogram. A genogram provides a structure and conventional means of documenting the nature of relationships within and between generations, a history of loss events, grieving patterns and subsequent coping strategies, along with an indication of the nature of relationships and support systems. A genogram is the starting point of family care and as such should be part of routine family assessment also useful to CBRAT.

The entire team should be skilled at developing and interpreting a genogram as it engenders confidence for the client and caregiver that the health professional conducting assessment:

- believes family factors influence health;
- understands that illness affects the family; and
- the clinician is open to discussions on family matters.

The genogram has been widely promoted as a useful tool for gathering, recording and displaying family information in order to provide client and family-centred care. A genogram also:

- displays the emotional bonds among individuals composing a family or social unit. This type of information is invaluable for a counsellor/social worker;
- functions as an assessment tool to measure the cohesiveness of the family group in order to determine the care that is needed;
- provides nurses and allied health professionals such as family counsellors or therapists with a starting point to explain family dynamics to a client who is going through personal or family therapy; and
- can be used to examine interesting and/or complex family history such as, rivalry, facing adversity and/or other significant events.
Insert Genogram
(sample genograms below)

![Genogram Diagram]

**FIGURE 1**

**GENOGRAM SYMBOLS**

- □ Male (age)
- ○ Female (age)
- ○ Marriage (include date)
- □ Divorce (include date)
- ✗ Death (include exact date and cause of death)

- `Conflictual relationship`
- `-` Close relationship
- `.....` Distant relationship
- `Members of one household`
- `Draw relatives with black pencil`
- `draw significant others with green pencil`
The bereavement experience will vary in intensity from person to person\textsuperscript{17}. It is therefore difficult to make safe predictions in terms of longer term functioning\textsuperscript{18} of bereaved people before a minimum of six months after a death\textsuperscript{19}.

### Bereavement Support Strategies

<table>
<thead>
<tr>
<th>Component</th>
<th>Description</th>
<th>Examples of Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Universal</td>
<td>Grief is normal after bereavement and most people manage without professional intervention. Many people however lack understanding of grief after immediate bereavement. All bereaved people should be offered information about the experience of bereavement and how to access other forms of support. Family and friends will provide much of grief support, with information being supplied by health and social care professionals providing day-to-day care to families.</td>
<td>Bereavement information leaflets Literature – adult grief Literature – children’s grief Telephone support to acknowledge death Sympathy cards or letters to acknowledge death Information/education sessions on bereavement Memorial services</td>
</tr>
<tr>
<td>2. Selective</td>
<td>Some people may require a more formal opportunity to review and reflect on their loss experience, but this does not necessarily have to involve professionals. Volunteer bereavement support workers/befrienders, self-help groups, faith groups and community groups will provide much of the support at this level. Those working in Component 2 must establish a process to ensure that when cases involving more complex needs emerge, referral is made to appropriate health and social care professionals with the ability to deliver Component 3 interventions.</td>
<td>Telephone support One-to-one support Home visits Referral to support groups run by other agencies Provide support group Provide one-to-one volunteer support Referral to one-to-one volunteer support provided by an external agency</td>
</tr>
<tr>
<td>3. Indicative</td>
<td>A minority of people will require specialist interventions. This will involve mental health services, psychological support services, specialist palliative care services and general bereavement services, and will include provision for meeting the specialist needs of bereaved children and young people.</td>
<td>One-to-one support by formally trained bereavement support worker Home visits by formally trained bereavement support worker Bereavement counselling Clinical Psychology Mental Health Services / Psychiatry</td>
</tr>
</tbody>
</table>
The recommended bereavement support include two types of strategies:

1. Universal strategies targeted at all carers and bereaved people; and
2. Specialist bereavement support strategies directed at those at risk of developing complicated grief or currently experiencing psychosocial and/or spiritual distress

1. **Universal strategies include:**

   - Conducting bereavement risk assessment either at admission or at any phase during the episode of care if bereavement risk factors start to emerge;
   - Promoting effective symptom management of the palliative care client to reduce the impact of refractory symptoms and difficult death on carers and clients themselves;
   - Provision of formal/structured written and verbal information and clinical support at various points of the grief trajectory such as:
     - following admission to the palliative care program that includes:
       - palliative care and external services available;
       - strategies that may assist the primary caregiver to support their relative i.e. symptom management and psychosocial support; and
       - self-care strategies and respite.

   - **When death appears imminent:**
     - ensure the caregiver/family are aware that death is imminent;
     - assess their understanding and preparedness;
     - provide succinct and practical information such as:
       - signs and symptoms of imminent death
       - funeral arrangements
       - Centrelink, wills and financial matters
     - site of death decisions:
       - establish and/or corroborate where the client and family would like death to occur**
       - who is to be notified
       - would a nursing visit be required for verification?
       - who is certifying the death?

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Immediately following death:
- provide assessment of separation distress and degree of trauma to the bereaved if death experienced as sudden;
- follow up with formalised psychosocial support for those identified to be at risk of complicated grief; and
- conduct a multidisciplinary death review:
  - each team member involved in the death is provided with an opportunity to reflect on the experience of the client’s death and its impact on the team individually and collectively.

12 weeks post death:
- follow up phone call for all primary carers:
  - explore/discuss issues such as:
    - degree of current social support;
    - plans to return to work;
    - any health relate issues i.e. insomnia, anxiety, exacerbation of previously existing psychological or physical conditions;
    - any dramatic changes for the person over the last three months that may require specialist bereavement interventions; and
    - ongoing contact with GP
- provide information on supports available such as social/loss and grief support groups

At six months after death:
- conduct formal bereavement assessment, using a validated tool\(^1\) for those previously identified as being at risk of prolonged or complicated grief
- identified established or emergence of symptoms which may include:
  - sense of disbelief regarding the death;
  - persistent intense longing and preoccupation with the deceased; and
  - recurrent images of the dying person; and avoidance of reminders of the death experience\(^2\)\(^,\)\(^3\).
Around 12 months after death
- send an anniversary card that includes information regarding self-assessment; hand-written bereavement cards are considered to be more personal;
- information must be succinct and clear including useful contacts and facts about grief and bereavement
- and/or memorial service invitation.

Provide access to evidence based supportive structures and strategies, which may include:
- participation in bereavement information session to provide caregiver/family opportunities to reflect and to share on the loss and grief experience; and
- activity-based structures such as walking, meditation, music therapy and art therapy groups.

2. Specialist bereavement support strategies:

a. for those who met the criteria for prolonged grief:
   i. refer to an experienced bereavement health professional within the organisation or to an external provider for bereavement counselling and psychotherapy using evidence-based specialist interventions for complicated grief

b. for those assessed as having moderate psychosocial distress or moderate risk of prolonged or complicated grief:
   i. referral to support or social groups;
   ii. support may be offered by unpaid staff such as trained volunteers;
   iii. introduce formal opportunities for caregivers/family to review and reflect on their grief; and
   iv. remember that family and friends network and support remains a significant supportive component throughout the grief trajectory.

There is no “cut off time” for providing bereavement support- a carer may present at any time for bereavement support. A single agency, particularly 12 months post death, must take full responsibility for follow-up to reduce duplication. 24
Appendix 4

After bereavement phone call and/or visit

1. Record the phone call in deceased client’s progress notes. Document potential risks. It is suggested to use the PCPSS clinician assessed ‘Family/carer distress’ tool, and the rating scale
2. Complete the CBRAT tool check boxes if risks are identified
3. Assign a risk level in the care plan under care support or nominated bereavement field as per organisational requirements

If LOW RISK
- No further follow-up required
  (but carer has or will receive cards, letter & brochure)

If MEDIUM & HIGH RISK
- Further follow up may be required
- Complete CBRAT
- If unsure about emerging issues, consider referral to Specialist Grief Counsellors at Gippsland Regional Palliative Care Consultancy Service (GRPCCS).
  - Discussion may be required with GRPCCS staff to identify why referral is indicated (state reason, utilizing CBRAT and own assessment – queries/doubts, etc)
- Does the issue require urgent attention? Discuss concerns with team and/or nurse coordinator
  Clearly indicate a time frame for follow up; e.g. within a week, fortnight, within a month.
References

2. 1 Aoun S. M., Breen L. J., O’Connor M., Rumbold B., & Nordstrom C. A public health approach to bereavement support services in palliative care. Australian and New Zealand Journal of Public Health 2012 Vol.36 No. 1
12. John Clabby, PhD UMDNJ-Robert Wood Johnson Medical School, CentraState Family Medicine Residency and Geriatric Fellowship Program Freehold, New Jersey jclabby@centrastate.com (accessed March 2016)


17. Ibid1 Standard 4, Bereavement support standards for palliative care services: Post death screening and assessment, The PG-13 pp 28


