

***Guidelines for the Assessment  
of Bereavement Risk in Family  
Members of People Receiving  
Palliative Care***

*Centre for Palliative Care*

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## Executive Summary

Australia is predominantly a healthy country. Age-standardised death rates more than halved in the period 1921-1992 and continue to fall. Males born in 1992 could expect to live until 74.5 years and females to 80.4 years<sup>1</sup>. However, it is a universal truth that each of us will die and those who are in a relationship with us will be affected by our death.

The care of people who are dying and their families is an important health care issue reflected in the commitment by Federal and State Governments to making palliative care services available to all Australians. Improvements in the delivery of palliative care to dying Australians have led to a closer examination of the needs of bereaved family members. The Victorian State Government has also risen to this challenge by providing significant increases in funding for bereavement services.

These guidelines aim to assist providers of services to families of dying people to identify family members at risk of complicated bereavement outcomes based on best available evidence. The guidelines were developed through a comprehensive review of the available evidence on risk factors associated with complicated bereavement outcomes and through an expert review process.

Unlike other evidence-based guidelines, these guidelines are not predominantly concerned with making recommendations about interventions, but with establishing a process of complicated bereavement risk assessment to guide effective use of resources. As a result these guidelines draw predominantly from expert opinion (Level IVb evidence) about the process of bereavement risk assessment, while guideline 3 outlining risk factors draws on Level III and IVa evidence gained from cohort and descriptive studies exploring bereavement outcomes. The process outlined in the guidelines provides a useful framework for the development of intervention research in the future.

This report will provide a valuable resource for the delivery of services to dying people and their families. In addition to the guidelines, the report contains an overview of guideline implementation, an outline of key bereavement theories necessary to interpretation of risk factors and a summary of the literature on risk factors.

Implementation of the guidelines has the potential to ensure family members at risk of complicated bereavement outcomes will be identified early, facilitating early intervention approaches to bereavement support. Most of the guideline recommendations require a refocusing of existing services rather than additional personnel or infrastructure. It is hoped the guidelines will stimulate considerable reflection within the health care system about the process of bereavement risk assessment and empower health professionals to work more effectively with family members in risk assessment.

## Part 1

## Introduction

The aim of this project was to develop guidelines to assist palliative care providers to identify family members at risk of complicated bereavement outcomes. Identification of the risk of complicated bereavement outcomes in people utilising palliative care services is a Victorian and Australian performance indicator<sup>2</sup>. This performance indicator asks services to record the number of people they assess as being at risk of complicated bereavement outcomes. The assessment of risk for complicated bereavement assists targeting of services to those at high risk, although not all at risk individuals will be available for assessment or intervention.

While the project focuses on the specialist palliative care context the guidelines are applicable to any setting involved in the care of people who are dying, for example in aged care. The project was commissioned by the Victorian Department of Human Services as one part of a program of research aimed at improving the provision of bereavement services (Appendix 1). The impetus for the project was growing concern about the significant variability in the provision of bereavement support across. The issue of complicated bereavement risk assessment is seen as an important first step in determining the need for bereavement services and in assisting with targeting services to those most in need. The establishment of such risk in any individual is underpinned by several important assumptions that require elaboration. These are that:

1. Risk for complicated bereavement outcomes can be identified in family members experiencing the loss of a person significant to them.
2. Grief is a normal reaction to bereavement, which is usually managed effectively by the family members concerned. Where there is no or little indication of high risk for complicated outcomes family members should be offered education and information about normal grief and access to general support.
3. Where high risk of complicated outcomes is identified, these individuals and families should be offered more intensive support and access to bereavement counselling services. Such targeting of services is at present a theoretical principle partially supported by observational studies but not randomised trials.

The bereavement literature dealing with risk factors is a complex, highly varied body of work spanning more than four decades. The quality of the research is mixed and little rates above Level IV on a hierarchy of evidence (Section 2.1). Given the exploratory and descriptive nature of such research this is not altogether surprising, although study quality is still hampered by frequent absence of an appropriate control group and/or pre-death baseline data for comparison of outcomes. This makes it difficult to determine if measured variables are pre-existing or result from the loss. Where research exists, the predominant focus is on analysis of demographic variables such as age and gender, which are easy to measure but offer little direction for

interventions. These variables probably confound with other more complex variables, such as grieving style, that have not been systematically studied in relation to risk for complicated bereavement reactions. Alternatively the emphasis is on anxiety and depression, with little empirical direction for differentiating these from grief.

There is considerable evidence that the experience of bereavement has potential negative effects on the mental and physical health of the bereaved. Despite these negative outcomes, most people recover from their loss and the psychological distress wanes over time, although studies vary as to the length of follow-up. However, high risk people are more likely to suffer serious and ongoing adverse effects of bereavement. For example, Prigerson and colleagues<sup>3</sup> found surviving spouses who exhibited complicated grief reactions six months after the death were more likely to suffer negative health outcomes, such as cancer, cardiac disease, suicidal ideation and change in eating habits, than those not exhibiting complicated grief reactions. These health outcome differences remained at thirteen and twenty-five month follow-up. Thus, while most people are able to adapt to the experience of bereavement without professional intervention, identification of those at risk of complicated bereavement outcomes will facilitate access to appropriate support.

## Chapter 1

### The approach to complicated bereavement risk assessment

Complicated bereavement risk assessment (CBRA) is a poorly understood and researched process featuring high variability across the service system and between professionals. It is important therefore that users of the guidelines understand something of the approach to CBRA that guided this project. Of key significance are the concepts of risk, risk of complicated bereavement, risk assessment, complicated bereavement outcomes, importance of targeting bereavement interventions and the implications of undertaking CBRA.

#### *1.1 What is risk?*

Risk was originally a neutral term associated with epidemiological studies of susceptibility to disease; however, common usage of the term carries negative connotations.<sup>4</sup> Risks are not always dangerous but the community may perceive them this way. Perceptions involve belief systems operating within complex social and cultural frameworks. Thus the concept of risk is closely linked to concepts of vulnerability, uncertainty and susceptibility and the probability of risk gives life a sense of danger or gamble. However, risk is based on associations without inevitability of a negative outcome.

#### *1.2 What is risk of complicated bereavement?*

Risk of complicated bereavement, in the context of these guidelines, refers to the extent to which a person is susceptible to adverse outcomes associated with loss of someone significant through death. The identification of risk suggests the probability of adverse outcomes rather than an indication of cause and effect. Thus, though a person may be identified as being at high risk of complicated bereavement outcomes, this may not occur, despite the probability of adverse outcomes being increased in the group displaying these risk characteristics. Similarly, a person may be judged at low risk but still develop complicated bereavement outcomes. The assessment of risk for complicated bereavement outcomes is a process of balancing probabilities based on best evidence with clinical judgement and input from the patient and family. The synthesis of all this information can then be used to target support resources effectively. In relation to bereavement, Stroebe, Stroebe and Hansson<sup>5</sup> define risk factors as characteristics of bereaved people or features of their situation that increase vulnerability to the loss experience or slow down adjustment to bereavement. CBRA empowers the provision of preventative support with the potential to reduce overall morbidity.

### **1.3 *What is risk assessment?***

These guidelines are based on the assumption that the death, or anticipated death, of a relative or friend is the antecedent that must occur before the concept of risk becomes meaningful. CBRA is therefore precipitated by the referral of a person to palliative care, where anticipated death is acknowledged. The time lag between referral and death offers the opportunity to engage in risk assessment prior to the death, unlike the situations of unanticipated death where bereavement risk assessment will follow a sudden or traumatic death such as suicide or accident.

Little evidence is available to guide the process, rather than the content, of CBRA. Therefore, the process of risk assessment recommended in these guidelines is based primarily on expert opinion and the philosophy of palliative care. Palliative care is a style of care characterised by the involvement of patients and families in decisions affecting their care. This principle underpins the active involvement of patients and families in the assessment of personal risk recommended within these guidelines. However, this approach presupposes that health professionals involved in CBRA have access to the education and skill development necessary to actively engage people in the assessment of their risk of complicated bereavement outcomes.

CBRA is commonly focused on those closest to the dying person, and is often confined to the primary carer as access to this person is facilitated by their role in the dying person's care. However, CBRA ideally encompasses all people in the dying person's immediate family and extends to those with a significant relationship to the person. Family is defined here as those people making up the closest social network for the patient. While most often consisting of people related by birth or marriage, this definition includes those who self define as family, e.g. same sex relationships.

### **1.4 *What is meant by risk of complicated bereavement outcomes?***

A small proportion of people will be at high risk of severe effects of the bereavement experience referred to here as complicated bereavement. Complicated bereavement is variously defined (Chapter 4) but is considered a maladaptive response to loss that may feature intense and prolonged mourning, depressive disorders, anxiety disorders and poor physical health. Most studies in this area focus on measures of psychological distress and ill health in determining outcomes post-bereavement, with laudable attempts to form agreed definitions of complicated bereavement.<sup>6</sup> However, the work predominantly medicalises grief and complicated grief and fails to explore social understanding (Section 4.4).

The literature also fails to take full account of differences in grieving style that may impact on manifestations of distress and responses to questions posed to elicit distress. The conventional view is that emotional distress is a key indicator of complicated bereavement. From this perspective the central tasks of grieving are the management of emotional distress and the seeking of social support. While conventional, this style of grieving is increasingly understood as feminine (not equated as female). An alternative or masculine (rather than male) style of grieving

has also been identified and is a more active and cognitive but private style that can be undertaken alone. As a consequence measures of risk may fully assess bereavement outcomes of those with conventional grieving styles but may miss risk in people with the more cognitive, private grieving style. Differentiating grieving style may be important when considering appropriate interventions for those at risk. For example, while support groups may be appropriate to those with the conventional grieving style a more active approach, such as a walking group, may be more suited to the other style. Until research evidence indicates CBRA processes that take account of grieving style, clinical judgement will be vital to ensure both appropriate assessment and intervention.

Two questions should guide the determination of risk:

- What factors effect vulnerability to negative bereavement outcomes?
- What factors impede or promote adjustment to the bereavement experience?

Having knowledge about these vulnerability and adjustment factors will assist in identifying those at risk of adverse effects of bereavement and provide opportunities to target resources appropriately. Importantly, many authors<sup>7-9</sup> believe that assessment of the grief experience is indicated by evidence that early and prompt interventions help to minimise adverse consequences of bereavement. A limitation of CBRA at present is that the literature focuses on the negative outcomes of bereavement. Little information is available to determine those factors that might make a person/family more resilient or help facilitate adjustment even in the context of determined vulnerability.

### ***1.5 Why is it important to target bereavement interventions?***

Walshe's<sup>10</sup> key review identifies four reasons why bereavement interventions should be targeted to people at increased risk of complicated bereavement.

- 1) Targeting bereavement interventions allows health professionals to respect a bereaved person's resilience and to tailor approaches to bereavement support that maximise coping strengths. Thus provision of universal help is counterproductive. Most bereaved people are able to mobilise the coping strategies and inner strengths necessary to deal with their situation.
- 2) There is evidence that focused bereavement interventions do reduce risk and improve bereavement outcomes, but unselective services may lack overall beneficial effects.<sup>8</sup>
- 3) The limited availability of resources for bereavement services necessarily means limits to access to support and follow-up. Such limitations support targeting of resources to those at highest risk of adverse outcomes.
- 4) Provision of bereavement services that rely on self-referral assumes those who need help are able to recognise, and then act on this need. It is probable that those most able to access support independently have high resilience and are theoretically at lower risk.

## **1.6 What are the implications of CBRA?**

Undertaking assessment of risk for complicated bereavement will have implications for the bereaved person, the involved health professionals and the service. At an individual level benefits include the potential for taking positive steps in managing their bereavement and the opportunity to assist more vulnerable family members. Negative effects might include the potential for increased anxiety as a result of recognising personal risk.

Health professionals involved in CBRA may feel inadequately prepared to undertake the level of assessment suggested within these guidelines and may be unprepared for working with families in the ways suggested. It follows that implementation of the guidelines will require attention to staff development issues and these are more fully explored in section 4.

At a service level a number of ethical issues arise that need to be considered when incorporating CBRA as a component of service delivery. The following questions highlight these ethical issues and may guide discussion within each service:

- How will professionals respond when an at risk person refuses support?
- Who should be informed when a family member is identified as at risk of complicated bereavement outcomes?
- How might a service respond when refused access to a person identified as at risk?
- What are the implications of determining risk in the context of limited resources?

## Chapter 2

### The guidelines

The guidelines consist of two key elements intended to assist clinicians to undertake CBRA - a summary of the evidence on the prediction of complicated bereavement outcomes and recommendations centred on distillation of this literature in the context of contemporary practice. The document also includes a checklist to guide the clinical assessment of risk for complicated bereavement outcomes.

The following steps were undertaken to achieve these guidelines:

- A comprehensive literature review that yielded in excess of 400 articles (Appendix 2). Of these, 69 were research articles related to the identification of risk factors and formed the basis of the overview provided in Chapter 5;
- Four focus group meetings involving 28 health professionals from community palliative care services (Appendix 3);
- A telephone survey of 29 services providing palliative care within Victoria (Appendix 4)
- Guideline review by an expert panel and a steering committee, which assisted with the clinical relevance of the guidelines and identification of unpublished evidence.

#### **2.1**      *How was the evidence rated?*

The evidence rating system used in the reviews of the scientific literature is based on a rating system developed by the US Preventative Services Task Force. The project steering committee, like the National Breast Cancer Centre Psychosocial Working Group, expanded the rating system in order to incorporate evidence from well-conducted descriptive studies and expert opinion. The evidence-rating system used in these guidelines<sup>11</sup> is:

- |                  |   |
|------------------|---|
| <b>Level I</b>   | evidence is obtained from a systematic review of all relevant randomised controlled trials, usually found in meta-analyses  |
| <b>Level II</b>  | evidence is obtained from at least one properly designed randomised controlled trial  |
| <b>Level III</b> | evidence is obtained from well-designed controlled trials without randomisation; or from well-designed cohort or case control analytic studies, preferably from more than one centre of research; or from multiple time series, with or without the intervention. |

- Level IVa** evidence is obtained from descriptive studies of provider practices, patient behaviours, knowledge, or attitudes or a systematic review of the descriptive studies
- Level IVb** represents the opinions of respected authorities based on clinical experience or reports of expert committees.

As research surrounding assessment of bereavement risk does not lend itself to a methodology that provides Level I and II evidence, most of the evidence informing these guidelines is from non-controlled trials, case studies and expert opinion (Level IVa and b). Guidelines based on lower levels of evidence are included because well-designed descriptive studies have clinical significance. Guideline 3 has more supportive evidence from controlled and uncontrolled cohort and longitudinal studies (Level III). A summary of the literature review can be found in section 5.

## **2.2** *Who will use the guidelines?*

These guidelines target all health professionals involved in the provision of palliative and aged care, whether within specialist palliative or aged care services or in other areas of health care. The guidelines were developed for use by all team members, including bereavement counsellors, social workers, psychologists, pastoral care workers, nurses and doctors. While some components of bereavement care, including pre-death risk assessment, are common to the entire team, various team members will be responsible for specific aspects of CBRA at different times.

## **2.3** *A caveat when reading these guidelines*

A major limitation in the literature on bereavement and CBRA is the lack of attention paid to cultural factors and their influence on grief and bereavement. The available research is predominantly undertaken in western countries featuring mainly white participants. Despite this there is evidence that grieving is a universal response to the loss of a close person.<sup>12</sup> Similarly, most cultures contain beliefs systems that support the idea of continuation of the person in some way beyond death. However, there are important cultural differences in defining appropriate expressions of grief.

It is impossible to describe here all the various cultural differences in expression of grief. What is important is that grief be understood as encompassing a wide range of responses each of which may be legitimate within the person's cultural context. If a grief response is observed that seems unusual to the health professional, hypotheses about the meaning of the response should be reserved until appropriate information is obtained. An important adjunct to the literature in this area is the book by Parkes, Laungani & Young,<sup>13</sup> that explores death and bereavement across cultures. However, it is important not stereotype grief responses.

What is critical about cultural differences in responses to loss is an avoidance of ethnocentrism - a view that places one's own culture at the centre and other cultural responses are judged from this perspective. Ethnocentric approaches will alienate the

bereaved and may result in provision of interventions that harm the person. We therefore urge that these guidelines are used in the context of practitioner awareness of cultural safety. Cultural safety features both an acknowledgment and respect for difference and implementation of strategies in a manner that promotes and nurtures the cultural identity of the person and family.<sup>14,15</sup>

## 2.4 Summary of guidelines

The following table provides a summary of the guidelines for the assessment of bereavement risk in family members of dying people. The evidence that informed these guidelines is summarised more fully in Chapters 4 and 5.

	<b>Level</b>	<b>Section</b>
<b>Guideline 1</b> Family members should be involved in assessment of risk of complicated bereavement outcomes.	IVa	2.4.1
<b>Guideline 2</b> Complicated bereavement risk assessment forms part of the palliative care team's duty of care and is a process requiring input from a range of professionals involved in the care of the patient and family.	IVb	2.4.2
<b>Guideline 3</b> Complicated bereavement risk assessment should commence at the point of referral to palliative care, and continue through care provision, patient death and early bereavement.	IVb	2.4.3
<b>Guideline 4</b> Complicated bereavement risk assessment requires structured documentation, review in team meetings and the use of family assessment.	IVa	2.4.4
<b>Guideline 5</b> Complicated bereavement risk assessment involves four key categories of information: the illness terminal care and the nature of the death; characteristics of the bereaved; interpersonal relationships including family functioning; and characteristics of the deceased.	III	2.4.5

### 2.4.1 Guideline 1

#### **Family members should be involved in assessment of risk of complicated bereavement outcomes. (Level IVa)**

The evidence supporting this guideline is that those most closely connected to the dying person will experience grief as a result of bereavement, with grief intensity usually proportional to the closeness of attachment. These people are an appropriate target group for risk assessment. A close relationship does not presuppose that the relationship is supportive or amicable, indeed close relationships may be ambivalent or even conflictual (Section 5.3). However close relationships are in some way significant and the death will constitute a loss. Silverman, Johnson and Prigerson<sup>16</sup> suggest vulnerability to complicated bereavement may be grounded in childhood experiences, therefore assessment of all family members is warranted.

Under current practice, the primary carer of a person receiving palliative care – usually a spouse or child of the dying person – is commonly assessed for bereavement risk. Other members of the family are less often assessed. This narrow scope of assessment results from a combination of historical conventions, resource limitations, service structure and limited access to family members not resident with the dying person or available during visits to the home. As services reconsider CBRA in light of these guidelines, it is important to move beyond assessment of the primary carer or relationship.<sup>17</sup>

One mechanism is to see CBRA as a service that can assist people involved with a dying person to make decisions concerning use of bereavement services. This approach emphasises open communication and engagement of family members in risk assessment. There is support in the literature for engaging family members in evaluation of their risk for complicated grief<sup>18</sup> and such engagement provides opportunities for early intervention and may motivate people with high risk to access support. There is also evidence that family members may be good predictors of their response to loss. When working with families it may be useful to ask if they: 1) have lost a close friend or relative to death at some point in their life, and 2) have continuing difficulty with that loss.<sup>19</sup> Zisook and Lyons believe an affirmative answer to one or both questions may indicate unresolved grief and subsequent higher risk for complicated bereavement outcomes. A third question appropriate in this context may be "How did you cope with previous losses?"

A second mechanism is to integrate sensitive inquiry of risk factors into an overall family assessment, which can be done non-intrusively and without risk to those involved. This would be consistent with the stated philosophy of palliative care to treat the family as the unit of care. Under such an approach questions related to family life events and family functioning are incorporated as routine history taking items.

#### 2.4.2 *Guideline 2*

##### **Complicated bereavement risk assessment forms part of the palliative care team's duty of care and is a process requiring input from a range of professionals involved in the care of the patient and family. (Level IVb)**

Responsibility for CBRA varies in current clinical practice. Multidisciplinary input can help to ensure that the widest range of insights is gained in assessment of each person's risk of adverse bereavement outcomes. Each discipline brings a different perspective on the person's life history and experience. It is helpful for one professional to coordinate this input and to take responsibility for recording the assessment.

CBRA may also involve professionals outside of the palliative care team who have a long-standing relationship with the family, for example general practitioners and members of the clergy. These professionals are potentially key informants on how individual family members are dealing with the loss during the early bereavement

period. Where previous psychiatric illness is identified a treating psychiatrist, psychologist or counsellor may also be a relevant informant.

#### 2.4.3 *Guideline 3*

**Complicated bereavement risk assessment should commence at the point of referral to palliative care, and continue through care provision, patient death and early bereavement. (Level IVb)**

Admission to palliative care occurs when the person's death is expected in days, weeks or at most months. This guideline assumes that information required to assess risk of complicated bereavement needs to be gathered from the point of referral, continue over the course of the admission to the palliative care service<sup>17</sup> and extend into early bereavement. The rationale is that circumstances for the dying person and his or her family change over the course of the illness and that prevention of complications is more beneficial than instigation of interventions once complicated grief reactions are observed.<sup>20,21</sup>

To comply with this guideline the health professional should think of bereavement as a continuum with death being one stage. Bourke<sup>18</sup> suggests that how the bereaved deals with grief before the death is predictive of how he/she will deal with grief after the death. The person with uncomplicated grief before the death is less likely to experience complicated bereavement outcomes following the death.

A summary of risk factors should be presented to the entire team both at admission and at the time of death to assist decisions about appropriate support, eg. bereavement education, support groups or individual counselling. In some instances specific support and grief education can commence before death. Regular review of the bereaved is required during early bereavement and referral made to bereavement services should appropriate support be unavailable within the palliative care service.

As information is gathered health professionals should try to hypothesise about what is happening for each family member. This hypothesising results in some health professionals instinctively wanting to provide support to everyone, which is inappropriate,<sup>22</sup> and may be alleviated by team decision making.

#### 2.4.4 *Guideline 4*

**Complicated bereavement risk assessment requires structured documentation, review in team meetings and the use of family assessment. (Level IVa)**

Documentation of the team's assessment of bereavement risk is an important component of CBRA. Documentation can then be used to support team consideration of risk for each family member. Therefore, multidisciplinary team meetings are important for review of all relevant information throughout the admission, death and

early bereavement. Structured documentation may consist of a checklist or risk assessment form and a structured family assessment.

Several CBRA forms are cited in the literature with most being measures of grief intensity. Grief measures include: the Expanded Texas Inventory of Grief<sup>23</sup> the Bereavement Experience Questionnaire,<sup>24</sup> the Grief Experience Inventory;<sup>25</sup> the Bereavement Risk Index;<sup>26</sup> the Bereavement Phenomenology Questionnaire;<sup>27</sup> Core Bereavement Items<sup>28</sup> and the Inventory of Traumatic Grief.<sup>29</sup> However, there is debate about the advantages and disadvantages of deciding on degree of risk based on a measure of grief intensity given that some people may be more or less likely to display overt distress. Scoring of risk is also potentially problematic. A low bereavement risk score does not guarantee good outcomes; likewise a high score may not always equate to poor outcomes. Thus any score should be seen as one of a number of considerations that contribute to an understanding of the situation. The Middleton<sup>28</sup> and Prigerson<sup>29</sup> tools are more recent empirically derived tools that may prove to be reliable indicators of risk in the future. (Appendix 5 - Inventory of Traumatic Grief)

Due to the difficulty in score interpretation these guidelines do not endorse a particular CBRA or grief intensity measure but suggest that the factors identified are considered in the assessment. To this end the guidelines include a checklist of factors influencing bereavement outcomes as a means of recording the findings of risk assessment (Appendix 6) and to precipitate more in-depth assessment of those at risk. The findings must be combined with clinical judgement and the family member's perceptions of risk, in order to make decisions about risk and bereavement service provision.

### ***Family meetings and genogram use***

The research evidence around CBRA is predominantly focused on the individual. However, increasing recognition of the importance of family to the mediation of bereavement outcomes means family approaches are an important future direction for bereavement care. Thus training in the conduct of family meetings is an essential component of staff development.

Family meetings provide an important opportunity to learn about family functioning and coping and where possible should commence prior to the death of the patient, allowing the patient to be an informant. In addition, family meetings allow information provision and facilitate early planning for bereavement. The assessment undertaken in a family meeting can be as informative of bereavement risk as a screening questionnaire if the right questions are asked. Potential questions for use in a family meeting include:

- How are family members coping with this and previous deaths?
- How supported by family and friends do individuals feel?
- Will any family member(s) need counselling?

- How will the children be prepared for the death?
- How well does the family communicate?
- How effective is the family's teamwork and support of one another?
- Are there conflictual relationships?
- How does the family resolve conflict?

The clinician should hear the story of significant events in the family, particularly stories of family distress or breakdown and of family recovery and growth. These data enable the clinician to identify issues or concerns and set agendas with the family for change. Interviewing family members is an intervention in itself as they open up opportunities for targeted individual support. Additionally, family members are given the opportunity to voice concerns and fears while also providing useful information about relationships, differences in opinion and belief patterns, and any changes to relationships that have occurred during the illness. Circular interviewing, for example asking a carefully selected third person to comment on the relationship between two family members, can also be an effective technique in CBRA.

A family approach avoids stigmatising any individual through setting collective responsibility and nurturing shared problem solving as a solution. Moreover, clinical staff can build a working alliance with family members considered to be at greater risk, while goal directed palliative care occurs. The relationship that develops with the bereaved can be naturally sustained post-death of the patient and avoids the resistance to "counselling" often seen if the first contact with the bereavement team does not occur until post-death.

One method of pictorially representing key findings of a family assessment is the genogram. A genogram provides a structured 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. According to Parkes<sup>20</sup>, a genogram is the starting point of family care and as such should be part of routine family assessment also useful to CBRA. The entire team should be skilled at developing and interpreting a genogram.

The act of constructing the genogram will provide an opportunity for the health professional to ask pertinent questions of individual family members or can be used as part of a family meeting. The genogram becomes a useful pictorial record summarising important family information and easily interpreted by all team members and may act as a useful point of reflection for the family.

### ***Family Relationships Index (FRI)***<sup>30</sup>

The Family Relationships Index is a simple and effective 12-item screening tool that identifies dysfunctional families and subsequently those who may be at risk of complicated bereavement (Appendix 7). The FRI is a well-validated self-report

questionnaire with predictive validity evidenced by extensive research. All family members should be invited to complete the questionnaire. Kissane, Bloch, McKenzie, McDowall and Nitzan<sup>31</sup> suggest a family be deemed at risk if one or more members scores nine or less out of 12, or less than four on cohesiveness. In earlier work Kissane, Bloch, Burns, McKenzie and Posterino<sup>32</sup> found cohesiveness to be the most sensitive predictor of poor bereavement outcome. Preventive work with families of concern can then be undertaken in order to increase the likelihood of positive bereavement outcomes.

#### 2.4.5 *Guideline 5*

**Complicated bereavement risk assessment involves four key categories of information: the illness, terminal care and the nature of the death, characteristics of the bereaved, interpersonal relationships including family functioning, and characteristics of the deceased.**

The literature abounds with characteristics or factors that are considered useful in identifying who is at risk of complicated bereavement. Guideline 3 has been divided into four areas that reflect the literature along with an additional section dealing with factors that may facilitate recovery.

#### ***Characteristics of the illness, terminal care and nature of the death (Level III)***

The literature shows that outcomes for the bereaved can be influenced by the duration of the illness and experiences surrounding the period of terminal care and the death. Health professionals involved in CBRA should be aware that there is greater risk of complicated bereavement when:

- the death is sudden or unexpected particularly if:
  - the death occurred under traumatic circumstances;
  - the death is stigmatised e.g. a result of suicide, murder or HIV/AIDS;
  - the bereaved did not have the opportunity to discuss death with the deceased before the death occurred, i.e. there was no warning or period of anticipation.

The bereaved is also at risk of complicated bereavement if the illness was of very short duration or if the illness has been long and the bereaved is middle aged. Death following a short illness, perceived by the bereaved as unexpected or sudden, may leave the bereaved feeling unprepared. Perceptions of prematurity of death are important. For example, death at age 65 years may be perceived by some as too young to die. Alternatively, a long illness may overburden the caregiver's coping mechanisms.

### ***Characteristics of the bereaved (Level III to Level IVa)***

A great deal of attention is paid to the characteristics of the bereaved in the literature. Several key factors have been identified as playing a role in bereavement outcomes and should be considered by health professionals working with the bereaved. These factors include:

- stage of the life cycle particularly when:
  - the bereaved is an adolescent and it is a parent who dies and family support is perceived as inadequate
  - a bereaved spouse is young
  - the bereaved is a spouse/partner widowed at an elderly age and after a long relationship with the deceased
  - the surviving parent of a deceased child is a single mother as a result of divorce or being widowed
- a history of previous losses, particularly if unresolved. Losses may include:
  - infidelity
  - divorce
  - loss of a job
  - loss of a pregnancy
- the presence of concurrent or additional stressors such as:
  - family tension
  - compromised financial status
  - dissatisfaction with caregiving
  - reliance on alcohol and psychotropic medications, pre-bereavement
- physical and mental illness particularly:
  - current/past history of mental health problems that have required psychiatric/psychological support
  - family history of psychiatric disorder
- high pre-death distress
- poor initial adjustment to the loss exemplified by intense emotional distress or depression
- inability or restriction in use of coping strategies such as:
  - maintenance of physical self-care
  - identification of prominent themes of grief
  - attributing meaning to the loss
  - modulation of the distressing components of grief,
  - differentiation between letting go of grief and forgetting the bereaved
  - accessing available support
- isolated, alienated individuals
- being a parent of a child that dies
- low levels of internal control beliefs, such as feeling as if he/she has no control over life

The pre-death assessment of risk may be supplemented post-death by attention to recently established diagnostic criteria for traumatic grief.<sup>33</sup> The consensus criteria for traumatic grief can be found in appendix 8.

### ***Interpersonal relationships (Level III to IVa)***

There is evidence to suggest that level of social support, the nature of the relationship between the deceased and the bereaved, and the level of family functioning can influence bereavement outcomes. Kissane and Bloch<sup>34</sup> suggest that when health professionals become aware of tension within a family during an illness, preventative intervention prior to death may result in positive bereavement outcomes. Therefore, assessment of such factors should be incorporated into CBRA.

Factors that influence complicated bereavement are:

- the availability of social support, particularly if:
  - people in the immediate environment are, or are perceived to be, unsupportive
  - people in the immediate environment are perceived as being antagonistic or unsympathetic
- the bereaved lack a confidant with whom to share feelings, concerns, doubts, dreams and nightmares, reluctance's and other existential issues
- the bereaved experience a disturbance in their social support systems such as not seeing old friends as often as prior to the death
- the bereaved is dissatisfied with the help available during the deceased's illness
- support from family and friends immediately prior to death was good and following the death it subsided
- an ambivalent or dependent relationship between the bereaved and the deceased
- unusually good, long-term, and relatively exclusive marriages
- the family is characterised by lower levels of cohesion, communication and conflict resolution (Section 5.3)

### ***Characteristics of the deceased (Level IVa)***

The final category of information that provides useful insight when determining risk of complicated bereavement relates to characteristics of the deceased. Many of these overlap with risk factors identified above, as the opposite component of the situation and have not been repeated here. The remaining risk factors associated with the deceased are in the subset of age. Age of the deceased influences bereavement outcomes particularly if:

- the deceased is a child or an adolescent;
- the child's death is a result of an inherited disorder or is sudden or violent;

- the deceased is a parent of children, adolescents and young adults:
  - particularly if the surviving parent copes poorly and is themselves at increased risk of complicated bereavement outcomes.

### ***Factors facilitating recovery***

Much of the bereavement literature discusses the risk of psychological distress following a major stressful event such as the death of a family member or friend. In fact, these guidelines attempt to identify risk factors that predispose the bereaved to psychological distress and in turn complicated bereavement outcomes. The polar position to the identification of risk is the identification of factors that facilitate recovery from a stressful life event such as bereavement.

The literature on positive outcomes of bereavement is considerably less than that on the negative aspects of bereavement but is growing. The impetus for investigating the possibility of stressful events providing the opportunity for psychological development comes from anecdotal accounts and the observations of clinicians.<sup>35</sup> Viktor Frankl<sup>36</sup> wrote one of the most well known accounts of finding meaning in adversity. Frankl used his experience of surviving shocking conditions in a concentration camp as the cornerstone of his approach to psychotherapy. It appears that the ability to identify positive aspects of suffering can translate into factors that can facilitate recovery.

Bereaved people also identify factors that appear to facilitate recovery. In broad terms positive outcomes relate to self-perception or social support systems.<sup>35,37</sup> Participants in these studies reported positive changes in self perception that included: feeling stronger, wiser, more mature and independent and better able to face other crises; having a better understanding of others; feeling more patient, tolerant, empathic and courageous; and, being better able to express emotions, thoughts and feelings. Positive changes related to social support systems included strengthening relationships with family and friends and having more positive experiences with social support systems.

It is important to note that positive outcomes are beliefs about what facilitates recovery as opposed to coping strategies.<sup>37</sup> Such beliefs may be the result of a search for meaning in the negative experience. Beliefs need to be distinguished from coping strategies that are intentional cognitive or behavioural attempts to deal with a stressor. Optimism and hope are examples of beliefs that may facilitate recovery from adversity by encouraging ‘benefit finding behaviour’. Similarly perceptions of personal control over a negative event and the belief that one is relatively better off than another are beliefs that facilitate recovery.<sup>37</sup>

When using these guidelines to assist in the identification of those at risk of complicated bereavement outcomes the health professional must also consider positive factors identified by the bereaved that may facilitate their recovery. Positive outcomes such as feelings of increased self-efficacy and experiencing positive

interactions with social support systems may be expressed prior to the death. Others such as feeling better equipped to face other crises may be expressed after the death. Therefore, assessment of factors that may facilitate recovery as well as factors that are indicative of increased risk of complicated bereavement outcomes should take place from the time the patient and family are admitted to the palliative care service and continue throughout the episode of care and into early bereavement.

## Chapter 3

### Implementation of the guidelines

The guidelines and associated recommendations may challenge the current practices of many health professionals involved in providing care and bereavement support to palliative care patients and families. Therefore, consideration must be given to strategies for the successful implementation of the guidelines into practice.

#### *3.1 Core elements for successful implementation*

Kitson, Harvey and McCormack<sup>38</sup> suggest three core elements are required to successfully implement research into practice; namely: the level and nature of the evidence, the practice context or environment, and the method or way the process is to be facilitated.

##### *Evidence defined*

Evidence is defined as the combination of research, clinical expertise, and patient choice.<sup>39</sup> Each occurs along a continuum of potential for influencing implementation and are described by Kitson, and colleagues<sup>38</sup> in terms of polar opposites. For example, for research there are low levels of evidence, including anecdotal evidence and descriptive information. High levels of evidence include randomised-controlled trials, systematic reviews and evidence-based guidelines. Low levels of clinical experience might be divided expert opinion, whereas high levels come from expert opinion with a proportion of consensus and consistency of views. Partnerships with patients provide high levels of evidence in comparison to no involvement by patients in providing evidence.

In theory successful implementation of research requires evidence from the ‘high’ end of each of the evidence elements described. However, if an intervention derived from a randomised controlled trial, the ‘gold standard’ of evidence for interventions, is rejected by clinicians and patients its high standing in the evidential hierarchy is worthless. Conversely, if an intervention is poorly supported by the evidence but is popular with patients and clinicians it is more likely to be successfully implemented and continued.

##### *Context defined*

Kitson, Harvey and McCormack<sup>38</sup> define the context as the environment or setting in which the change is to be implemented. The three elements of context are culture, leadership and measurement. An environment that is defined as low in terms of culture is one that is task driven with little regard for individuals and provides little or

no education. In contrast, an environment with a change enhancing culture supports values, people, learning and patients and places importance on ongoing education.

Low levels of leadership are easily identified by poorly defined team roles and poor organisation. In contrast high levels of leadership are characterised by clear roles and leadership, and effective teamwork. Low levels of measurement are evidenced by the absence of peer review, audit and feedback, external audit and performance review of junior staff. All these components are present in an organisation that has high levels of measurement. Staff members are more likely to accept new evidence if the work context values people, has effective organisational structures and feedback is common place.

#### *Facilitation defined*

Facilitation refers to the support needed to assist people to change their attitudes, skills, beliefs and ways of working.<sup>38</sup> The facilitator's role is critical to the successful implementation and ongoing integration of research into practice. The facilitator assists people to understand why change is necessary and how they need to change to achieve desired outcomes. The dimensions of characteristics, role and style are all part of the facilitation role. A facilitator needs to be open, supportive, reliable, and self confident, and must not be judgemental. The role of the facilitator must be clearly defined in terms of authority, access and the change agenda. Finally the facilitator must provide consistent support as well as flexibility of style. The implementation of change will not be successful, even if the context is receptive, if the facilitator is ineffective.

### **3.2 Barriers to guideline implementation**

Barriers to the implementation of these guidelines were identified in two ways; via the focus group interviews and via the telephone survey (appendix 3 and 4). Participants provided insights into current CBRA practice useful to understanding the process of implementation. The barriers can be broadly classified as relating to practice issues and resources and are addressed in relation to the core elements proposed by Kitson and colleagues.<sup>38</sup>

#### ***Resource issues***

##### *Educational preparation of staff*

Educational preparation of staff straddles both resources and practice, but has been placed here to highlight that preparation of staff will be a critical factor in the implementation process and will require resources. Staff education requirements are a key facilitation issue because of the support required to encourage people to change their attitudes, skills and ways of thinking and working. For example, treating bereavement risk assessment as a service offered to people, rather than as task to be carried out by professionals alone, constitutes a major departure from current practice that may be resisted.

Following the identification of a facilitator, staff in each agency should address their educational needs in relation to the guidelines. Topics that might be appropriate to this education include:

- Communication skills
- Facilitation of family meetings
- Completion and interpretation of a genogram
- Use of the Family Relationships Index<sup>30</sup>
- Using a bereavement risk assessment checklist
- Consideration of the ethical issues raised by CBRA

The educational process should also engage staff in a consideration of the process of guideline implementation and of the roles different people in the organisation will undertake.

#### *Staffing levels*

The level and skill mix of staff will influence the practice context and impact on decisions about implementation. Focus group participants indicated that staff shortages translated into lack of time to undertake comprehensive bereavement risk assessment. Pressures, such as low staffing levels, are not conducive to change and may manifest as resistance to the guidelines.

Where increased staffing levels are not an option, consideration should be given to alternative models of work allocation and delivery to facilitate guideline introduction. For example, involving all staff in bereavement risk assessment, rather than placing the entire burden on the bereavement team, spreads the impact over a larger group of people. Involving family members in their own assessment also relieves assessment burden and provides opportunities for earlier intervention. More accurate identification of those in need of increased bereavement support will free current resources and facilitate service targeting that more effectively allocates available resources.

#### *Availability of bereavement support*

While these guidelines stop short of recommendations for bereavement services, greater identification of at risk individuals is only ethical where there are appropriate support services available. This issue is beyond the scope of these guidelines but is being addressed in two ways. Over the last two years an additional \$120,000 has been made available in each Victorian health region by the Department of Human Services for bereavement care within palliative care services. Additionally, a DHS funded project to develop minimum standards for bereavement support will be completed in September 2000. These standards will inform bereavement support provision and should be used alongside these guidelines.

### *Practice issues*

Many practice issues identified in the focus groups and the telephone survey fall into the core element of nature and level of evidence.<sup>38</sup> It appears that practice, while drawing on selected evidence, has not developed from a comprehensive understanding of the research evidence but is predominantly grounded in the practitioner's beliefs, experiences and preferences. This is not surprising given the complexity of the literature and the need for critical appraisal skills to interpret conflicting results.

Importantly, there was little indication that assessment of bereavement risk was used to guide subsequent decisions about the level and type of bereavement support offered. Instead all clients were likely to be offered the same standard support with an ad hoc method of determining who should be referred for more tailored support either within or externally to the palliative care service.

The variations in practice that will impact on the implementation of these guidelines are:

#### *Staff members who do the assessment*

Individual nurses or allied health team members predominantly undertake bereavement risk assessment alone, with little team interpretation or client involvement. One service relied on medical input to inform bereavement risk assessment.

#### *Timing of assessment*

Timing of bereavement risk assessment varied across services, occurring either on admission to the service, throughout the episode of care or following death of the patient. Few services see the assessment as a process commencing at admission, continuing through the episode of care and extending into early bereavement.

#### *Which families and family members are assessed?*

Variations of who was assessed were also apparent and it was not uncommon for bereavement assessment to only be undertaken on a sub-sample of family members or the primary carer alone at the discretion of the individual practitioner. The practitioner's perspective also influenced decisions about whom, within the family, was assessed. It is unknown whether this is a resource issue or historical convention. The outcome is that only those families with obvious risk factors are likely to be further assessed.

*Format of the assessment*

Currently the format of bereavement risk assessment is varied. Those services that use a structured tool use one that includes yes/no responses accompanied by written comments. Few services utilise a scoring system with a 'cut off' figure that separates those at high risk from those at low risk.

*Factors included in the assessment*

Many services currently assess most of the risk factors identified in these guidelines. However, some services gather information on factors believed to contribute to risk that are not supported by evidence. Limiting assessment of risk factors to those with an evidential base provides the most useful information, promotes the effective use of resources and encourages consistency in data collection on risk assessment.

## Part 2

## Chapter 4

### Theories of grief and bereavement

The death of a partner, relative or friend is one of the most distressing events in a person's life. At the time of death, and in the following weeks, months or even years, the bereaved experience a range of emotions and reactions to the loss. Those directly experiencing the loss, as well as those associated personally or professionally with the bereaved, often use terms such as bereavement, grief and mourning interchangeably. For the purposes of these guidelines, the following definitions are used:

*bereavement*: the situation of anyone who has lost a person to whom they are attached;

*grief*: the physical, emotional, social, spiritual, philosophical and cognitive reactions to bereavement;

*mourning*: the public expression of grief, which is a lifelong adaptive process that is returned to again and again whenever loss is experienced.

A number of key theories of grief and bereavement can be identified in the literature, each having an impact on the conceptualisation of bereavement risk and coping with bereavement. Much of what is written on bereavement lacks an explanation of the theoretical view upon which it is based.<sup>40</sup> Knowing the theoretical base is important because each theory emphasises a different process of mourning, even though they may overlap. Taken together, they contribute to current understanding of grief and bereavement and may provide guidance to clinicians, but are as yet not sufficiently advanced to be of benefit to bereaved people directly.<sup>22</sup>

Historically the four most influential theories are: psychodynamic, psychoanalytic-cognitive, behaviourally orientated, and sociological. Middleton and colleagues<sup>40</sup> found attachment and psychodynamic models to be the most influential according to 'experts' in the field. They surveyed 77 prominent researchers, clinicians and authors in bereavement, most with more than five years experience. Over 75% of respondents rated attachment theory in their top three preferred conceptual frameworks; psychodynamic theory was nominated by over 65%.

#### 4.1 *Psychodynamic theory*

Psychodynamic theory is a broad term that encompasses theories that emphasise change and development, and/or theories that place motivation and drive as central concepts. Psychoanalytic approaches to bereavement support, common in practice, are a subset of psychodynamic theory.

Psychoanalytic theory comes from a personal dynamic perspective, emphasising the question: ‘Why does this person react in this way?’ The main tenet of psychoanalytic theory is that intrapsychic processes dictate the course of grief. Internalisation of the dead is part of grief work and is the preliminary stage of letting go of the deceased. Differences in functioning are explained by characteristics of early bonding or cathartic experiences of the bereaved. The bereaved person identifies with the lost figure and the shared relationship influences the bereavement process.

Freud<sup>41</sup> proposed one of the most influential psychoanalytical theories, which was later seminal in the work of Lindemann,<sup>42</sup> Parkes<sup>43</sup> and Marris.<sup>44</sup> Freud believed that when a person realises an object is gone for ever he/she has to work through a review of the nature and value of the relationship in order to detach emotionally from the person. This catharsis is difficult and often resisted but when accomplished the person re-engages more fully in life again. Melancholia (or depressive illness) results from a loss that is thought about ambivalently or causes guilt. Abnormal grief may result from ambivalent feelings towards the deceased, both love and hate, that are unacknowledged.

Essentially, psychoanalytic approaches to grief and bereavement emphasise the need to mourn adaptively, before being able to successfully re-engage in life. Review of relationships, both past and present, is at the centre of the psychodynamic approach to bereavement. A key example of this approach can be seen in the work of Lindemann,<sup>42</sup> which continues to influence current bereavement practice. Lindemann’s theory of grief was based on observations of, and interviews with, people who experienced acute grief following the death of a relative in the Boston Cocoanut Grove night club fire and in World War II. Lindemann believed that recovery from bereavement involves emancipation from the relationship with the deceased, readjustment to the environment, and formation of new relationships. Accomplishing these steps requires analytic grief work including verbalising feelings of guilt, expressing a sense of loss and dealing with any feelings of hostility. However, Lindemann’s work failed to differentiate the effects of pre-existent psychopathology or effects of post-traumatic stress disorder from issues of bereavement, making extrapolation of his findings to other populations more difficult.

#### **4.2 *Psychoanalytic-cognitive theories***

Psychoanalytic-cognitive theories link psychodynamic approaches with Bowlby’s attachment theory from the 1960s and are popular among bereavement health professionals. Bowlby’s<sup>45</sup> theory of attachment presupposes unconscious processes and considers bonding experiences in childhood to be important in later development. Attachment behaviour serves to commit one person to another, is goal directed, common to many species, and functions to aid species survival. One of the first attachment relationships experienced by most people is that between mother and child. Loss of a child is commonly cited as a risk factor for complicated bereavement (Section 5.4); an observation based on attachment theory. Bowlby believed children formed one of several types of attachment bonds to their parents. Anxious attachment to parents resulted in insecure and dependent relationships to partners. An alternative

was a self-reliant, independent child reluctant to accept care but who felt abandoned. The compulsive caregiver was the one who always cared for others rather than received care. After a loss, the anxious attached person is likely to exhibit chronic grief, the self-reliant person denial and delayed grief, and the compulsive carer chronic grief, although this outcome is stated less strongly than for the other two groups.<sup>40</sup>

Van Doorn and colleagues<sup>46</sup> agreed with Bowlby's<sup>45</sup> view that when an insecurely attached person loses a partner he/she may be predisposed to anxiety and depression disorders. They suggest one modification, insecure attachments alone may not contribute to complicated grief. Rather, people with certain attachment styles whose marriage served a compensatory function may be the ones at risk of complicated bereavement outcomes. This modification was supported by their prospective longitudinal study of 59 widowed spouses which found that having a secure, supportive spouse and an insecure attachment style are factors that contribute to complicated (traumatic) bereavement. These factors contribute independently but not interactively to the severity of bereavement distress. Interestingly, Van Doorn and colleagues suggest neither security increasing marriages or insecure attachment styles appear to influence symptoms of depression.

From the perspective of attachment theory, grief is understood to grow out of initial separation anxiety caused by involuntary separation from an attachment figure. Grief behaviour is characterised by protest and then searching, followed by despair and possibly depression. Resolution of grief emphasises the need for detachment from the deceased with such reorganisation requiring cognitive restructuring of the situation. While some have interpreted this as the need for the bereaved to detach from the deceased, this may not be necessary. Cleiren<sup>21</sup> states: "In contrast to Freud, Bowlby asserts that in a healthy bereavement process, the relationship with the deceased is often not broken. The bereaved may have a feeling of 'inner presence' of the deceased that is comforting and supportive in restructuring their lives" (p. 16). Worden<sup>47</sup> proposed a reconceptualised relationship in which memories of the deceased are taken forward and used adaptively in life. Similarly, Klass, Silverman and Nickman<sup>48</sup> proposed that the resolution of grief involved the survivor maintaining a continuing bond with the deceased. Walter<sup>49</sup> also encourages the bereaved to retain the deceased in their life rather than letting go in order to move on.

Cleiren<sup>21</sup> describes this attachment model as biologically based and that Bowlby stressed the instinctual basis of the grief process. Recovery from loss is seen as corresponding to recovery from disease. An underlying problem with this theory is the assumption that related processes in human and animal infants underlie similar behaviours and that childhood responses are a model on which adult behaviours are subsequently based.

Attachment theory is often used in combination with psychoanalytic and/or cognitive approaches to bereavement and has been described as a cognitive psychoanalytic theory with psychoanalytic elements still recognisable and cathartic elements present in the recovery process.<sup>21</sup> Parkes<sup>43</sup> and Parkes and Weiss,<sup>26</sup> whose work has been influential in the bereavement field, describe one such model. Like Bowlby, Parkes<sup>20</sup> views grief in terms of separation anxiety and bereavement as the response to that separation. Cathartic elements consist of encouraging and supporting the bereaved to fully experience feelings of guilt or anger so that alternative ways of thinking can be sought. According to Parkes, normal bereavement involves a period of grieving characterised by distress and impaired functioning, followed by recovery. Recovery involves replanning and attaining a new level of functioning. Conversely, an abnormal reaction is one in which recovery does not occur.

Bowlby's<sup>45</sup> influence is seen in Parkes'<sup>43</sup> description of the phases experienced by the bereaved. Following a loss, the bereaved searches for the deceased until the loss becomes more real and permanent. This search leads to despair and disorganisation when the world, as known prior to the loss, is shattered. The final stage involves creating a new world, which is predictable and controllable. Parkes stresses that cognitive restructuring is needed in order to come to terms with the new reality. He believes that the bereaved has to go through the pain of the loss, and consciously acknowledge and express associated feelings. Suppression of the pain may prolong or pathologise the grief process.

Marris<sup>44</sup> proposed another psychoanalytic-cognitive theory. Marris complements attachment behaviour and instinct with an understanding of the meaning of these attachments and the way they define involvement and interactions. Following the loss of a person who held an important place in the environment of the bereaved, life is less predictable and new structures of meaning have to be established.

Marris<sup>44</sup> believes predictability is central to survival and without it we cannot interpret the meaning of things that occur. To deal with uncertainty the bereaved either imagines the time before the death (hallucinations, yearning) or forgets or denies what has happened. Resolution of grief depends on working out these conflicting tendencies. The person may need to sort out these conflicts in order to restabilise predictability and meaning in their world.

### **4.3 Behaviourally oriented theories**

Behavioural approaches to bereavement tend to be more change-oriented and primarily concerned with how to promote change after bereavement. Symptoms of bereavement are ascribed to conditioning by the environment. These theories tend to view grief as a normal reaction to loss and concentrate on disruptions to this process. Most behavioural theories therefore seek to identify complicated grief and related interventions. Unlike psychodynamic approaches, behavioural theories do not focus on intrapsychic processes of meaning, but concentrate on the observable manifestations of grief.<sup>21</sup> These include behaviours indicating distress, such as

sobbing, crying, searching, but also behaviours consistent with the presence of the deceased, such as setting their place for dinner. Interventions are then focused on behavioural change.

Links exist between learned behaviours and the reinforcements that result from them. Following death some of these reinforcements are no longer available, such as touching the deceased, while others may remain available but have lost their reinforcing quality. For example, the bereaved may still dress up for dinner but the compliments of their deceased partner no longer reinforce the behaviour.<sup>50</sup>

These theories offer a plausible explanation for a number of symptoms characteristic of normal grief such as searching for the deceased and protesting against the loss. Similarly lost motivation to continue behaviours associated with the deceased can be related to the loss of reinforcement.

From the perspective of this theory, prediction of risk for complicated bereavement is derived from understandings of the degree to which the death results in reduction of behavioural reinforcement. Grief severity is predicted by the magnitude of this reduction. Thus, theoretically, a happy marriage giving significant amounts of positive reinforcement to the bereaved will lead to greater grief severity than when the marriage is unhappy; a finding consistent with some research evidence.<sup>46</sup> However this assumption is inconsistent with psychoanalytic predictions of poor bereavement outcome within ambivalent relationships, also supported by research findings.<sup>7,51</sup> This may mean that negative reinforcement may be as powerful a behavioural stimulus as positive reinforcement.

Some behavioural theorists reinforce the complex but stereotypical response pattern of grief behaviours and suggest a biological basis to observed physiological and psychological symptoms.<sup>52</sup> Others attest to the important role social environment plays in the development of pathological grief. According to Gauthier and Marshall<sup>53</sup> the suddenness of the loss, the significance of the loss and the availability of a replacement for the deceased determine the severity of the bereavement reaction. In addition, social reinforcement for grieving or avoidance of grieving may contribute to complicated bereavement outcomes.

#### **4.4 Sociological theory**

Sociological perspectives on bereavement pay particular attention to the grief responses of family members and their wider social network. Sociological perspectives also emphasise how the strategies adopted by professional carers are shaped by the society and culture that they are immersed and participate in. Some studies focus upon ways in which classic social variables, such as gender, class or ethnicity, affect bereavement.<sup>54</sup> The findings of these studies are similar to those in social psychology. Other sociological studies describe the rituals societies use to manage death, conferring particular identities and allocating specific social roles to mourners and to the dead themselves.<sup>55,56</sup> Others again investigate ways bereavement

theories and strategies reflect the societies in which they are developed, and how they reinforce and reproduce the values and assumptions of those societies.<sup>57</sup>

Every society needs institutionalised means for integrating its members and regulating their passions, an assertion made originally by Durkheim in his classic study of suicide and later developed comprehensively by Talcott Parsons.<sup>58</sup> This need for social integration applies to the dying, the dead, and those who grieve for them: all require a place within the world of the living, but participation in must adhere to cultural norms about how they should behave and feel.<sup>59</sup> Thus the concept of good grief, like that of a good death,<sup>60,61</sup> describes a society's preferred ways of integrating mourners and regulating their behaviours.

Because contemporary western societies are in transition, bereavement practices may reflect various forms of social organisation. Some practices are derived from traditional social forms, where religion is the central authority. Here members of local communities support each other through commonly understood public rituals, and mourners are returned to active social participation by taking their place in these rituals. Other practices reflect modern social organisation, where medicine is the central authority. Emotional and spiritual responses to personal dilemmas are regarded as private matters, so the public response expected of mourners is that of stoical reserve, albeit with covert indications of private pain.<sup>62</sup>

The understandings and strategies summarised in these guidelines reflect for the most part late modern forms of social organisation, where previously private expressions of grief are being brought into public awareness. Professional insight and expertise mediate this process, and good grief is characterised by expressive talk, usually with a counsellor.<sup>63</sup> A further shift, from late modern toward postmodern forms of social organisation, now challenges the professional management of bereavement. Here the authority is one's self, not the professional caregiver, for priority is given to experiential knowledge. Support is found primarily in the mutual help group, and good grief is seen as the mourner's capacity to construct narratives, which make their experiences public, within the group or to a wider audience. In this way the dead have a continuing existence; they live on in the narrative.

This brief precis indicates that sociological perspectives deal as much with bereavement care as with the experience of bereavement. In particular they call attention to the dominance of expressive models of grief and to the importance attached to professional intervention. It is important to remember that mourners may not share the social assumptions underlying current bereavement theories and practices. Professional practitioners need to be aware of a range of interventions in order to be responsive to individual mourning styles and beliefs, rather than impose a ritualised approach to mourner support.<sup>64</sup>

According to this sociological perspective indicators of risk include:

- the bereaved has no continuing relationship with someone who has known the deceased;<sup>49</sup>
- the bereaved's social network has no place for mourners and/or no place for the dead – for example, certain religious groups allow no place for mourning, while materialist ideologies may have no place for the dead;
- the groups to which the bereaved belongs have no process for returning the mourner to active participation in society;
- the bereaved has been referred to an inappropriate therapist or mutual help group.

#### **4.5 Models Used to describe the grief process**

Bereavement literature provides models that have been developed to systematically describe the grief process and usually draw on one or more theories of grief and bereavement. According to Cleiren<sup>21</sup> most models are either stage or phase related, or involve tasks in the adaptation after bereavement. Clinical use of various models is often undertaken without necessarily understanding the theoretical perspectives from which they are developed.

Phase models mainly describe the characteristics and order of intrapsychic states and behaviour of the bereaved and predominantly draw on psychodynamic theories. Commonly cited examples include models by Kubler-Ross<sup>65</sup> and Parkes.<sup>20</sup> These models usually attempt to order the reactions chronologically after loss. However, authors differ in how stages are separated. Recently doubts have been raised about the validity of phase models as they are not supported by empirical literature despite their clinical popularity.

Task models draw on adaptation and behavioural theories and tend to promote the completion of tasks or behaviours that facilitate adaptation following bereavement. Worden's<sup>47</sup> tasks of grief is a well-recognised example of this type of model. It is future oriented, focuses on adaptation to the loss and does not prescribe a fixed order of phenomena. Task models tend to be descriptive rather than explanatory and tasks are formulated and initiated by the bereaved in an effort to adapt to the loss.

Health professionals commonly draw on components of both models. This allows them to pay less attention to ordering of reactions on a time scale and to place emphasis on recognising the variety of emotional states often present.<sup>21</sup> The use of elements of several theories in clinical practice reinforces that no one model has as yet taken account of both the dynamic nature of mourning and the multiple influences on adaptation.

#### 4.6 *Normal versus abnormal grief*

Grief is the anticipated and expected reaction to the death of a family member or close friend. It is a normal response, accompanied by distress for almost everyone who experiences a significant loss. Mourning should be viewed as a process that evolves over time and includes the reaction to loss and change.

The assessment of bereavement risk presupposes that some individuals will display a grief reaction that does not fit a 'normal' or expected pattern or level of intensity. 'Abnormal' grief has many names including: pathological, unresolved, complicated, chronic, delayed, exaggerated, absent, morbid, distorted maladaptive, truncated, atypical, intensified, prolonged, unresolved, neurotic and dysfunctional. Middleton and colleagues<sup>40</sup> believe that lack of agreement on commonly used terms hinders communication within the field, which in turn hinders attempts to research this area. Prigerson and colleagues<sup>6</sup> add that this hinders the diagnosis of complicated grief.

In an attempt to identify commonly used terms Middleton et al<sup>40</sup> sought consensus on terminology for pathological grief from colleagues. Rank ordering of degree of support for seven nominated syndromes (most to least) was as follows: delayed; chronic; anticipatory; absent; unresolved; inhibited; and distorted grief. It would appear that the popular syndromes were the more self-explanatory ones, rather than those that rely on a theoretical explanation. Middleton et al noted that inhibited and unresolved grief were generally described by one of the first four terms, and distorted grief received very little support.

According to Middleton's et al's<sup>66</sup> review, delayed grief is characterised by a minor grief reaction at the time of loss followed by weeks, months or perhaps years before a 'typical', or in most cases severe, grief reaction occurs. Raphael<sup>67</sup> believes that delayed or absent grief can be problematic when related to avoidance of the pain of the loss; or when grief is set aside because of fear of loss of control, guilt or anger. Delayed grief may also occur when the death is not accepted or because of situations that do not allow for expression of grief, e.g. loss of the partner in an extra-marital affair.

Chronic grief is characterised by symptoms resembling depression and by being excessive in duration without coming to a satisfactory conclusion.<sup>66</sup> Usually the bereaved is aware of not progressing in his/her mourning and feels a degree of dissatisfaction. The bereaved may be chronically angry or guilty, withdrawn and preoccupied with the deceased and may behave as if the deceased will return.<sup>67</sup>

Anticipatory grief is largely described in the context of normal grief following an expected death.<sup>66</sup> The nature of the death allows for preparation for the loss. In the same study, absent grief was defined as being characterised by few or no signs of grief. Causes of this syndrome can be attributed to denial, repression or inhibition of emotions.

Jacobs<sup>68</sup> acknowledged the inherent difficulties with definitions and suggests that 20% of the bereaved population experience some form of complicated grief. According to Rando<sup>69</sup> complicated mourning is a useful term because it suggests that the bereaved is experiencing reactions to a loss that have become complicated and therefore can again become uncomplicated. Complicated bereavement (or mourning) implies that some of the variables contributing to this state are external to the bereaved. These guidelines provide evidence of pre- and post-death variables or risk factors that affect the bereaved individual despite his or her psychological state. For the purpose of these guidelines, 'complicated' grief will be used to describe grief that is, or has the potential to be, abnormal.

Prigerson and colleagues<sup>70</sup> describe complicated bereavement as involving "...features that characterise extreme, debilitating reactions to loss that include symptoms of psychological trauma" (p.2). Many authors have described such features of both complicated and uncomplicated grief. However, differences between authors are common and can usually be traced to differences in theoretical framework.

Although mourning was a grave departure from the normal attitude of life, Freud did not believe that the clinical challenge was to differentiate normal grief from depression (melancholia). Freud felt normal grief was self-limiting, was solved by reality and therefore interference with it was useless and might even be harmful.<sup>71</sup> In Freud's view normal mourning was:

- a profoundly painful dejection;
- a loss of capacity to adopt new love objects;
- inhibition of activity or turning away from activity not connected with thoughts of the loved person; and
- a loss of interest in the outside world in so far as it does not recall the deceased.

Mourning was a process where the bereaved gradually withdrew the libido invested in the deceased in preparation for reinvestment in a new object.

Similarly, Lindemann<sup>42</sup> considered uncomplicated grief to be a definite syndrome with pathognomonic symptoms and a predictable course. Lindemann reported two abnormal grief syndromes:

1. delayed grief which could last for years; and,
2. distorted grief which could consist of social withdrawal, psychosomatic illness, manic over activity and development of deceased's symptoms.

In Parkes's<sup>72</sup> view bereavement requires a balance between avoidance and confrontation that leads toward a gradual coming to terms with the situation. If avoidance is the dominant response, grief may be delayed or distorted. On the other hand, obsessive grieving can result in chronic grief and depression.

For Lazare<sup>73</sup> signs of complicated bereavement include: the inability to speak of the deceased without experiencing fresh intense grief; repeated themes of loss; history of sub-clinical depression; compulsion to imitate the dead; self-destructive impulses; uncontrollable sadness at certain times of the year; and phobia about illness and death.

Middelton and colleagues<sup>40</sup> conclude that an adequate definition of normal and pathological grief is difficult to settle on no matter which framework is used. Stage theories of grief, like those based on the psychoanalytic theories of Freud, do not account for diversity of outcome and, as Wortman and colleagues<sup>74</sup> suggest, do not explain why one person is devastated by a loss and another is not. More recently, theorists and researchers have used a multidimensional approach and make use of family system theory, stress theory, developmental theory and personality theories, as well as attachment and psychoanalytic theory to explain pathological grief.<sup>5</sup>

Important recent work by Horowitz and colleagues<sup>75</sup> and Prigerson and colleagues<sup>33,70</sup> sought to develop and refine diagnostic criteria for what Prigerson refers to as 'traumatic grief' and what Horowitz calls 'complicated grief disorder'. These researchers believe the advent of diagnostic criteria will aid in the early identification and subsequent targeting of interventions for those experiencing a maladaptive response to the loss of a significant person.

The term traumatic grief does not refer to a traumatic mode of death such as murder but refers to a separation trauma that is ground in a strong attachment to the deceased.<sup>76</sup> The separation resulting from death leads to extreme feelings of distress. By six months approximately 20% of bereaved individuals in their research continue to experience significant and lasting consequences in terms of their own identity and coping capacity as a result of being bereaved.<sup>77</sup> Many of the symptoms associated with grief are similar to those resulting from post traumatic stress disorder, hence the use of 'traumatic grief'.

The diagnostic criteria developed for both 'traumatic grief' and 'complicated grief disorder' are similar. The criteria for complicated grief disorder include current experience of intrusive thoughts, distressing yearnings, feeling alone, maladaptive loss of interest, avoiding reminders of the deceased (not an element of traumatic grief) and sleep disturbances.<sup>75</sup> Prigerson and colleagues<sup>77</sup> suggest the core symptoms of traumatic grief are yearning, pining or searching for the deceased, loneliness and a sense of losing a part of the 'self' following the death.

Each of these criteria has been validated by methodologically sound research and support the construction of a diagnostic category of traumatic or complicated grief. However, in the palliative and aged care setting using such a diagnostic category has limitations. Most importantly, treatment relies on a diagnosis of complicated grief rather than emphasising preventative approaches. Indeed, Horowitz et al<sup>75</sup> suggest a diagnosis cannot be made under 14 months after the death, a time when most family members will no longer have contact with palliative care. In contrast Prigerson and

colleagues<sup>77</sup> suggest a diagnosis can be made after two months although this time frame is yet to be empirically tested.

#### **4.7 *Differentiating complicated grief from other disorders***

In practice, one of the major problems with defining complicated grief or distinguishing between normal and abnormal is the lack of operationalised criteria for pathological grief, including the inability to separate complicated grief from other syndromes such as anxiety, depression or post-traumatic stress disorder.<sup>66</sup> It may be helpful for clinicians to recognise complicated grief syndromes as maladaptive processes that precipitate the development of psychiatric disorders as a means of overcoming the absence of grief specific psychopathology.

##### *4.7.1 Depression*

Depression has been closely associated with grief in the literature and attempts to measure bereavement outcomes commonly utilise depression measures. This focus on depression may mean that the incidence of complicated bereavement is underestimated.<sup>75</sup> Many items on a depression scale are features of bereavement – for example, feeling sad or blue, experiencing appetite and sleep disturbances, and lack of interest in life and activities. However, depression tools may be useful during assessment of grief to help differentiate normal grief from depression, but not as the only assessment.

Clayton and colleagues<sup>78</sup> identify differences between typical depression and bereavement-related depression. Symptoms rare in bereavement but frequent in severe depression include hopelessness, worthlessness and a loss of interest in friends and, in psychotic cases, the depressed person experiences delusions. Robinson and Flemming<sup>79</sup> believe cognitive attitudes form key distinguishing features between depression and normal grief: persistent, distorted and negative perceptions of self, life and the future are rare in uncomplicated bereavement.

Zisook and Shuchter<sup>80</sup> found that a full depressive syndrome is not uncommon following a spousal death. It may occur early and resolve of its own accord, or it may continue for an extended period. Alternatively, a depressive syndrome may occur some time after the death. Zisook and Shuchter caution that depression presenting soon after bereavement should be taken seriously and treated with counselling and, where necessary, with medication. In a later analysis of the same study Zisook and colleagues<sup>81</sup> report that depression at two months predicted depression for at least the following two years. Similarly Horowitz et al<sup>75</sup> found that those bereaved with a history of major depressive disorder were more vulnerable to complicated bereavement.

The key difference between normal grief and depression is that the grieving person remains responsive and can experience pleasure in an appropriate context, the sadness coming and going in waves. Depression on the other hand involves sustained sadness

with loss of pleasure and non-responsiveness in a context where one would expect the mood to react to the environment. The time course or trajectory of development is different and needs to be traced to confirm the differentiation between normal grief and depression.

Jacobs<sup>82</sup> and others have described that grief and depression are on a biological continuum, causing the threshold that is used to differentiate them to have arbitrary rules, but ones that can be pragmatically applied. Intensity of symptoms, maladaptive behaviours and time course of evolution are the key guidelines that define this threshold. Raphael and Minkov<sup>83</sup> suggest symptoms of grief specific reactions decline in a similar manner to depressive symptoms and that those who are predisposed to depression are likely to experience complicated bereavement.

#### 4.7.2 *Anxiety disorders*

Anxiety measures tend not to be used as widely as depression measures in the bereaved population as the associated morbidity is less devastating. Nonetheless anxiety remains an important indicator of grief intensity. Jacobs et al.<sup>84</sup> operationalised separation anxiety as part of bereavement phenomenology by combining common anxiety items (e.g. feeling tense or nervous) with attachment items (e.g. longing for one's spouse).

Jacobs<sup>85</sup> and colleagues reported 44% of bereaved spouses reported at least one type of anxiety disorder during the first year of bereavement. This is supported by a later small study of 25 widows and widowers that of those with complicated grief, 94% also exhibited signs of depression and 82% exhibited generalised anxiety disorder.<sup>86</sup> Thus complicated bereavement may share symptoms or occur at the same time as anxiety and depression. However, the work of Horowitz et al<sup>75</sup> and Prigerson and colleagues<sup>6,33</sup> may assist in the differentiation of complicated grief as a discrete identity.

#### 4.7.3 *Post-traumatic Stress Disorder (PTSD)*

Bereavement is one cause of PTSD when there is trauma associated with the loss. Even before PTSD was identified, Raphael<sup>7,67,87</sup> suggested traumatic circumstances surrounding a death, such as sudden, unexpected, violent or untimely death, may contribute to bereavement problems.

It may be difficult in such situations to distinguish between the effects of the trauma and the presence of complicated grief. Features of normal grief and PTSD may overlap or PTSD may dominate. One suggestion is that when trauma and grief co-exist, it is necessary to work through the effects of trauma before grieving can begin.<sup>88</sup> This is reinforced by one study of children following exposure to a school sniper.<sup>89</sup> This found that effects of the trauma were associated with PTS, while grief correlated with closeness of the relationship with the deceased children. Sometimes these phenomena were separate but at other times there was interplay.

In short, PTSD complicated bereavement is likely to be differentiated from a “normal bereavement” by intrusive phenomena that reflect the scene of the trauma and distressing images of the situation, contain affects of anxiety, hyperarousal, nightmares and other re-occurring or avoidant phenomena. The bereaved not suffering PTSD complicated bereavement is more likely to yearn for the deceased with later sadness and nostalgia.

#### *4.7.4 Somatic symptoms and disorders*

Recent bereavements need to be taken into account when someone presents with somatic complaints. Symptoms experienced by the bereaved that are similar to those experienced by the deceased are thought to represent a form of identification. For example Parkes’<sup>20</sup> study of widows and widowers over 60 years of age showed the bereaved visited general practitioners with muscle and joint conditions particularly osteoarthritis. Prigerson et al<sup>33</sup> found widowhood, compared with separation or divorce, to be associated with poor health outcomes but not with greater health service use. A biosocial approach that understands the whole person is critical in the care of the bereaved.<sup>90</sup>

### ***Summary***

The above evidence suggests there is considerable overlap between symptoms thought to represent complicated grief and other defined syndromes such as anxiety, depression, and PTSD. Although the work of Prigerson and Horowitz would suggest there is growing evidence that traumatic or complicated grief should be considered as a discrete clinical entity.

## Chapter 5

### Literature Review

#### 5.1 *Characteristics of the illness, terminal care and nature of the death*

##### 5.1.1 *Length of illness*

Length of illness is a frequently identified component of bereavement risk assessment, mostly used to assess whether the death was expected or unexpected. While sudden death is easy to define as unexpected, deaths due to long-term illness can also be perceived as unexpected by the bereaved. Additionally, little consistency exists as to the definition of short versus long illness or expected versus unexpected death. For example, Stroebe Stroebe and Hansson(**Level IVa**)<sup>91</sup> defined an unexpected death as that occurring with less than 1 day warning of the impending death. In contrast, analyses by Steele<sup>92</sup> divided the bereaved group according to those who cared for patients who were ill 6 months or less from those with longer illnesses. We have chosen to deal with sudden death as an aspect of ‘nature of the death’ rather than as related to length of illness in order to separate concepts of length from those of expectedness.

The frequently quoted Harvard study by Parkes(**Level III**)<sup>93</sup> examined widows and widowers aged less than 45 years. The study found that death from an illness of short duration (less than two weeks warning of seriousness and less than three days of deterioration before death) was the highest ranked of 55 antecedent variables that predicted poor bereavement outcomes after 13 months. Parkes found that widows and widowers who had a shorter time to prepare for the death of a spouse suffered more general psychological disturbance, were disinclined to take part in social activities, suffered from severe and lasting distress, and had difficulty coping with significant roles. These problems continued throughout the first year of bereavement and were accompanied by a persistent orientation towards the deceased. Similarly, a prospective longitudinal study of 162 widows found a short duration of illness (less than two months) to be significantly related to poor bereavement outcomes at both one month and at two years(**Level III**).<sup>94</sup>

Sanders(**Level IVa**)<sup>95</sup> studied 86 bereaved family members, spouse and parents and divided them into a sudden death group, a short-term illness (less than six months) group and a long-term chronic illness group (more than 6 months). Similar levels of grief within the groups were found soon after death, but by 18 months the short-term illness group was better off than the other two groups. Depression, somatisation, anger, physical symptoms and feelings of loss of control were more problematic at 18 months than at 2 months for the sudden death group.

Cleiren<sup>21</sup> believes these results must be viewed with caution because the groups were not controlled for kinship. The short-term illness group consisted of more parents than family members and spouse, and there were more child deaths in the sudden death group. It is possible that the nature of the lost relationship, rather than the length of the illness, contributed to bereavement outcomes.

In a later study, Steele(**Level IVa**)<sup>92</sup> found that survivors of those who were ill 6 months or less had significantly higher scores on the sub-scales of dependency, social isolation, and anger/hostility, but lower ones on loss of control when assessed a mean of 11.4 months following the death. These survivors also experienced more anger, irritation and feelings of injustice over the death, but felt they had more control over the events surrounding the death. Clayton et al.<sup>71</sup> also reported that survivors of relatives with a short terminal illness suffered from statistically significantly more anorexia/weight loss than survivors of people with a longer illness.

In contrast, an early study of older spouses by Gerber et al.<sup>96</sup> found that when a spouse suffered a longer illness before dying, the surviving spouse had a poorer outcome after bereavement than spouses of people who died after a shorter illness. Fulton and Gottesman<sup>97</sup> and Sheldon<sup>98</sup> support this finding. Ball(**Level IVa**)<sup>99</sup> also found prolonged illness caused more upset for the bereaved especially if they were middle aged, i.e. 47–59 years. Clayton et al.<sup>100</sup> reported a higher incidence of guilt and irritability in surviving spouse after a prolonged illness. Rando<sup>101</sup> also believes death from an overly lengthy illness is one of several factors that contribute to complicated mourning. She believes stress associated with long-term illness can come back to haunt survivors, which may interfere with healthy adaptation.

The relationship between length of illness and bereavement outcomes is theoretically linked to ideas about the role of anticipatory grief in bereavement adaptation but confounded by carer burden, guilt and related emotions. While there is reasonable evidence that an opportunity to work through the death in situations where the death is expected might reduce adverse bereavement outcomes, this finding is not universal. Other factors associated with either long or short duration of illness, such as the nature of the death and caring experience, may act to confound these results and inflate the importance of illness duration in assessing risk of adverse bereavement outcomes.

### 5.1.2 *Nature of the death*

The literature commonly reports that sudden unexpected deaths can lead to complicated bereavement(**Level III**)<sup>51,67,102,103</sup>; (**Level IVa**)<sup>5,101,72,98,104</sup>. Zisook, Shuchter and Lyons(**Level IVa**)<sup>105</sup> report that participants whose spouse died suddenly had higher depression scores than those whose spouse died after a prolonged illness, a finding supported by others (**Level III**)<sup>96,93,94</sup>. However, relatively little is known about variables affecting bereavement in these two contexts. Hayslip et al(**Level IVa**)<sup>106</sup> suggest that when such events occur it may be due to one or a

combination of the following factors: lack of opportunity to grieve beforehand; the often abhorrent nature of the death; the stigmatised nature of the death such as in suicide or murder; the nature of the loss itself, or the fact that the deceased was young.

According to Lundin(**Level III**),<sup>107</sup> Parkes and Weiss<sup>26</sup>, Rando<sup>108</sup>, and Raphael<sup>67</sup>, sudden unexpected death has been shown to have a debilitating effect on the bereaved in that shock acts to prolong grief and produce excessive physical and emotional trauma. Raphael<sup>7</sup>, in a study of 200 Australian widows, found that traumatic circumstances surrounding the death of a spouse was indicative of poor bereavement outcomes.

It seems the lack of time to prepare psychologically for death is initially more difficult to cope with and is more likely to lead to long-term problems, in contrast to when the death is anticipated(**Level III**).<sup>109</sup> Raphael<sup>67</sup> reviewed retrospective and prospective studies that delineate the importance of the nature of the death. Sudden, unexpected, and unanticipated deaths, especially of the young, are associated with poor outcomes. The bereaved feels a great sense of helplessness leading to feelings of vulnerability and personal threat.

Stroebe, Stroebe and Domittner(**Level III**)<sup>103</sup> also reported sudden death to be linked to adverse bereavement outcomes. However, these researchers describe expectedness of loss to be only weakly associated with depressive symptoms and somatic complaints, and then only during the first six months after loss. Unexpectedness seemed to be of great importance to those individuals who also reported low levels of internal control beliefs, with these individuals improving very little over 2 years of follow-up. In later publications Stroebe, Stroebe and Hansson<sup>5</sup> argue that a sudden or unexpected death confirms for people their belief that they have no control over events in their life, leading to ineffective efforts to cope with their loss and feelings of depression.

But findings of the relationship between sudden death and poor outcomes are inconsistent<sup>5</sup>. Unexpected loss does seem to increase the immediate vulnerability to the loss experience, but prolonged dying can also heighten risk of grief problems (**Level IVa**).<sup>110; 5; 105</sup> Clayton(**Level IVa**)<sup>111</sup> found no difference between a group of elderly survivors who were bereaved by a sudden death and those bereaved by an anticipated conjugal death, a view supported by Fulton and Gottesman.<sup>97</sup> Parkes and Brown<sup>51</sup> replicated the Maddison and Viola(**Level III**)<sup>112</sup> study using matched controls and concurred with the original findings: sudden death or death with minimal warning does not necessarily lead to worse bereavement outcomes than bereavement outcomes following an expected death. Sanders(**Level IVa**)<sup>113</sup> also found no differences in bereavement outcomes between bereaved who lost a close family member after an illness of short duration or following a lengthy chronic illness.

Parkes **(Level III)**<sup>93</sup> and Raphael<sup>67</sup> suggest prolonged suffering during the terminal illness and the nursing care required may emotionally drain the bereaved and heighten ambivalence and dependence in the relationship. Unexpected death usually refers to death resulting from accident, suicide or heart attack. In a palliative care setting, it is not uncommon for families to consider a death after a long illness as sudden, leaving the family members feeling shocked and surprised. A large retrospective study (n = 483) by Hayslip et al<sup>106</sup> found that survivors of an expected death reported lower bereavement adjustment scores which indicate more adequate functioning **(Level IVa)**. The authors reasoned that those bereaved by an expected death were more likely to have support networks that were present during the illness and at the time of death. However, these findings only applied if the bereaved reported being emotionally close to the deceased.

Stroebe, Stroebe and Domittner **(Level III)**<sup>91</sup> used a longitudinal study to show the lasting effects of an unexpected death on bereaved spouses. Bereaved who lost their partners without warning and who, in addition, felt they had little influence over events in their lives were more likely to suffer long-term consequences of bereavement. Depressive symptoms and somatic complaints improved very little over two years. The involuntary loss of a harmonious marriage i.e. being widowed as opposed to divorced or separated appears to make the loss especially distressing and may foster a sense of helplessness **(Level IVa)**.<sup>114</sup> Widows suffered more depressive symptoms even when controlled for duration of the spouse's illness.

A prospective longitudinal study of 115 families of patients who died of cancer revealed that the unexpectedness of the death did not influence the bereavement outcome **(Level III)**.<sup>115</sup> This finding held true for other psychosocial variables including: caregiving stress; witnessing the pain in the patient; the effect of illness overall on the family; saying goodbye; and being left with unanswered questions about the illness and death. The same study revealed that the length of the illness was weakly correlated with measures of distress or grief. A study by Helsing, Szklo and Comstock<sup>116</sup> also reported no association between unexpected death and poor outcomes **(Level III)**.

Parkes **(Level III)**,<sup>93</sup> supported by Sanders<sup>102</sup> suggested the mode of death was one of the primary predictive factors involved in spouses' bereavement outcome. Other variables that contribute to a poor outcome such as exacerbated grief were short duration of illness, cause of death not being cancer, and no opportunity to discuss pending death with spouse. Parkes describes this as "unexpected loss syndrome" characterised by social withdrawal, continued bewilderment and protest. This syndrome impairs functioning and uncomplicated recovery could not be expected. Lundin,<sup>107</sup> in a controlled and matched prospective study, found a sudden death resulted in significantly more somatic and psychiatric illnesses when compared to expected death **(Level III)**. When bereaved who anticipated the loss were in poorer health before bereavement, they suffered no increase in health consequences after the loss. After 8 years there was no difference in satisfactory and poor outcomes between

groups. When Lehman, Wortman and Williams<sup>109</sup> examined the long-term effects of losing a spouse or child in a care accident, they did not find these recovery effects (**Level III**). Results suggest that four to seven years after the accident the bereaved showed significantly greater distress than matched controls. Both spouses and parents indicated severe depression and lack of resolution. Sanders<sup>95</sup> reported that survivors of sudden death showed more anger and suffered more physical symptoms than bereaved that had lost someone to a chronic illness. Unexpected deaths left survivors with feelings of loss of control and loss of trust in the world.

## 5.2 *Characteristics of the bereaved*

### 5.2.1 *Demographic factors*

While demographic factors are consistently identified as relating to bereavement outcomes, a recent review found demographic factors to be poor predictors of bereavement outcomes.<sup>10</sup> Importantly, demographic factors such as age, gender and socio-economic status may affect health independently of bereavement, raising serious questions about the importance of these factors in determining the person's risk of adverse bereavement outcomes.<sup>102</sup> The purpose here then is to review some of the evidence supporting the role of demographic factors in determining bereavement risk and to highlight the reasons why cautious interpretation is recommended.

#### **Age**

Age is a consistently used demographic variable in studies of bereavement risk, possibly because data on age is easy to collect. Several studies report that younger age is associated with poorer outcomes (**Level III**);<sup>94,117,118</sup> (**Level IVa**),<sup>105,119,120</sup> However, it may be important to consider when in the bereavement period these studies were undertaken. For example, while Sanders'<sup>118</sup> early longitudinal, matched control study of 45 bereaved spouses reported that younger spouses initially manifested greater intensity of grief, this trend was reversed at 18 months with older spouses showing exacerbated grief reactions (**Level III**). Similarly, Vachon et al<sup>94</sup> found that while young age was a predictor of grief intensity at one month, this was no longer the case at 24 months (**Level III**).

Age may be more of an indicator of differences in grieving style than a specific indicator of risk. In Sander's<sup>118</sup> study younger spouses scored higher on guilt while older spouses were higher on denial (**Level III**). At follow-up, only guilt and anger were higher for younger compared with older spouses. However, for the older spouses there was significant elevation on denial and physical symptoms. Denial appears to be operating as a suppressor variable against anxiety, giving evidence of a more diminished emotional grief reaction in the older bereaved. Older spouses were also more likely to have elevated scores on social isolation, depersonalisation, death anxiety, despair, loss of emotional control, rumination, somatisation, sleep disturbance and loss of vigour. Over time younger spouses reported significant reductions on all scales except denial. In the interpretation of this result, Sanders

suggests that age itself is not responsible for intense bereavement reactions rather it is the isolation and loneliness of the older women that lead to these reactions.

A cross-sectional study by Sable<sup>121</sup> found that regardless of time since loss, older widows exhibited higher levels of distress, including anxiety and depression, than younger widows (**Level IVa**). Distress levels tended to persist for up to 3 years with only minimal reduction in that time. Sable<sup>121</sup> suggests that on account of many of the conditions that accompany aging, such as poor health, a decrease in income, an elderly person is looking for support from someone they trust. However, as age increases so do the chances that this trusted person may die. Age may therefore indicate differences in grieving style rather than differences due directly to age.

Steele's<sup>120</sup> descriptive non-control study also found manifestations of grief differed according to the age of the bereaved. In this study, age significantly correlated with denial, despair, anger/hostility, loss of vigor, optimism/despair and social desirability (**Level IVa**). As age increased there was a tendency to deny both feelings and the death. The very young (25–35 years) reported feelings of despair and hopelessness, high degrees of loss of meaning, anger and hostility. Steele's findings suggest that the young (25–35) and the elderly (66–85) should be carefully observed for despair, hopelessness and loss of meaning in life. As age increased so did the tendency to respond in a socially desirable or acceptable manner.

Adolescents are often claimed to be a specific group in relation to bereavement risk. A recent review article by Mearns<sup>122</sup> claims that there is sufficient evidence that adolescence is a specific risk factor for complicated bereavement. Mearns argues that “loss and grief evoke feelings of helplessness and loss of control, in opposition to the adolescent's developmental needs of independence, power and self-control” (p. 14).

Littlewood<sup>123</sup> suggests that adolescent grief differs from both adult and child grief because the increased rate of change in emotional and psychological development during adolescence makes death more difficult to cope with. Evans<sup>124</sup> believes a significant loss or bereavement may exacerbate the psychological turmoil experienced during adolescence. According to Raphael<sup>67</sup> and Henshelwood<sup>125</sup>, sudden death may make the situation worse for an adolescent and should be considered a risk factor for complicated bereavement. However, qualitative research<sup>126,127</sup> indicates that adolescents' emotional responses to grief are similar to those experienced by adults. One explanation of this contradiction may lie in the claim that while the range of emotions is similar, the process of grieving is different to that experienced by adults.<sup>67,128,129</sup>

Qualitative research into adolescent sibling bereavement suggests that adolescent grief has an element of timelessness; of ongoing attachment often with hope of future spiritual reunion.<sup>130,131</sup> Hogan<sup>132</sup> stresses that adolescent grief is a prolonged process. As new levels of development are attained the adolescent experiences fresh aspects of grief. Several studies<sup>133-135</sup> suggest that after the death of a parent, the adolescent may experience a loss of identity, combined with the loss of a role model and a major

support system. Therefore, adolescents with a close social network of family and friends providing open, supportive communication have healthier bereavement outcomes than those without such supports. Abrams<sup>135</sup> suggests that the lack of informal and formal support for adolescents may exacerbate feelings of abandonment and isolation. A lack of support to deal with losses, both past and present, may result in violence toward self or others.<sup>136</sup>

Adolescents may also suppress or deny their grief.<sup>124,125,127,135</sup> This can be considered normal for adolescents but may contribute to complicated bereavement outcomes. Adolescents may keep grief and distress private because appearing to be in control is important to them. Grieving in private precipitates a high risk of isolation, loneliness and feelings of abandonment.<sup>128</sup> A lack of experience in facing death may result in denial being used as a coping mechanism.<sup>124</sup> According to Worden<sup>47</sup> denial amongst western adolescent boys is common because of the expectation that males should be 'strong' and not express emotions. This is consistent with findings that adolescent boys felt they had to suppress their emotions in order to prevent further distress to the grieving parent.<sup>127,134</sup> Weitz<sup>127</sup> also found boys feared losing control of their emotions and appearing different and then being stigmatised by their peers. As a consequence, adolescents strive to continue with normal activities that may be interpreted by other family members as uncaring behaviour<sup>132</sup> or as a sign of coping successfully with the loss.

Social support is of paramount importance for healthy outcomes for teenagers. Sach<sup>137</sup> identifies adolescents as one of two groups of family members who need particular attention and bereavement support when a child dies (the other is grandparents). Most adolescents will turn first to family whose ability to provide support is often related to each member's own ability to deal with grief. If family support is insufficient teenagers may then go outside the immediate family to peers who, unfortunately, may not have the maturity or experience to provide the necessary support. Evans<sup>124</sup> says it is essential that teenagers be given the opportunity to express their distress and sadness in a safe and supportive environment.

Palliative care team members are in a position to provide this environment and encourage adolescents to express their sadness and distress. This encouragement should be given before and after bereavement. If adolescents are reluctant to accept individually focused intervention then professionally organised support groups may provide a more acceptable type of formal support<sup>122</sup>.

In summary, while younger age is consistently reported as associated with more intense grief reactions, this may be confounded by the lack of sensitivity of current measures of grief intensity, and variations in grief manifestation across age groups. Similarly, the cause of death should be considered as a confounding factor. Often younger bereaved people experience the death of a young partner or friend that is unnatural e.g. the result of an accident. Therefore the cause of death may contribute to bereavement outcomes. While adolescents may be particularly at risk of complicated bereavement outcomes, the evidence to support their particular risk is likely to be

associated with other factors such as family function, social support and style of grieving rather than as a function of age alone.

The evidence suggests that older bereaved may also be at risk of complicated bereavement, a finding that challenges the assumption that the elderly are prepared for death because it is an expected event in the life cycle and therefore have better outcomes. For many elderly people grief reactions increase with time rather than improve. Societal expectations of how the elderly respond to death, i.e. the elderly feel they are expected to cope, may also contribute to grief reactions. In addition the elderly may have multiple points of vulnerability following the loss of a significant support person. Therefore the elderly, as well as the young and adolescents should be carefully assessed for complicated bereavement outcomes.

### **Gender**

Gender has been identified as impacting on bereavement risk. Women are likely to report more distress (**Level IVa**)<sup>138</sup> and may exhibit greater levels of physical and somatic complaints than men (**Level IVa**).<sup>120</sup> Males in Steele's study scored higher on guilt and were more likely to engage in self-blame. Steele suggests that males need to be carefully assessed for signs of withdrawal, social isolation and dwelling on the death, while the physical health of women requires more careful monitoring. However, both of these studies were small.

The largest study identified in terms of gender issues is a comparison of 1204 males and 2828 females widowed between 1963 and 1974 in the USA with a married control group matched for age, race, gender, socio-economic status and smoking (**Level III**).<sup>116</sup> In this study widowed males were more likely to die after bereavement than married males of the same age even after adjustment for effects of other risk factors. This excess mortality was statistically significant for widowers in two age groups: 55–64 and 65–74.

However, in interpreting the role of gender in bereavement risk, it is important to acknowledge that the research literature is heavily biased towards the inclusion of women in samples. The selection bias towards women is exacerbated by self-selection of women over men in studies developed from convenience samples – women appear more willing than men to participate in this research, particularly when the study involves interviews likely to involve emotions (**Level III**).<sup>103</sup> Importantly, the role of gender in bereavement risk may be confounded by gender differences in grief manifestations. For example, Parkes and Brown<sup>51</sup> conclude that men typically report fewer affective disorders and symptoms than women thereby making women appear more distressed than men.

### **Socio-economic status**

Studies have reported socio-economic status to be significantly related to bereavement outcomes. A longitudinal study by Zisook, Shuchter and Lyons (**Level IVa**)<sup>105</sup> of 189 widows and widowers concluded that, at two months post-bereavement, family income (along with age and gender) was related to bereavement

outcomes. This finding was consistent with earlier work by Parkes **(Level III)**<sup>93</sup> and Vachon et al. **(Level III)**<sup>94</sup> who report socio-economic status as a predictor of bereavement outcome.

Socio-economic status is unlikely to link directly to bereavement risk because being poor may be a general risk factor for adverse mental and physical health outcomes. For example, in an early study using the Grief Experience Inventory, Sanders **(Level IVa)**<sup>113</sup> found that both the bereaved and controls in the low socio-economic group reported higher scores on all relevant measures. Death itself did not exacerbate or exaggerate differences beyond those already present due to limited finances. Sanders concludes that upper class persons feel more in control of their emotional and physical environment, have decreased feelings of anger, hostility and guilt and less shock, numbness and confusion than lower class survivors. Such a conclusion is supported by Kissane, Bloch and McKenzie **(Level III)**,<sup>115</sup> who identified residential problems as a predictor of poor outcomes particularly 6 months after bereavement, given that residential problems are likely to be associated with financial circumstance.

### Summary

In summary, while the demographic factors of age, gender and socio-economic status are commonly reported as related to bereavement risk, it is likely that they are of little importance in determining an individual's specific risk of complicated bereavement outcomes. The influence of age and gender are likely to reflect differences across these variables in the ways individuals display their grief and the lack of sensitivity in current measurement instruments to their influence. Socio-economic status is likely to be confounded by the role of poverty in determining the mental and physical health of people in low income groups.

#### 5.2.2 *Additional stresses/concurrent life crisis*

A number of studies have shown that stressors pre-bereavement can influence bereavement outcome. However, Cleiren<sup>21</sup> warns that natural intertwining of stressful life events with aspects of personal functioning makes a causal inference difficult.

Parkes<sup>43</sup> found that London widows who experienced multiple stressful life events in the two years prior to the death of their spouse did not adjust as well to bereavement as those who did not experience such stressful events. In a later study Parkes and Brown<sup>51</sup> found that the occurrence of multiple concurrent life crises was a predictor of poor bereavement outcomes 12 months after the loss of a partner. Similarly, Parkes later found pre-bereavement crises such as infidelity, loss of job or loss of pregnancy and previous divorce contributed to negative bereavement outcomes **(Level III)**.<sup>93</sup> These early findings are supported by a more recent longitudinal study of 131 widowed spouses that identified concurrent stressors to be highly correlated with survivor stress and depression over an 18-month period **(Level IVa)**.<sup>139</sup>

McHorney and Mor<sup>140</sup> consider the presence of family tension to be an additional stressor during bereavement. In their study survivors who reported the presence of

family tension had 1.4 times the odds of depression than survivors without such tensions (**Level III**).

According to preliminary work by Silverman, Johnson and Prigerson<sup>16</sup> previous stressors that occurred in childhood may also influence current bereavement outcomes (**Level IVa**). They found that spouses reporting prior stressors such as the death of a parent, sibling or previous sexual abuse were more likely than those not reporting such stressors to be distressed as measured by the symptoms for traumatic grief, a major depressive episode and post traumatic stress disorder (PTSD). They concluded that losses occurring in childhood appeared to influence psychological distress, ie complicated bereavement, more so than adversities that occurred during adulthood, which appeared to result in PTSD.

Likewise, dissatisfaction with care-taking abilities may be classified as an additional stressor. Survivors who reported such dissatisfaction were twice as likely to report depression as those who did not experience dissatisfaction with their ability to care for their relative (**Level III**).<sup>140</sup> Similarly, Vachon et al<sup>141</sup> report that bereaved widows who rated their husband's illness as stressful were more likely to experience high levels of distress one month after bereavement than those who did not perceive the illness in this manner (**Level III**).

### 5.2.3 *Personal characteristics*

Lund, Caserta and Diamond<sup>142</sup> report that personal characteristics of the bereaved, such as positive self-esteem and personal competency in managing daily tasks, are highly predictive of better bereavement outcome (**Level III**). Individuals unable to trust themselves or others are more vulnerable to poor bereavement outcomes.<sup>20</sup> Middleton et al.<sup>40</sup> suggest that pre-existing personality problems may be made worse by grief and may be the cause of forms of complicated bereavement (**Level IVa**). Vachon et al.<sup>94</sup> report similar variables as predictive of poor bereavement outcomes, namely: the need for pre-bereavement psychiatric support and a continued sense of the deceased husband's presence (**Level III**).

Kissane, Bloch and McKenzie<sup>115</sup> identified the need for psychotropic medication or alcohol by the bereaved spouse as a correlate of poor bereavement outcome (**Level III**). Similarly, concern for self and level of contentment were related to bereavement outcome at six and 13 months post-bereavement. A spouse's need to receive counselling during the deceased's illness correlated weakly with measures of distress or grief. Zisook and Lyons<sup>19</sup> also found that bereaved who experienced complicated grief were more likely to have a history of alcohol problems than those not experiencing complicated grief (**Level IVa**).

Powers and Wampold<sup>143</sup> examined the influence of behavioural strategies on adjustment to bereavement. They report that cognitive-behavioural responses to bereavement do significantly predict post-bereavement distress (**Level IVa**). In particular, the ability to cognitively organise one's grief experience and to maintain effective personal health practices was found to be strongly associated with

bereavement adjustment even taking into account the impact of social or demographic variables. It appears that the extent of self-care during bereavement, rather than the bereavement itself, may contribute to post-morbid health. Therefore, those at risk of poor adjustment because of a lack of support, being young or experiencing additional stressors may benefit from the utilisation of certain cognitive-behavioural strategies. Survivors who devote time to reflecting on the role of the deceased in their life and observing feelings and thoughts they experience as they grieve are likely to do better than those who do not participate in these types of behaviour.

Powers and Wampold<sup>143</sup> also examined the influence of demographic variables and social support on bereavement outcomes. While demographic and cognitive-behavioural variables jointly predicted 63% of the variance in post-bereavement adjustment scores, the cognitive-behavioural responses predicted post-morbid adjustment after controlling for the influence of demographic factors (**Level IVa**). When combining cognitive-behavioural, demographic and social support variables, cognitive-behavioural strategies accounted for twice the variance accounted for by the other sets of variables.

### **Psychological health – past history and current status**

Few of the studies examined included psychological assessments prior to death as a baseline from which to examine post-bereavement outcomes. Most use retrospective recall by the bereaved or official health records to determine the state of mental health pre-bereavement. Gamino, Sewell and Easterling<sup>144</sup> found mourner liabilities, measured as a history of other losses or history of mental health problems, to be significantly related to grief affect ( $R = .30, p < .02$ ). However, the effect was due almost entirely to presence of mental health problems ( $r = .27, p < .01$ ) (**Level IVa**). Scores on anger/hostility, social isolation and somatisation were higher for mourners with psychiatric problems than those with no problematic psychiatric history. However, there are significant problems with interpreting this study as the single post-bereavement scores were taken from 74 individuals whose bereavement experience ranged from one month to 25.6 years.

An earlier large ( $n = 1447$ ) prospective study of bereaved caregivers by McHorney and Mor<sup>140</sup> found poor pre-bereavement physical and mental health to be an important determinant of post-bereavement depression (**Level III**). In their study the odds of depression were 1.8 times greater for surviving caregivers with pre-bereavement physical health limitations and twice as great for those reporting depressed mood in the pre-bereavement phase.

Kurtz, Kurtz, Given and Given<sup>145</sup> compared pre-bereavement assessments of depressive symptomatology with assessments taken at three months post-death and at three monthly intervals for five assessments for 114 caregivers. They report that caregivers with high pre-bereavement depression scores tended to have higher post-bereavement scores, while a higher level of optimism predicted lower post-bereavement depressive symptomatology (**Level III**). Caregiver optimism and pre-

bereavement depressive symptomatology were also predictive of whether caregivers' depressive symptomatology would improve over time or not. Caregivers showed improvement in their depression scores during the bereavement period if they were optimistic at intake or if they were more depressed pre-bereavement. When spouses were examined separately, high pre-bereavement scores and high pre-bereavement levels of social support were predictive of high post-bereavement depressive symptomatology.

A prospective, longitudinal, control study of 350 widows and widowers and 126 married men and women by Zisook, Paules, Shuchter and Judd<sup>81</sup> also found that a history of major depression pre-death predicted increased risk for major depression following bereavement and for at least two years (**Level III**). Individuals who respond to bereavement with minor or sub-syndromal depression spend less time depressed over the following two years than those who respond with major depression. However, people with initial minor/sub-syndromal depression suffer more depressive episodes than those with no initial depression. Only 7% of subjects who began with no sign of depression at two months following bereavement went on to develop major depression.

Another longitudinal study of 46 spouse/partners of patients with lung cancer by Robinson, Nuamah, Lev and McCorkle<sup>146</sup> found significant differences between groups of spouses/partners grouped according to their risk of experiencing complicated bereavement. Differences were found on four dimensions of the Brief Symptom Inventory namely: somatisation, interpersonal sensitivity, depression and anxiety. Both groups, high risk and low risk, exhibited similar patterns of change over time (**Level III**). Comparison of data from the low risk group sample at 13 weeks and a 'normal' sample showed significant differences on the dimensions of obsessive-compulsive behaviour, depression and psychoticism. The dimensions of obsessive/compulsive and depression are symptom patterns characteristic of bereavement based upon Lindemann's descriptors. It appears that within the low risk group, these two symptom patterns had not yet diminished to a non-detectable level by 13 months.

It appears from the Robinson et al's <sup>146</sup> study that similar paths of bereavement are followed regardless of the magnitude of the psychological distress. Psychological distress for both high and low risk groups peaks at the six-week point following the death and gradually decreases; the level of distress between the two groups is no longer statistically different at 25 months. In other words the difference in bereavement experience between the two groups relates to the level of intensity rather than in the pattern of symptoms.

#### **Early distress as a predictor**

Robinson Nuamah, Lev and McCorkle's (**Level III**)<sup>146</sup> finding that the pattern of psychological distress is similar across risk groups points to a need to explore the role of high levels of early distress in predicting long-term outcomes. This idea is supported by the findings of several studies across the last three decades. Parkes<sup>93</sup>

found that survivors with early overall negative affect and disturbance scores went on to have poor bereavement outcomes (**Level III**). Likewise, Vachon, Rogers, Lyall, Lancee et al<sup>94</sup> found that widows who report high levels of distress one month after bereavement are likely to continue to report high distress levels at two years (**Level III**). Zisook and Shuchter<sup>147</sup> believe the strongest indicator of outcome at seven months is outcome soon after bereavement (**Level IVa**). Similarly, good initial adjustment has been found to be predictive of longer-term adjustment (**Level III**).<sup>142</sup>

Therefore, it seems possible to identify those who are likely to need ongoing support soon after bereavement. It may be possible to do this quite simply by asking the bereaved about their adjustment. Zisook, Shuchter and Lyons<sup>105</sup> reported that widows and widowers who described themselves as continuing to grieve at two months had higher scores on depression, general health ratings, and early grief reactions than those who felt their grieving was complete (**Level IVa**). This finding is supported by the work of Kissane, Bloch and McKenzie<sup>115</sup> where the spouse's perception of overall family coping was an important correlate of outcome on the dimensions of grief intensity, psychological distress, depression and social adjustment (**Level III**). When family coping is perceived as poor this is linked to poor outcomes. If higher scores early in bereavement are predictive of long-term outcomes and the bereaved can self-identify distress or risk, assessment processes that involve the bereaved in monitoring their early reactions may assist in identifying those at risk.

### **5.3** *Interpersonal relationships*

#### *5.3.1 Social and family support*

In an early review of predictors of bereavement outcome, Windholz, Marmar and Horowitz<sup>148</sup> concluded that the lack of, or perceived lack of, social supports was a consistent predictor of complicated bereavement outcomes. The early work in this area has supported the role of social support in mediating bereavement outcomes in the following areas:

- women who feel unsupported by people in their environment or perceive these people as antagonistic or unsympathetic may be likely to suffer complicated bereavement outcomes (**Level IVa**);<sup>117</sup>
- lack of interpersonal support significantly related to poor outcome one year after bereavement (**Level IVb**);<sup>149</sup>
- elderly people in a stable social network capable of positive adaptation to death of a spouse;<sup>150</sup>
- presence of a confident the elderly bereaved can turn to and discuss feelings may act as a 'buffer' to negative aspects of bereavement;<sup>151</sup>
- social support significantly differentiated the depressed bereaved from the non-depressed; those clinically depressed at one month remained depressed at one year;<sup>152</sup>

- lack of close family alliance and church affiliation together relate to exhibition of more intense grief reactions including anger and less optimism than when family support and regular church attendance are present (**Level IVa**);<sup>113</sup>
- disturbance in a widow's social support system an important predictor of maladjustment at one month (**Level III**)<sup>94</sup> dissatisfaction with help available predicted a higher level of distress at two years in this group.

A more recent longitudinal study by Kurtz, Kurtz, Given and Given<sup>145</sup> of 114 patient–caregiver dyads continues to support this early work but raises a more complex picture of the relationship between social support and depressive symptomatology. They suggest the critical factors in determining levels of post-bereavement (PB) depressive symptomatology were levels of social support from friends, caregiver optimism and pre-bereavement depressive symptomatology (**Level III**). (The last two factors are discussed in other sections.) Caregivers who had high levels of pre-bereavement support from friends had higher scores on post-bereavement symptomatology measures suggesting more depressive symptomatology. However, depression scores improved if the bereaved received social support from family during the post-bereavement period. The hypothesis may be that pre-bereavement support mediates long-term bereavement outcomes only if it is maintained across time. Similarly, social and spiritual support were found to be negatively correlated with stress and depression in a longitudinal study by Levy, Martinkowski and Derby (**Level IVa**).<sup>139</sup> These authors suggest these correlations reflect, to some degree, the individual's coping resources as well.

Lopata<sup>153</sup> describes support systems as either economic, service, social or emotional and these systems are the link between an individual and society. Lopata describes economic supports as income, housing, clothing and monetary gifts. Service supports include transportation, housekeeping and gardening. Social supports tend to be culture bound and include church attendance, team sporting events and visiting or entertaining. Emotional supports are either relational i.e. having a confidant or preferred source of support; or aspects of self concept i.e. being made to feel important, secure or accepted by a particular person.

Lopata and colleagues studied the support systems of widows in Chicago and found that when support systems fail, i.e. links are broken, some widows become socially isolated, economically destitute and unable to create new support networks (**Level IVa**). The widow's ability to actively create links with various support systems is an important factor in adjustment to widowhood.

### 5.3.2 *Family functioning*

Social support may also closely relate to more recent investigation of the role of family functioning in mediating risk of adverse bereavement outcomes. Kissane and Bloch<sup>34</sup> explored family functioning with the goal of 1) developing a typology of families and 2) identifying dysfunctional groups and those at risk of poor bereavement outcomes. These authors also sought to examine any associations between family type and individual psychological and social morbidity. Results

suggest that cohesion, expressiveness and conflict are useful parameters in discriminating adaptive families from those coping poorly, and whose members may go on to develop psychological morbidity.

Kissane and Bloch<sup>155</sup> describe the following family typology:

*Supportive families* – cohesion is the striking quality of this group. Members are intimate with each other, share their distress and provide mutual support. They have low levels of psychological morbidity and function competently.

*Hostile families* are the most dysfunctional of the groups and this is discriminated by high levels of conflict between family members. Hostile family groups consisted of members with the highest levels of psychological morbidity and the poorest social adjustment. It was common to find high numbers of offspring in this group.

*Sullen families* were the second most dysfunctional group characterised by moderate levels of conflict and a tendency to have poorer cohesion and expressiveness. Sullen families exhibited high levels of psychological morbidity and were socially dysfunctional. It is common to find depressive syndromes among family members.

*Conflict resolvers* were characterised by moderate levels of conflict but high levels of cohesion and moderate expressiveness. This suggests that a degree of conflict, difference of opinion and negative feeling can be tolerated and is not in itself a marker of a dysfunctional status.

*Intermediate families* were characterised by an intermediate range of cohesion, expressiveness and conflict. Individual psychological morbidity such as depression and anxiety is exhibited by members who are also less able to function well socially. This group harbours sufficient morbidity to warrant intervention.

These authors have developed this work further in prospective longitudinal study that found the level of family functioning to be a powerful predictor of bereavement outcome (**Level III**).<sup>115</sup> The spouse's perception of overall family coping was a correlate of bereavement outcome on several dimensions: grief intensity, psychological distress, depression and social adjustment. When family coping was seen as poor, greater psychological morbidity ensued. The dimensional scale of 'overall family coping' corresponds with the family typology reported in the earlier work. Other dimensions of social support, such as that received from friends, and time spent with friends and extended family members, also correlated with bereavement outcome but was weaker than overall family coping. According to the family typology model the sullen, hostile and ordinary families carry more psychological morbidity and as such are described as at risk of complicated grief. Kissane and colleagues suggest clinicians conduct an assessment of family issues to identify those at risk of complicated grief.

### 5.3.3 *Type of relationship*

#### **Ambivalent relationships**

Parkes and Brown<sup>51</sup> suggest poor prior marital relationships are a predictor of poor outcome 12 months after the loss. In an early study of psychiatric patients Parkes<sup>154</sup> found that patients who had an ambivalent relationship with the deceased were more likely to suffer from complicated grief than those with a healthy relationship (**Level IVa**). However, given that psychiatric morbidity is itself a risk factor, this finding is questionable. However, the findings are supported in a replication longitudinal Harvard study of widows and widowers under 45 years (**Level III**).<sup>93</sup> The first interview revealed little difference between surviving spouses with high or low levels of ambivalence in their relationship with the deceased. At the second interview (six weeks after bereavement) the low ambivalence group was more disturbed; however, this reversed at 13 months. At two to four years after bereavement survivors reporting high ambivalence in their relationship were more depressed, experienced feelings of guilt, tended to be more socially withdrawn and experienced worse physical health than survivors who did not report an ambivalent relationship. Raphael<sup>7</sup> drew the same conclusion from a study of 200 Australian widows, where an ambivalent marital relationship was found to be a risk factor for complicated bereavement (**Level III**). Similarly, Zisook, Shuchter and Lyons<sup>105</sup> found surviving spouses who rated their marriage in negative terms to be more likely to have poor bereavement outcomes (**Level IVa**).

Complicated bereavement outcomes can also be predicted by identifying conflictual relationships within a family, which often identify dysfunctional families (**Level IVa**).<sup>155,156</sup> These families fail to plan activities carefully, are often late, lack structure and order and arguments destroy the ability to work together.

Gamino (personal communication) describes a variation on the ambivalent relationship that involves someone who is 'difficult to love'. Gamino describes reasonably healthy, adjusted people who are expected to care for a person who is a challenge to get along with due to physical or mental health problems, personality problems or control issues. The death of someone like this may result in the bereaved feeling relieved and not guilt-ridden which may effect bereavement outcomes.

#### **Dependent relationships**

Sable<sup>121</sup> found that widows who were close to their husbands were more distressed following the death (**Level IVa**). Sable suggests this finding identifies a link between attachment and prolonged grieving which may have a negative impact on the bereaved. A very close relationship may be considered a form of attachment. Steele<sup>120</sup> also examined quality of the spousal relationship as a potential risk factor for complicated bereavement. Surviving spouses who rated themselves as somewhat close to the deceased scored higher on anger, hostility, social isolation and optimism/despair. In contrast, those who described themselves as extremely close and very close to the deceased scored high on guilt and rumination and those extremely close scored high on depersonalisation, physical symptoms, loss of vigor and

somatization (**Level IVa**). In a review article of previous studies Sanders<sup>102</sup> suggests a dependent or ambivalent relationship with the deceased is a risk factor for adverse psychological outcomes. Early work by Raphael (**Level IVa**)<sup>7,67</sup> and Parkes and Weiss<sup>26</sup> also found ambivalence towards and dependence on the spouse to be determinants of bereavement outcome. The loss of ambivalent and dependent relationships can result in chronic, inhibited or disturbed grief.

Gamino, Sewell and Easterling<sup>144</sup> retrospectively studied 74 individuals after the death of a significant person in their life. The presence of a problematic relationship with the deceased, as opposed to a positive healthy relationship, was predictive of higher grieving affect (**Level IVa**). Despair, anger/hostility and death anxiety, subscales of the Grief Experience Inventory, reflected the negative quality of the relationship. Similarly other studies showed conflictual relationships resulted in higher levels of depression following bereavement (**Level IVa**).<sup>105,157</sup> In contrast a prospective longitudinal study of bereaved spouses' found that marital quality was not predictive of depressive symptomatology (**Level IVa**).<sup>46</sup> In fact bereaved spouses who reported supportive relationships characterised by positive interactions were likely to have higher levels of traumatic grief (**Level IVa**).<sup>76</sup>

In summary, it appears that ambivalent, dependent and conflictual relationships are predictive of complicated bereavement outcomes. The influence of such relationships on bereavement varies over time with evidence of poor outcomes soon after death, some improvement by twelve months and then deterioration by two years. The influence of marital quality on bereavement outcomes is more difficult to interpret. There are studies that report good marital relationships are protective in bereavement and others report it acts as a vulnerability factor resulting in poor outcomes.

## **5.4**      *Characteristics of the deceased*

### *5.4.1*      *Age*

The age of the deceased is consistently cited as a risk factor for complicated bereavement in surviving relatives, particularly in relation to the death of child. The intensity of grief relates to the strength of the attachment and strong bonds of attachment are generally found in mother-child relationships. Bonds of attachment are more relevant than age of deceased or long marriages but age may be associated with bonds of attachment.

Retrospective studies have consistently found age to be related to bereavement outcomes. Gamino, Sewell and Easterling<sup>144</sup> found that the younger the deceased the greater the degree of negative grief affect (**Level IVa**). Negative grief affect manifested as anger/hostility, despair, guilt, loss of control, rumination, depersonalisation and somatisation. Similarly, Yancey and Greger<sup>138</sup> found age of the deceased to be a significant predictor of grief resolution, functional ability and emotional distress (**Level IVa**). When the deceased was older at death, survivors reported a more positive bereavement outcome. This supports an early study of

widows by Maddison and Walker<sup>117</sup> where the younger the deceased, the greater the widow's illness scores indicating adverse effects on physical and mental health (**Level IVa**).

Prospective studies, while few in number, also report the age of the deceased as a factor influencing the bereavement experience. Bereaved participants of deceased aged below 65 years were found to be 1.8 times more likely to experience depression than the bereaved of deceased aged over 65 years at death (**Level III**).<sup>140</sup> However, the major limitation of this work is that the characterising of age into above and below 65 is not representative of major age categories, particularly death of a child.

#### 5.4.2 *When a child dies*

"The death of a child creates a disequilibrium in the social world of the parent and it creates a disequilibrium in the psychic structure of the parent. Grief is the process by which the parent moves towards new equilibria. Some of the dynamics which were important in the creation and development of the attachment to the child are important dynamics as the parent grieves toward new equilibria".<sup>158</sup> (pp. 45–6)

Literature consistently identifies the death of a child as an overwhelmingly painful and untimely life tragedy with the potential to result in long-lasting grief (**Level III**).<sup>109</sup> Rando<sup>101</sup> and Parkes<sup>159</sup> believe the death of a child contributes to complicated mourning and is a risk factor associated with difficulties during bereavement. Children are intimately linked to parental expectations for the future, play a pivotal role in family life, and parents rarely consider the possibility of out living their children. Therefore, loss of a child represents not only the loss of a family member but also the loss of future expectations. Various authors claim that parents are at risk of depression, sleeping problems, anxiety, somatic complaints, alcohol abuse and loss of appetite, marital difficulties, separation and divorce following the death of a child.

Theories about the relationship between a child's death and parental bereavement outcomes are predominantly based on professional opinion gained through clinical experience rather than research evidence.<sup>160</sup> Dijkstra and Stroebe<sup>160</sup> provide a very useful review of studies of parental grief that use controls or norm groups for comparison and report on health complaints, state of marriage, psychological, physical and psychosocial problems. Findings are summarised below according to how the death of a child may impact upon parents in terms of mortality, morbidity, separation and divorce, and impact on marital closeness.

#### **Mortality**

Four empirical studies explore the impact of death of a child on parental mortality compared to the mortality of a control group (**Level III**).<sup>109,161-164</sup> Rees and Lutkin originally reported no difference at one year in mortality between bereaved parents and a control group of relatives matched for age, sex and marital status. However, Levav's longitudinal reanalysis of this study found that at five years the bereaved parents had significantly higher mortality rates. While Lehman Wortman and

Williams<sup>109</sup> did not statistically compare mortality rates of bereaved parents and control parents, they reported that 7% of bereaved parents died after the loss of a child while none of the controls died. Clerico et al. and Levav et al. found no difference in mortality for married couples versus a control group. However, the control group in the Clerico study consisted of parents whose child had survived cancer, which may have influenced the results of their study. Importantly, Levav et al. did identify a significantly increased mortality for bereaved single mothers versus bereaved married mothers. This large study compared 6300 parents with matched against population statistics for mortality rates among Israeli-Jews matched for age, sex and calendar year. The remaining three studies were small (35, 44 and 86 participants) making conclusions related to mortality difficult.

It appears that parents in general are not at high risk of mortality after the loss of a child unless they are divorced or widowed mothers. Dijkstra and Stroebe<sup>160</sup> suggest two possible explanations for this. First, marriage may act as a social buffer against the detrimental effects of bereavement, and second, the loss of both a spouse and a child may make bereaved single mothers especially vulnerable to complicated bereavement outcomes.

### **Morbidity**

A large number of studies suggest negative effects on parental mental and physical health following the death of a child but most do not make comparisons with control groups, norms or the situation prior to the loss. For example Sanders<sup>113</sup> compared grief of spouse, parents of children, and adult children of older parents. Significant intensities of grief were noted in parental bereavement. Parents reported more somatic reactions, higher levels of depression, more anger and guilt and feelings of despair than the groups of spouses or older offspring (**Level IVa**).

Various methods were utilised by researchers to investigate the impact of a child's death on parental morbidity, ranging from secondary sources such as national surveys and doctors records; self-reports of mental and physical health; and severity of impact comparisons with other bereaved populations.

The overall consensus in the literature from secondary sources is that bereaved parents are no more at risk of increased morbidity than non-bereaved parents (**Level III**);<sup>165,166</sup> (**Level IVa**).<sup>157</sup> Morbidity was operationalised as new or recurrent illness, doctor/nurse visits or hospitalisations. Conversely Lundin<sup>107</sup> reported an increase in psychiatric morbidity for some parents (**Level IVa**), and Nixon and Pearn<sup>167</sup> report differences in morbidity between bereaved and non-bereaved parents (**Level III**).

Dijkstra and Stroebe's review of self-reports suggests that bereaved parents suffer adverse mental health effects and have poorer physical health than non-bereaved controls. Statistical support for this is provided by five studies (**Level III**).<sup>165,168-171</sup> Two more claim such support without published evidence.<sup>172,173</sup> Three studies found no difference at all (**Level III**).<sup>166,174,175</sup> Birenbaum, Stewart & Phillips<sup>176</sup>, found physical health to be significantly better for bereaved compared to non-bereaved

**(Level III).** This study is likely to be confounded by better baseline physical health in the bereaved group than for the controls. Difficulties interpreting this data arise given the relatively small sample sizes (range 18–337, mean 97), the selective recruitment strategies utilised, and the retrospective nature of the studies, the consequence being the absence of pre-loss data for comparison. Many of the studies are also confined to parents of children who died from cancer where findings may not be generalisable to a wider population of parents. Additionally, the studies are more likely to focus on mothers than fathers, with the data also representing parents of children ranging from the very young and adolescent through to adult children. Our conclusion is that the available data suggests the potential for a relationship between post-bereavement physical and mental health and death of a child that is worthy of further investigation.

#### **Severity of impact**

Some studies compare parents that have lost a child with persons who have suffered other bereavements to test the hypothesis that bereavement outcomes are worse when the deceased is a child. The results of these studies are mixed. Cleiren<sup>21</sup> found bereaved parents exceed other bereaved sub-groups in some health-related aspects and not in others. It is not clear if differences were statistically examined. Differences in levels of emotional symptomatology were found between bereaved parents and parents of handicapped children, or immigrants. Gender differences were also identified and may be explained by differences in the way men and women express grief and differences in family support roles following the child's death.

#### **Separation and divorce**

Two controlled studies suggest that separation and divorce are more prevalent in bereaved parents than in other bereaved groups. These results are interesting because the researchers used two very different samples at very different times post-bereavement. In each case controls were parents with a living child. Lehman Wortman and Williams<sup>109</sup> reported on 41 parents who lost a child in a motor car accident with data being collected 4–7 years after the loss. Najman et al<sup>177</sup> reported on 373 parents who lost a child to SIDS, stillbirth or neonatal death two years after the loss. A further study found no difference in separation/divorce rates between bereaved parents and control parents.<sup>161</sup> The validity of the first study must be questioned because the control group consisted of parents with a child who had cancer and survived. Having a child with a life-threatening illness may be enough in itself to cause marital problems.

Two other studies by Mekosh-Rosenbaum and Lasker<sup>178</sup> and Nixon and Pearn<sup>167</sup> did not report any statistical analyses. In the first study the separation/divorce rate does not seem excessive but in the second study the separation rate was 24% in the sample compared to 0% in the control group. However, marital strife was a common antecedent of the accident (this study compared parents of children who had died as a result of drowning with parents who had a child who almost drowned) in both groups making the results questionable. This information is only relevant to a select group of parents and is not generalisable.

One methodological problem in the studies was the lack of evidence of control for length of marriage. This concern is based on the assumption that patterns of divorce and separation may vary according to the duration of the marital relationship. Lehman et al<sup>109</sup> controlled for parental age, which is presumably correlated with length of the marital relationship, but there is no indication this was done in the other studies. However, the duration of the marital relationship may still have to be considered a confounding factor.

In summary, two studies found no difference between bereaved parents and controls, two did not adequately test for such a relationship, and two did find evidence that the death of a child may be associated with higher divorce/separation among parents. Again there is evidence to suggest that the death of a child may impact upon parental divorce and separation but evidence is not conclusive. It seems likely that this difference is due as much to the pre-morbid relationship as to the death of the child.

### **Marital closeness**

Even if it can be shown that marital break up is more common among bereaved parents, few parents actually separate – just as risk for dying is higher for bereaved than non-bereaved very few bereaved actually die as a result of bereavement. The impact of bereavement on marital intimacy and satisfaction may be a more relevant point of investigation, however most studies that examine these variables lack control groups.

Fish<sup>179</sup> studied the grief of parents and found mothers experience greater levels of grief than fathers even two years after the loss. Mothers also experience greater social isolation. Rando's<sup>108</sup> work showed parental grief escalated in the third year, making the mourning long and drawn out which further exhausted family resources. Marital support that has previously been present was also lacking as parents found it difficult to communicate with each other. A potential consequence was threat to the stability of the marriage. Lansky and colleagues<sup>180</sup> suggest the marital relationship is stressed by the demands of the sick child and the treatment needs, which may separate parents and increase work and financial strain. These authors suggest marital disharmony is significant but mental breakdown is not increased.

Lang and Gottlieb<sup>181</sup> and Mekosh-Rosenbaum and Lasker<sup>178</sup> found no differences in marital intimacy and satisfaction between bereaved parents and non-bereaved controls up to 24 months after the loss. In a control study of parents where one group had lost a baby and the other group were parents with a living child. Another study found no difference in marital communication between the groups two months after the loss. At six months after bereavement mothers seemed to experience poorer communication with their spouses than controls.<sup>160</sup>

Stroebe and Schutt<sup>160</sup> suggest there may be two processes operating following the loss of a child. Firstly, there is an enhancement effect on the relationship (increased support and protection). Secondly, there is enduring stress and mutual aggravation, due to circumstances of this type of bereavement.

Sach<sup>137</sup> interviewed 28 parents of children with life-limiting/life-threatening conditions and their responses form the basis of a report *When a child dies: Caring for children with life limiting/life threatening conditions*. Sach found that the parents' experience of the death of their child was unique; however, the common thread was the need for support during bereavement. Importantly, Sach believes, most bereaved parents are not in a position to identify their own need for bereavement support or able to seek it out: "It needs to come to them". Sach concluded that family support at the time of death was valuable but there is a need for someone who is independent and a good listener to be available for bereavement support. Particular attention needs to be given to siblings, adolescents and grandparents. At the time the report was published there was no clearly identifiable pathway to bereavement support, especially if the child died unexpectedly.

In summary, the pattern emerging from this limited body of research is that the effect of the loss of a child extends beyond psychological distress for a limited duration or simple grief, to long-term effects on mental and physical health, and probably a somewhat higher risk of dying. Child loss seems to have an effect on marriage as well – indications that more couples break up after the death of a child than would be the case had the child not died. It is also important to consider that some parents will become closer, while others move apart after the death of a child.

#### 5.4.3 *When a parent dies*

In a community palliative care setting children are rarely deemed the primary carers of a parent with a life threatening illness. However, children are part of the family unit, which according to systems theory, will be affected by the death of a family member. Systems theory states that all members of a family system affect each other, and symptoms in an individual member are the result of interactive forces within the family. Stokes, Pennington, Monroe, Papadatou and Relf<sup>182</sup> note that every year many children experience a sudden death in the family however, there is often little support available to them.

The palliative care team should note the presence of children in a family where a parent is dying. Parkes<sup>72</sup> lists death of a parent in early adulthood or adolescence as a traumatic circumstance, which contributes to the risk of complicated bereavement. Controlled studies based on general population samples suggest bereaved children have a significantly increased risk of developing psychiatric disorders and the impact on the child, psychologically and socially, may last throughout childhood and into adult life.<sup>183-185</sup> The risk of complicated bereavement is also increased if children received inadequate physical and emotional care, particularly after the loss of a mother.<sup>186</sup> Rosenbiem<sup>187</sup> suggests that children often know things are wrong but need this knowledge acknowledged, the result being decreased anxiety.

Death of a parent is the second most common reason (most common is death of a spouse) for someone to seek psychiatric help following a bereavement. The

bereavement period may be even more difficult for a child if the surviving parent or carer is having difficulty coping with his or her own grief. This research by Pynoos and colleagues<sup>89</sup> involved a sample of children bereaved by a natural disaster therefore, caution must be taken when extrapolating findings to a palliative care setting.

### *Conclusion*

In conclusion the literature review provides an analysis of the extensive literature on risk factors for complicated bereavement outcomes. Empirical evidence has shown that factors such as sudden, unexpected death, a stigmatised death, a perceived lack of social support and the presence of multiple concurrent stressors contribute to the development of complicated bereavement outcomes. Other factors such as being bereaved and having self-care difficulties or being reluctant to face the impending death are often assessed in practice but are not well supported by empirical evidence.

It is hoped that these guidelines will inform the practitioner so that risk assessment for complicated bereavement outcomes is comprehensive, resource effective and based on sound evidence.

## Appendices

## **Appendix 1: Project terms of reference**

### ***Background***

Palliative care services identify the unit of care as the ill person and their family. The provision of support to family members during the immediate bereavement period is thus a standard component of palliative care. However, this bereavement support is generally framed within a model of uncomplicated bereavement and focuses on support of family members when dealing with ‘normal’ bereavement experiences. Palliative care services are largely concerned with support of normal bereavement adjustment.

Ensuring continuity of care across the transition from the phase of palliative care to bereavement assists the palliative care team to make judgements about the nature of bereaved family members’ adjustment.

Complicated bereavement outcomes, outside of this normal grief framework, are acknowledged to occur within the context of palliative care. It is imperative therefore that mechanisms exist to identify those family members who are at increased risk of complicated bereavement outcomes. Identification of those at risk of complicated bereavement outcomes will both influence the bereavement support provided and facilitate early referral to specialist bereavement services.

The Department of Human Services (DHS) has recently developed a range of performance indicators for palliative care services. One of these relates to the assessment of complicated bereavement risk in family members of people receiving palliative care. DHS has provided funding to support the development of a risk assessment tool for use in palliative care services. This document outlines a process to develop clinical guidelines for the assessment of risk for complicated bereavement within the context of a family-centred approach to the provision of palliative care.

### ***Protocol***

This project will seek to develop consensus guidelines for a clinical approach to the assessment of risk for complicated bereavement in families of palliative care patients. The protocol utilises a framework for guideline development outlined in the NH&MRC document ‘A guide to the development, implementation and evaluation of clinical practice guidelines’ (NH&MRC 1999). The guideline development process outlined in this document includes the following steps:

- Determine the need for and scope of guidelines
- Convene a multidisciplinary panel to oversee the development of guidelines
- Define the purpose of and target audience for the guidelines
- Identify health outcomes

- Review the scientific evidence
- Formulate the guidelines
- Formulate a dissemination and implementation strategy
- Formulate an evaluation and revision strategy

*Determine the need for and scope of guidelines*

The need for the guidelines proposed here is established. Approximately 20% of bereaved individuals will develop complicated grief with associated psychosocial morbidity. Preventative approaches to interventions with those at risk will reduce distress and its associated morbidity. Previous work by the Department of Human Services revealed a lack of consistency in services approach to bereavement care, including risk assessment. The guidelines are necessary to provide an evidential base for the assessment of risk for complicated bereavement in the palliative care setting and will provide a consistent standard of care across the palliative care service system. Reporting bereavement risk is a requirement for palliative care services, and thus it is essential that the assessment undertaken is based on best available evidence.

*Convene a multidisciplinary panel of oversee the development of guidelines*

Two levels of expert involvement will be established to oversee the development of these guidelines. The first will be a steering committee whose function is to provide ongoing support to the project officer and guide the process of guideline development. This committee will consist of the following individuals:

Associate Professor Sanchia Aranda (Chief Investigator)  
 Professor David Kissane  
 Professor Sid Bloch  
 Mr Chris Hall  
 Ms Julie Edwards  
 a DHS representative  
 Donna Milne (Project Officer)

In addition to this committee, expert opinion will be sought on the guidelines from a range of people with established clinical and/or research expertise in assessing risk for complicated bereavement. Establishment of this panel will be a task of the steering committee. In addition to the expert panel, opinion on the guidelines and their clinical utility will be sought from clinicians across a wide range of disciplines who are expected to undertake bereavement risk assessment in Victorian palliative care services.

*Define the purpose of and target audience for the guidelines*

The purpose of these guidelines is to provide guidance to palliative care services in the assessment of bereavement risk and further intervention and to outline a framework for reporting bereavement risk in accordance with relevant clinical performance indicators. Palliative care professionals working in the State of Victoria are the target audience for these guidelines. However, there is scope for the guidelines to be utilised beyond the State of Victoria in the long term. The guidelines will also be

developed in a sufficiently generic way to enable their utilisation in areas of bereavement care beyond palliative care.

#### *Identify health outcomes*

There are no direct health outcomes associated with these guidelines; however, referral for intervention for those identified as at increased risk will be an integral component of the guidelines. It is anticipated that the longer term outcome of the guidelines will be evidence related to the ability of risk assessment to predict bereavement outcomes in family members of people who died while receiving palliative care. The longer term aim is to target bereavement interventions to those family members with identified risk for complicated outcomes of bereavement.

#### *Review the scientific evidence*

A full review of the literature will be undertaken as phase one of the project and will be aimed at developing a broad understanding of the state-of-the-knowledge. It is acknowledged that scientific knowledge may not fully inform this project, with important knowledge available from clinical practice and human experience. Key words to guide the literature search will be developed by the steering committee. While the literature search will be broad, it will focus on identifying best available evidence that will ensure the guidelines are valid. The findings of the literature review will be used to develop early draft materials for discussion in the consensus process. The review will attempt to determine:

- recognised risk factors;
- recognised modifiers of bereavement outcomes;
- role of family functioning in bereavement risk assessment.

Just as discharge planning should commence at the time of admission, it is anticipated that bereavement planning will commence at the time of admission to palliative care. Early assessment of family coping and support is paramount. The knowledge review will incorporate these perspectives. Hence, in addition to the literature review, current practice related to family assessment in the area of complicated bereavement risk will also be explored. This exploration will consist of a survey of service providers and conduct of focus groups with clinicians involved in bereavement assessment and provision of bereavement support. This activity will examine current clinical practice and assessment tools, and will compare them to recommendations in the literature. This survey will also assist in development of the subsequent dissemination and implementation process.

#### *Formulate the guidelines*

The guidelines will be formulated on the basis of the literature review with input from relevant experts as outlined above. The guidelines will focus on establishing an evidential base for complicated bereavement risk assessment in clinical practice and provide a framework for implementing this evidence in practice. A tool will be included in the guidelines as a mechanism for recording assessment findings and summarising this information for subsequent clinical use and service reporting. The

clinical utility of the guidelines, assessment procedure and recording tool will be pilot-tested in clinical practice prior to being disseminated to Victorian palliative care services.

*Formulate a dissemination and implementation strategy*

A task of the steering committee will be to make recommendations for the dissemination and implementation of the guidelines across Victoria.

*Formulate an evaluation and revision strategy*

A further task of the steering committee will be to make recommendations about the process of evaluating the impact of the guidelines on clinical practice and to suggest a process and timeline for their revision.

*Draft timelines*

May – July 1999	First steering committee meeting Commencement of literature review Development of survey tool Identification of relevant experts
July – September 1999	Completion and write-up of literature review Conduct field survey and focus groups
October – December 1999	Development of guidelines, assessment procedure & reporting tool
January – February 2000	Circulation of draft guidelines for comment
March 2000	Pilot testing of guidelines, assessment procedure & reporting tool
April – May 2000	Finalise consensus guidelines Analysis of pilot data Write final report

**Note:**

This project is funded for a period of 12 months. Further testing of the risk assessment tool in terms of ability to predict complicated bereavement outcomes will not be possible at this point, but may be the subject of a further funding application to the department.

## Appendix 2: Search strategy

The databases used in this search were Medline 1986 – April 2000, Cinahl 1982 – March 2000, and PsycLit 1967 – March 2000. To gather evidence related to bereavement risk assessment the following terms and combinations of terms were used:

Bereavement; risk; assessment; risk factors; loss; grief, grieving; delayed; absent; palliat\* (this covered palliative, palliate, palliated); complicated; theory; death; outcome; determinants.

Comprehensive reviews of the published literature with regard to grief, bereavement and bereavement risk assessment were undertaken. The reviews included the following aspects of bereavement care:

- theoretical frameworks that underpin current practice;
- strategies for improving assessment of those at risk of complicated bereavement outcomes;
- strategies to maximise input into bereavement risk assessment from a range of stakeholders including the patient, family members, and the palliative care team; identification of factors thought, or known to, influence bereavement outcomes; and
- ways to identify family and friends who may benefit from targeted support both before and after death.

The reviewers examined studies paying particular attention to design and quality. The number of studies recovered in the search that specifically addressed the area of bereavement risk assessment was small therefore the guidelines have been informed by the best available evidence that includes empirical studies and expert opinion.

## Appendix 3: Focus groups

The aim of the focus groups was to inform the guidelines from the practitioner's perspective. All health professionals who identified themselves as being involved in bereavement care in a community palliative care service were invited to participate. In total, twenty-eight professionals, with a range of backgrounds participated in four groups, one in Melbourne and three in regional areas of Victoria. Participants were grouped according to geographical location rather than profession.

The groups ran for two hours each and predetermined questions were asked by the moderator. The discussions were tape recorded and the assistant moderator took notes and provided a brief summary of discussions before the group ended to ensure all aspects of bereavement risk assessment had been covered. Time was allocated for clarification and topics that had not been covered during the groups discussion.

### *Focus Group Questions*

1. I'd like everyone to tell us their name, what their role is and what you like to do when you are not working.
2. What does bereavement risk assessment mean to you?
3. Would someone like to share their experience of doing a bereavement risk assessment?
4. On the paper in front of you list the five most important elements of BRA.
5. When should BRA commence?
6. Who should do the assessment?
7. What form should it take?
8. What potential benefits do you see from using a BRA?
9. What are the potential or actual negative aspects of using BRA?
10. Of all the issues we have discussed which is the one you want us to take most notice of?

### *After Summary*

11. How well does this capture what has been said?
12. Have we missed anything?

## Appendix 4: Telephone survey

Representatives from thirty-one palliative care services, both community and inpatient settings, were asked to complete the survey. Twenty-eight participants completed the survey via the telephone, one completed it and returned by mail, therefore a total of twenty-nine professionals working with bereaved people completed this phase of data collection.

### *Instructions*

Please indicate your current bereavement risk assessment practice and then indicate what would be ideal. If bereavement risk assessment is not part of your current practice just complete the 'IDEAL' column to reflect what you would like to use.

### *Survey*

	PLEASE TICK	PLEASE TICK
	CURRENT PRACTICE	IDEAL PRACTICE
1. Who does the assessment?		
• Nurse	<input type="checkbox"/>	<input type="checkbox"/>
• Social worker	<input type="checkbox"/>	<input type="checkbox"/>
• Volunteer	<input type="checkbox"/>	<input type="checkbox"/>
• Counsellor	<input type="checkbox"/>	<input type="checkbox"/>
• Pastoral care	<input type="checkbox"/>	<input type="checkbox"/>
• Medical officer	<input type="checkbox"/>	<input type="checkbox"/>
• Various team members	<input type="checkbox"/>	<input type="checkbox"/>
• Other, specify	<input type="checkbox"/>	<input type="checkbox"/>
2. What form does the assessment take?		
• Formal tool	<input type="checkbox"/>	<input type="checkbox"/>
Name of tool:		
Already supplied <input type="checkbox"/>		
To be forwarded <input type="checkbox"/>		
Will not forward <input type="checkbox"/>		
• Combination of tools	<input type="checkbox"/>	<input type="checkbox"/>
Tool names:		
• Tool developed by service	<input type="checkbox"/>	<input type="checkbox"/>
• Unstructured	<input type="checkbox"/>	<input type="checkbox"/>
• Other, specify	<input type="checkbox"/>	<input type="checkbox"/>

3. If a tool is used does the assessor have?	<input type="checkbox"/> Formal training <input type="checkbox"/> Informal training	<input type="checkbox"/> Formal training <input type="checkbox"/> Informal training
4. Does the assessor have any education in bereavement support?	<input type="checkbox"/> Formal <input type="checkbox"/> Informal	<input type="checkbox"/> Formal <input type="checkbox"/> Informal
5. When is the assessment done?		
• On admission to the service	<input type="checkbox"/>	<input type="checkbox"/>
• Through out the episode of care	<input type="checkbox"/>	<input type="checkbox"/>
• After death of the patient	<input type="checkbox"/>	<input type="checkbox"/>
• At nurses discretion	<input type="checkbox"/>	<input type="checkbox"/>
• Other, specify	<input type="checkbox"/>	<input type="checkbox"/>
6. Which families are assessed?		
• All	<input type="checkbox"/>	<input type="checkbox"/>
• Ideally all but doesn't always happen	<input type="checkbox"/>	<input type="checkbox"/>
• Decided at multidisciplinary meeting	<input type="checkbox"/>	<input type="checkbox"/>
• Nurses decide	<input type="checkbox"/>	<input type="checkbox"/>
• Other	<input type="checkbox"/>	<input type="checkbox"/>
7. Who is assessed?		
• Primary family carer	<input type="checkbox"/>	<input type="checkbox"/>
• Other carers	<input type="checkbox"/>	<input type="checkbox"/>
• All family members	<input type="checkbox"/>	<input type="checkbox"/>
• Up to assessor to decide	<input type="checkbox"/>	<input type="checkbox"/>
8. Which factors are covered in the assessment?		
• Relationship difficulties		
• Dependence	<input type="checkbox"/>	<input type="checkbox"/>
• Ambivalence	<input type="checkbox"/>	<input type="checkbox"/>
• Conflict	<input type="checkbox"/>	<input type="checkbox"/>
• Communication difficulties	<input type="checkbox"/>	<input type="checkbox"/>
• Intellectual disability of bereaved	<input type="checkbox"/>	<input type="checkbox"/>
• Children or adolescents in immediate family	<input type="checkbox"/>	<input type="checkbox"/>
• Multiple deaths/losses	<input type="checkbox"/>	<input type="checkbox"/>
• Death of a child	<input type="checkbox"/>	<input type="checkbox"/>
• Death of an adolescent	<input type="checkbox"/>	<input type="checkbox"/>
• Age of deceased	<input type="checkbox"/>	<input type="checkbox"/>

• Sudden death	<input type="checkbox"/>	<input type="checkbox"/>
• Traumatic death	<input type="checkbox"/>	<input type="checkbox"/>
• Issues surrounding diagnosis/illness	<input type="checkbox"/>	<input type="checkbox"/>
• Recent diagnosis	<input type="checkbox"/>	<input type="checkbox"/>
• Reluctance to face illness/death	<input type="checkbox"/>	<input type="checkbox"/>
• History of psychiatric illness	<input type="checkbox"/>	<input type="checkbox"/>
• History of depression	<input type="checkbox"/>	<input type="checkbox"/>
• Anxiety about making decisions	<input type="checkbox"/>	<input type="checkbox"/>
• Presence of concurrent life crisis	<input type="checkbox"/>	<input type="checkbox"/>
• Other losses in family	<input type="checkbox"/>	<input type="checkbox"/>
• Suicidal thoughts	<input type="checkbox"/>	<input type="checkbox"/>
• Angry/aggressive outbursts	<input type="checkbox"/>	<input type="checkbox"/>
• Financial issues	<input type="checkbox"/>	<input type="checkbox"/>
• Loss of home, feared or actual	<input type="checkbox"/>	<input type="checkbox"/>
• Lack of spiritual support	<input type="checkbox"/>	<input type="checkbox"/>
• Lack of social support	<input type="checkbox"/>	<input type="checkbox"/>
• Lack of family support	<input type="checkbox"/>	<input type="checkbox"/>
• Isolation	<input type="checkbox"/>	<input type="checkbox"/>
• Self care difficulties	<input type="checkbox"/>	<input type="checkbox"/>
• Special issues with key person or family eg. Alcohol use, drug use	<input type="checkbox"/>	<input type="checkbox"/>
• Other, specify	<input type="checkbox"/>	<input type="checkbox"/>
9. How are factors measured?		
• On a continuum eg. poor _____ well, mark on the line	<input type="checkbox"/>	<input type="checkbox"/>
• On a scale eg. 1 to 5	<input type="checkbox"/>	<input type="checkbox"/>
• Present / absent	<input type="checkbox"/>	<input type="checkbox"/>
• Yes / No	<input type="checkbox"/>	<input type="checkbox"/>
• None, routine, refer on	<input type="checkbox"/>	<input type="checkbox"/>
• Written comment on each factor that applies	<input type="checkbox"/>	<input type="checkbox"/>
• Includes an overall score with a score greater than ? indicating "at risk"	<input type="checkbox"/>	<input type="checkbox"/>

10. How is the information used following assessment? <ul style="list-style-type: none"> <li>• Bereavement programs tailored according to risk</li> <li>• Visit by counsellor/ bereavement co-ordinator</li> <li>• Offer of support</li> <li>• Referral to an external support service</li> <li>• Other, specify</li> </ul>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>
11. How is this information conveyed within the organisation? <ul style="list-style-type: none"> <li>• Team meeting</li> <li>• Documentation</li> <li>• Assessor directly to appropriate team member</li> <li>• Other, specify</li> </ul>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>
12. How is this information conveyed to: a) an acute setting <ul style="list-style-type: none"> <li>• letter</li> <li>• phone</li> <li>• specific form</li> <li>• other, specify</li> </ul> b) a hospice <ul style="list-style-type: none"> <li>• letter</li> <li>• phone</li> <li>• specific form</li> <li>• other, specify</li> </ul>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>
13. What other elements do you consider essential in bereavement risk assessment?		

<b>Bereavement Follow Up</b>		
Do you:		
Send card/letter	<input type="checkbox"/>	<input type="checkbox"/>
• When		
Phone family	<input type="checkbox"/>	<input type="checkbox"/>
• When		
Send other information	<input type="checkbox"/>	<input type="checkbox"/>
• What form does it take		
Visit the family	<input type="checkbox"/>	<input type="checkbox"/>
• At what time intervals		
How long do you provide bereavement support?		
Who does the follow-up?		
• How is this decided?		

<i>Referrals</i>		
At what point do you refer on?		
To whom?		

<b>Staffing Profile</b>		
Do you have:		
• Social work	<input type="checkbox"/>	<input type="checkbox"/>
• Pastoral care	<input type="checkbox"/>	<input type="checkbox"/>
• Volunteers	<input type="checkbox"/>	<input type="checkbox"/>
• Psychologist	<input type="checkbox"/>	<input type="checkbox"/>
• Music therapist	<input type="checkbox"/>	<input type="checkbox"/>
• Counsellors	<input type="checkbox"/>	<input type="checkbox"/>
• Anyone else involved in bereavement care	<input type="checkbox"/>	<input type="checkbox"/>
How many nursing EFT's on staff?		
Average number of family members on bereavement program in last 12 months		
Average number of active patients on community program in last 12 months?		

## Appendix 5 - Inventory of Traumatic Grief (ITG)

Holly Prigerson, Ph.D., Stan Kasl, Ph.D., Selby Jacobs, M.D., M.P.H.

**PLEASE mark the circle next to the answer that best describes how you have been feeling over the past month. The blanks refer to the deceased person over whom you are grieving.**

Almost never=less than once a month

Rarely=once a month or more, less than once a week

Sometimes=once a week or more, less than once a day

Often=once every day

Always=several times every day

1. The death of \_\_\_\_\_ feels overwhelming or devastating.  
 almost never    rarely    sometimes    often    always
2. I think about \_\_\_\_\_ so much that it can be hard for me to do the things I normally do.  
 almost never    rarely    sometimes    often    always
3. Memories of \_\_\_\_\_ upset me.  
 almost never    rarely    sometimes    often    always
4. I feel that I have trouble accepting the death.  
 almost never    rarely    sometimes    often    always
5. I feel myself longing and yearning for \_\_\_\_\_  
 almost never    rarely    sometimes    often    always
6. I feel drawn to places and things associated with \_\_\_\_\_  
 almost never    rarely    sometimes    often    always
7. I can't help feeling angry about \_\_\_\_\_'s death.  
 almost never    rarely    sometimes    often    always
8. I feel disbelief over \_\_\_\_\_'s death.  
 almost never    rarely    sometimes    often    always
9. I feel stunned, dazed, or shocked over \_\_\_\_\_'s death.  
 almost never    rarely    sometimes    often    always

10. Ever since \_\_\_\_\_ died it is hard for me to trust people.  
 no difficulty trusting others  
 a slight sense of difficulty  some sense  a marked sense  
 an overwhelming sense
11. Ever since \_\_\_\_\_ died I feel like I have lost the ability to care about other people or I feel distant from people I care about.  
 no difficulty feeling close or connected to others  
 a slight sense of detachment  some sense  a marked sense  
 an overwhelming sense
12. I have pain in the same area of my body, some of the same symptoms, or have assumed some of the behaviours or characteristics of \_\_\_\_\_  
 almost never  rarely  sometimes  often  always
13. I go out of my way to avoid reminders of \_\_\_\_\_  
 almost never  rarely  sometimes  often  always
14. I feel that life is empty or meaningless without \_\_\_\_\_  
 no sense of emptiness or meaninglessness  
 a slight sense of emptiness or meaninglessness  some sense  
 a marked sense  
 an overwhelming sense
15. I hear the voice of \_\_\_\_\_ speak to me.  
 almost never  rarely  sometimes  often  always
16. I see \_\_\_\_\_ stand before me.  
 almost never  rarely  sometimes  often  always
17. I feel like I have become numb since the death of \_\_\_\_\_  
 no sense of numbness  
 a slight sense of numbness  some sense  a marked sense  
 an overwhelming sense
18. I feel that it is unfair that I should live when \_\_\_\_\_ died.  
 no sense of guilt over surviving the deceased  
 a slight sense of guilt  some sense  a marked sense  
 an overwhelming sense
19. I am bitter over \_\_\_\_\_'s death.  
 no sense of bitterness  
 a slight sense of bitterness  some sense  a marked sense  
 an overwhelming sense

20. I feel envious of others who have not lost someone close.  
 almost never  rarely  sometimes  often  always
21. I feel like the future holds no meaning or purpose without  
 no sense that the future holds no purpose  
 a slight sense that the future holds no purpose  some sense  
 a marked sense  
 an overwhelming sense
22. I feel lonely ever since \_\_\_\_\_ died.  
 almost never  rarely  sometimes  often  always
23. I feel unable to imagine life being fulfilling without  
 almost never  rarely  sometimes  often  always
24. I feel that a part of myself died along with the deceased.  
 almost never  rarely  sometimes  often  always
25. I feel that the death has changed my view of the world.  
 no sense of a changed world view  
 a slight sense of a changed world view  some sense  a marked sense  
 an overwhelming sense
26. I have lost my sense of security or safety since the death of  
 no change in feelings of security  
 a slight sense of insecurity  some sense of  a marked sense  
 an overwhelming sense
27. I have lost my sense of control since the death of  
 no change in feelings of control  
 a slight sense of control  some sense of  a marked sense  
 an overwhelming sense
28. I believe that my grief has resulted in significant impairment in my social, occupational or other areas of functioning.  
 no functional impairment  
 mild functional impairment  moderate  severe  extreme
29. I have felt on edge, jumpy, or easily startled since the death?  
 no change in feelings of being on edge  
 a slight sense of feeling on edge  some sense  
 a marked sense of feeling on edge  
 an overwhelming sense

30. Since the death, my sleep has been  
 basically OK  
 slightly disturbed  moderately disturbed  very disturbed  
 extremely disturbed
31. How many months ago did these feelings begin? Please specify when *in months* from loss:
32. How long have you been grieving? (0 = never).
33. Have there been times when you did not have pangs of grief and then these feelings began to bother you again?  
 Yes  No
34. Can you describe how your feelings of grief have changed over time?

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**For Office Purposes Only**

35. If interviewer-administered, does rater consider this respondent to have syndromal level Traumatic Grief?  
 Yes  No

36. Does respondent meet the following criteria for Traumatic Grief?

1 = Almost Never	1 = Adequate	1 = None	1 = No
2 = Rarely	2 = Slight	2 = Slight	2 = Mild
3 = Sometimes	3 = Moderate	3 = Some	3 = Moderate
4 = Often	4 = Very	4 = Marked	4 = Severe
5 = Always	5 = Extreme	5 = Overwhelming	5 = Extreme

Criterion A1:

- The death of a significant other is a prerequisite for completion of the ITG.

Criterion A2: Separation Distress: at least 3 of the 5 following symptoms must be greater than or equal to 4 "often" "very," "marked."

- Q2, Q3, Q5, Q6, Q22

Criterion B: Traumatic Distress: at least 6 of 12 must be greater than or equal to 4.

- Q4, Q7, Q8, Q9, Q11, Q13, Q14, Q17, Q19, Q21, Q23, Q26

Criterion C:

- Q32 greater than 2 months.

Criterion D:

- Q28 greater than or equal to 4 "severe."

Yes

No

## Appendix 6 - Risk Factors for Complicated Bereavement Outcomes Checklist

### *Characteristics of the bereaved*

Pre-death	Tick	Post-death	Tick
<p>The person is:</p> <ul style="list-style-type: none"> <li>• a child or adolescent</li> <li>• a young spouse</li> <li>• an elderly spouse in a long marriage</li> </ul> <p>The person has experienced:</p> <ul style="list-style-type: none"> <li>• cumulative multiple losses</li> <li>• multiple stressful situations</li> <li>• mental health problems</li> <li>• a family history of mental illness</li> </ul> <p>The person has:</p> <ul style="list-style-type: none"> <li>• few adequate coping mechanisms</li> <li>• high pre-death emotional distress</li> </ul>		<p>The bereaved person:</p> <ul style="list-style-type: none"> <li>• demonstrates signs of poor initial adjustment to the death</li> <li>• expressed dissatisfaction with their caregiving role during the person's illness</li> </ul>	

### *Characteristics of the dying person*

Pre-death	Tick	Post-death	Tick
<p>The dying person is:</p> <ul style="list-style-type: none"> <li>• a child or adolescent</li> <li>• the parent of young children</li> </ul>			

**Comments:** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

*Character of interpersonal relationships*

<b>Pre-death</b>	<b>Tick</b>	<b>Post-death</b>	<b>Tick</b>
<p>The person:</p> <ul style="list-style-type: none"> <li>• lacks social support</li> <li>• feels unsupported</li> <li>• feels support is antagonistic or unsympathetic</li> <li>• feels dissatisfied with help available during the illness</li> <li>• is isolated</li> <li>• has an ambivalent or conflictual relationship with the dying person</li> </ul> <p>The death ends an unusually close/exclusive marriage</p> <p>The family:</p> <ul style="list-style-type: none"> <li>• lacks cohesion</li> <li>• has poor communication</li> <li>• has difficulty resolving conflict</li> </ul>		<p>The bereaved person:</p> <ul style="list-style-type: none"> <li>• is isolated after the death</li> <li>• social support reduces after the death</li> </ul>	

*Characteristics of the Illness and Nature of the Death*

<b>Pre-death</b>	<b>Tick</b>	<b>Post-death</b>	<b>Tick</b>
<p>The person is dying from an inherited disorder</p> <p>The person is dying from a stigmatised disease</p> <p>The illness is lengthy and burdensome</p>		<p>The death was sudden or unexpected</p> <p>The death occurred in traumatic circumstances</p>	

**Comments:**

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NB: This checklist offers a summary of risk factors central to CBRA. For more detail see Chapter 2. Aranda, S. & Milne, D (2000) Guidelines for the Assessment of Complicated Bereavement Risk in Family Members of People Receiving Palliative Care. Melbourne: Centre for Palliative Care.

## Appendix 7: The Family Relationships Index (FRI)

The following statements help us to understand your family. Please read each statement below and place a tick in the column marked TRUE, if you think the statement is true of your family, or a tick in the column marked FALSE, if this statement is not true of your family.

		TRUE	FALSE
1.	Family members really help and support one another		
2.	Family members often keep their feelings to themselves		
3.	We fight a lot in our family		
4.	We often seem to be killing time at home		
5.	We say anything we want to around home		
6.	Family members rarely become openly angry		
7.	We put a lot of energy into what we do at home		
8.	It is hard to 'blow off steam' at home without upsetting somebody		
9.	Family members sometimes get so angry they throw things		
10.	There is a feeling of togetherness in our family		
11.	We tell each other about our personal problems		
12.	Family members hardly ever lose their tempers		

**Scoring Rules:**

Cohesiveness = 1True + 4False + 7True + 10True.

Expressiveness = 2False + 5True + 8False + 11True.

Conflict = 3True + 6False + 9True + 12False.

FRI = Cohesiveness + Expressiveness + reversed (out of 4) conflict scores.

## **Appendix 8 – Proposed Criteria for traumatic Grief**

### ***Criterion A***

1. Person has experienced the death of a significant other
2. The response involves intrusive, distressing preoccupation with the deceased person (e.g.: yearning, longing, searching)

### ***Criterion B***

In response to the death, the following symptoms are marked and persistent:

1. Frequent efforts to avoid reminders of the deceased (e.g., thoughts, feelings, activities, people, places)
2. Purposelessness or feelings of futility about the future
3. Subjective sense of numbness, detachment, or absence of emotional responsiveness
4. Feeling stunned, dazed, or shocked
5. Difficulty acknowledging the death (e.g. disbelief)
6. Feeling that life is empty or meaningless
7. Difficulty imagining a fulfilling life without the deceased
8. Feeling that part of oneself has died
9. Shattered world view (e.g. lost sense of security, trust, or control)
10. Assumes symptoms or harmful behaviours of, or related to, the deceased person
11. Excessive irritability, bitterness, or anger related to the death.

### ***Criterion C***

Duration of disturbance (symptoms listed) is at least two months

### ***Criterion D***

The disturbance causes clinically significant impairment in social, occupation, or other important areas of functioning.

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