Grief and Bereavement Care

THAPS Conference, 2017 (September 7-8, 2017)

Amy Y.M. Chow, Ph.D., R.S.W., F.T.
Associate Professor,
Department of Social Work & Social Administration,
The University of Hong Kong,
Hong Kong
What is the relationship between Palliative Care and Bereavement Care?
Bereavement Care and Palliative Care (Murray et al., 2005, p.1010)
Bereavement care as an integral part of end-of-life care

Amy Chow, Department of Social Work & Social Administration, HKU
Bereavement care as an integral part of end-of-life care

(NICE, 2017)

Amy Chow, Department of Social Work & Social Administration, HKU
The Controversies in Bereavement Care
The Controversies in Bereavement Care

1. Objective
2. Content
3. Effectiveness
4. Target
5. Timing

Amy Chow, Department of Social Work & Social Administration, HKU
The Controversies in Bereavement Care

1. Objectives
Objective of Bereavement Care

What should be the goal?

Recovery
Heal
Manage
Adapt
Deal with
Adjust
Redefine and reintegrate
Restoration
Resilience

The Controversies in Bereavement Care

2. Content
Bereavement can give rise to a wide range of needs: practical, financial, social emotional and spiritual.
NICE Guideline and Bereavement Care (NICE, 2004)

...needs for information about the loss and grief, needs to pursue particular cultural practices, needs for additional support to deal with the emotional and psychological impact of loss by death, or...specific needs for mental health service intervention to cope with a mental health problem related to loss by death.
3-component model of bereavement support (NICE, 2004 p. 161)

**Component 1** Grief is normal after bereavement and most people manage without professional intervention. Many people, however, lack understanding of grief after immediate bereavement. All bereaved people should be offered information about the experience of bereavement and how to access other forms of support. Family and friends will provide much of this support, with information being supplied by health and social care professionals providing day-to-day care to families.
3-component model of bereavement support (NICE, 2004 p. 161)

**Component 2** Some people may require a more formal opportunity to review and reflect on their loss experience, but this does not necessarily have to involve professionals. Volunteer bereavement support workers/befrienders, self-help groups, faith groups and community groups will provide much of the support at this level. Those working in Component 2 must establish a process to ensure that when cases involving more complex needs emerge, referral is made to appropriate health and social care professionals with the ability to deliver Component 3 interventions.
3-component model of bereavement support (NICE, 2004 p. 161)

**Component 3** A minority of people will require specialist interventions. This will involve mental health services, psychological support services, specialist counselling/psychotherapy services, specialist palliative care services and general bereavement services, and will include provision for meeting the specialist needs of bereaved children and young people (being developed as part of the National Service Framework on children and not covered here).
What is Grief Intervention?

“Grief Intervention…ranging from mutual –help groups open for anyone suffering a loss to full-blow therapeutic programs for complicated or pathological forms of grief.” (P. 705).

“... is a broad term, potentially covering help offered by family, friends, and neighbours after the loss of a loved one.” (P. 706)

What is Grief Intervention?

Nature

- Counseling
- Befriending
- Information
- Emotional support
- Training
- Tangible services
- Memorial, remembrance or anniversary services
- TLC (Tender loving care)
What is Grief Intervention?

**Modality of contacts**

- Printed materials (Letter, condolence cards, information booklets or pamphlets)
- Non face-to-face interactive means (e.g. telephone, internet, or SMS)
- Individual
- Group
- Activities
- Advocacy work
Definition by Taskforce of ADEC

“Grief counseling involves a professional relationship whereby the counselor, in conjunction with the client, assesses the impact of a loss and facilitates healthy adaptation and optimal mental health & wellness; enabling the client to achieve his/her self-determined goals within a reasonable time frame.”
Categorization of Bereavement Care: Inspiration from Palliative Care

- Specialized Palliative Care
- General Palliative Care
- End of Life Care Approach
Theories of Bereavement (Chow, in press)

**Descriptive Theories**

- Phase/Stage Theories
  (Kubler-Ross, Bowlby & Parkes)

- Coping and Adaption Theories
  (Dual Process Model [Stroebe & Schut]; Two Track Model [Rubin & Malkinson]; Relearning the world [Attig])

- Task Theories
  (4 Tasks [Worden], 6 R model [Rando])

**Explanatory Theories**

- Relational Theories
  (Continuing Bond [Klass & Silverman], Psychodynamics [Freud])

- Constructivist Theories
  (Meaning Making [Neimeyer])

- Neurological Theories
  (MRI studies)
Descriptive Theories

10 Phase/Stage theories
- Steps and process
- Focus of different phase/stage

10 Coping and Adjustment theories
- Teaching and learning
- Resources and support

10 Task theories
- Clear steps and process
Explanatory Theories

10 Relational Theories

- Relationship building (e.g. Continuing Bond)
- Communications
- Connections

10 Constructivist Theories

- Meaning making
- Narrative reconstruction

10 Neurological Theories

- Biological means
Hong Kong Development

- Dual Process Model Group Intervention
- ADAPTS intervention
- Integrated Family Intervention for Persons Bereaved by Suicide
- Reweaving Grief

Amy Chow, Department of Social Work & Social Administration, HKU
The Controversies in Bereavement Care

3. Effectiveness
Efficacy Studies

Effect Size: 0.34

Reviewed 35 studies, with Effect Size: 0.114
Efficacy Studies

- Reviewed 23 studies
- Effect size = 0.13
- Treatment induced deterioration (TIDE)

Efficacy Studies

Differentiated care for different targets

Tertiary Preventive Interventions
For bereaved persons with complicated mourning responses
generally successful when compared with control groups

Secondary Preventive Interventions
- Focused on high risk bereaved persons
more evidence of efficacy, but modest when compared with traditional psychotherapy outcome studies

Primary Preventive Interventions
- Design to prevent the development in the general population of bereaved persons
- receive hardly any empirical support for their effectiveness

**Efficacy Studies**

**Does Grief Counseling Work?**

**JORDAN, J. R. & NEIMEYER, R. A.**

The Family Loss Project, Sherborn, Massachusetts, USA

The University of Memphis, Memphis, Tennessee, USA

Most bereavement interventions are seen as efficacious. However, a summary of the bereavement literature suggests that the scientific basis for accepting the efficacy of grief counseling may be quite weak. This article summarizes the findings of four recent qualitative and quantitative reviews of the bereavement intervention literature. It then discusses three possible explanations for these surprising findings and concludes with recommendations for both researchers and clinicians on the methodology that could help focus efforts to answer the question of whether and for whom grief counseling is helpful.


10 **Limited Effect**

10 **Research methodological problem**

---


**DALE G. LARSON**

Saints Claus University

**WILLIAM T. HOYT**

University of Wisconsin – Madison

A pessimistic view of grief counseling has emerged over the last 7 years, prompted by R. A. Neimeyer’s (2000) claim that “such interventions are typically ineffective, and perhaps even deleterious, at least for persons experiencing a normal bereavement” (p. 541). The negative characterization has little or no empirical grounding, however. The claim rests on 2 pieces of evidence. The first is an unrepresentative analysis of intervention effects in 10 outcome studies in R. A. Neimeyer’s (1999) dissertation, usually attributed to Neimeyer (2000). Neither the analysis nor Neimeyer’s findings have been published or subjected to peer review, until now. This review shows that there is no empirical or empirical basis for claims about intervention effects in grief counseling. The 2nd piece of evidence involves what the authors believe to be flawed assumptions of conventional meta-analytic findings.

This reinterpretation of empirical findings has damaged the reputation of grief counseling in the field and in the popular media and often hinders both researchers and research consumers interested in the relationship between science and practice in psychology.

**Keywords:** grief therapy, grief counseling, treatment dissemination, scientific-practitioner model, bereavement


---

**Queries over research methodology of the meta-analysis.**
Efficacy Studies

Effect Size for bereavement Intervention is still small

= 0.14

### Efficacy Studies

#### Differentiate Intervention

<table>
<thead>
<tr>
<th>Primary</th>
<th>Results</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>16 studies before 2001</td>
<td>Not effective in most</td>
<td>Absence of effects possibly because nearly all studies used outreaching recruitment procedures (help offered rather than asked for)</td>
</tr>
<tr>
<td>4 studies after 2001</td>
<td>More positive results than previous studies. Suggestion of better results seen in females (adults and young girls) than young males. Better results in people with mental-health problems at baseline, for both adults and children.</td>
<td>Positive results possibly because three of four studies were inreaching studies (bereaved requested help). Efficacy for those with higher levels of mental-health problems before intervention suggests rationale for secondary intervention</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Secondary</th>
<th>Results</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 studies before 2001</td>
<td>Generally, though not unequivocally, more effective than primary intervention, though effects were modest and improvements were temporary</td>
<td>Effectiveness associated with strict use of risk criteria, showing need to differentiate more within groups and tailor intervention to the subgroup (eg, by gender)</td>
</tr>
<tr>
<td>3 studies after 2001</td>
<td>Improvements in children bereaved by suicide in group intervention (compared with community care). Families at high-risk showed slightly more improvement after family-focused grief therapy in terms of general distress (not family functioning). Those with worst symptoms had most improvement. No effects of a highly-specific (body touching) therapy on bereaved mothers. Emotion-focused interventions most effective for distressed widowers; problem-focused for distressed widows. Fathers in general, and mothers with low baseline values of distress and grief did not benefit from group intervention focused on problems and emotions; highly distressed or grieving mothers improved most through intervention.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Tertiary</th>
<th>Results</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 studies before 2001</td>
<td>Modest but lasting positive effects on symptoms of pathology and grief (individual and group interventions; from analytically oriented dynamic psychotherapy to cognitive and behaviour therapy)</td>
<td>Therapy for complicated grief or bereavement-related depression and stress disorders has led to substantial and lasting results. 3 additional studies were difficult to interpret (no non-intervention control group) but were interesting for future research. For example, gender differences in effects of time-limited supportive and interpretative group therapy in bereaved people with major depression: women improved more than men in depression, anxiety, avoidance and general distress; men reported less grief than women after interpretive group therapy. A specific individual treatment module for complicated grief was more effective than standard interpersonal psychotherapy</td>
</tr>
<tr>
<td>2 studies after 2001</td>
<td>Substantiate earlier findings: strong effects in terms of intrusion, avoidance, grief, depression &amp; anxiety. Assessed nortriptyline and interpersonal psychotherapy (alone and in combination) for people with bereavement-related major depressive episodes examined. Nortriptyline led to less remission than placebo and psychotherapy. Indication that combination of medication and psychotherapy gave best results</td>
<td></td>
</tr>
</tbody>
</table>

---

Efficacy Studies

Effect Size for bereavement Intervention is still small

= 0.14 - 0.38

Efficacy Studies

Grief Therapy
Evidence of Efficacy and Emerging Directions
Robert A. Neimeyer\textsuperscript{1} and Joseph M. Currier\textsuperscript{2}
\textsuperscript{1}Department of Psychology, University of Memphis, and \textsuperscript{2}Memphis VA Medical Center


Effect Size for bereavement Intervention is still small
= 0.14 - 0.38
Fig. 1. Overall effectiveness of grief therapies compared to general psychotherapy. Bars represent effect sizes for different classes of interventions relative to untreated controls, with taller bars indicating more effective treatments. Compared to general psychotherapy for other problems (see Wampold, 2001), the effects of grief therapy are unimpressive; the apparently more substantial effects for nonrandom studies of grief therapy likely reflect confounding factors, such as the assignment of more motivated clients to the active treatment condition.

Fig. 2. Effect sizes of grief therapies for targeted populations. At both posttreatment and follow-up, bereavement interventions for “indicated” groups of mourners suffering from clinically elevated symptoms outperform interventions for “selective” groups of “at risk” mourners (e.g., bereaved parents) and “universal” interventions for all bereaved people, regardless of risk or demonstrated distress. Effects for general psychotherapy for other problems (see Wampold, 2001) are included for comparison.
The Controversies in Bereavement Care

4. Target
3-level model of bereavement support inspired by Public Health Approach

- **Universal Care:** Everyone
  - **Risk Assessment**
  - **Outcome Assessment**

- **Selective Care:** High Risk Group
  - **Risk Assessment**

- **Indicated Care:** High Outcome Group
  - **Outcome Assessment**

- **3-level model of bereavement support inspired by Public Health Approach**
Map for Assessment

Risk Factor Assessment

Normal Group

High Risk Group

Outcome Assessment

Treatment as Usual

Specialized Grief Intervention
Assessment of Grief

By Risk Factor (Predictive) or by protective factors

Inter-rater reliability of the Bereavement Risk Assessment Tool

CARLIN ROSE, M.A., 1 WENDY WAINWRIGHT, M.Ed., 2 MICHAEL DOWNING, M.D., 1 AND MARY LESPERANCE, PH.D., R.N., 3

1Victoria Hospices Society, Victoria, British Columbia, Canada
2University of Victoria, Victoria, British Columbia, Canada
3Washington Hospices Society, Seattle, Washington, USA


ABSTRACT

Objective: The Bereavement Risk Assessment Tool (BRAT) was designed to consistently communicate information affecting bereavement outcomes, to predict the risk for difficult or complicated bereavement based on information obtained before the death, to consider resiliency as well as risk; and to assist in the efficacy and consistency of bereavement service allocation.

Families followed the initial development of the BRAT’s 40 items and its clinical use, this study set out to test the BRAT for inter-rater reliability along with some basic validity measures.

Method: Case studies were conducted based on actual patients and families from a hospice palliative care program. Bereavement professionals were recruited via the internet. Thirty-six participants assessed BRAT items in 10 cases and then estimated one of 5 levels of risk for each case. These were compared with an expert group’s assignment of risk.

Results: Inter-rater reliability for the 5-level risk scores yielded a Fleiss’ kappa of 0.82 and an intra-class correlation (ICC) of 0.82 (95% CI 0.5-0.89). By collapsing scores into low and high risk groups, a kappa of 0.63 and an ICC of 0.66 (95% CI 0.5-0.80) was obtained. Participant-estimated risk scores yielded a kappa of 0.54. Although opinion varied on the tool’s length, participants indicated it was well organized and easy to use, with potential in assessment and allocation of bereavement services. Limitations of the study include a small sample size and the use of case studies. Limitations of the tool include the subjectivity of some items and ambiguousness of unchecked items.

Significance of results: The collapsed BRAT risk levels show moderately good inter-rater reliability over clinical judgement alone. This study provides introductory evidence of a tool that can be used both prior to and following a death and, in conjunction with professional judgment, can assess the likelihood of bereavement complications.

KEYWORDS: Bereavement Risk, Bereavement Assessment, Risk Factor, Grief, Complicated Grief
Assessment of Grief

By Grief reactions (Outcomes)

- **Emotion**: Depression, Anxiety
- **Complicated Grief**
- **Functionality (disruption)**
- **Physical condition**
Six High Risk Factors  (Rando, 1994)

10 Suddenness and lack of anticipation
10 Violence, mutilation, and destruction
10 Preventability and/or randomness
10 Loss of a child
10 Multiple deaths
10 Person encounter with death secondary to threat of personal survival/ massive confrontation with the death
12 High Risk Factors (1) (McKissock & McKissock, 1999)

1. Sudden death
2. Child death
3. Traumatic witness
4. Centrality **
5. Preventability
6. Ambivalence
12 High Risk Factors (2) (McKissock & McKissock, 1999)

- Pre-existing problem (e.g. Alcoholism)
- Concurrent Crisis
- Decreased Social Support
- Decreased Role Diversity
- Overly prolonged dying process
- Lack of reality (Missing persons)
Integrated Model of Risk

A. Bereavement:
- Loss-oriented Stressors – LS
  - Traumatic (inc. sudden, unprepared, untimely)
  - Type loss (spouse, child)
  - Multiple concurrent losses
  - Quality of relationship
- Restoration-oriented Stressors – RS
  - Work /legal problems
  - Care-giver burden residue
  - Ongoing conflicts
  - Poverty / economic decline

B. Inter-/ non-personal Risk Factors:
- Social support / isolation
- Intervention programs
- Family dynamics
- Cultural setting/resources
- Religious practices
- Material resources (money; services)

C. Intrapersonal Risk Factors:
- Attachment style / Personality
- SES; gender
- Religious beliefs / other meaning systems
- Intellectual ability
- Childhood/multiple preceding losses
- Predisposing vulnerabilities (e.g.)
  - Mental health problems (depression; adjustment disorder, etc.)
  - Medical / physical health problems
  - Age-related frailty
  - Substance abuse

D. Appraisal & Coping:
- Cognitive / behavioral processes / mechanisms
- Emotion regulation (oscillation)

E. Outcome (changes in):
- Grief intensity
- (Exacerbation) LS & RS-related
- Psych. & phys. (ill) health
- Cognitive (debility)
- Social (dis)engagement

Fig. 1. The integrative risk factor framework for the prediction of bereavement outcome.
## Risk and Protective Factors (Stroebe, Schut, & Stroebe, 2007)

<table>
<thead>
<tr>
<th>Specific risk factor</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Situation and circumstances of death</strong></td>
<td><strong>Cause of death (including sudden, unprepared, untimely, traumatic)</strong></td>
</tr>
<tr>
<td></td>
<td>Inconsistent results for sudden vs expected deaths(^{111,112}), traumatic deaths: worse outcomes(^{89,113}) note also parents' reactions to traumatic deaths(^{36,50}). Sudden death likely to have the most effect on vulnerable people (eg, those with low self-esteem) and those who are personally less well-prepared(^{144,115}). Few differences in effect of suicide or non-suicide deaths in some studies, but longer adaptation and some aspects (eg, stigmatisation, shame) more of an issue after suicide deaths than after other deaths(^{116}). Excessive risk of mortality (including suicide) after suicide death.(^{31}) Suicide-bereaved children might be vulnerable(^{117}).</td>
</tr>
<tr>
<td><strong>Circumstances surrounding death or place of death</strong></td>
<td>Multiple (concurrent) losses; witnessing extreme distress in terminal illness increases effect of loss(^{118}) but a so-called good death (eg, appropriate medical care, reducing distress for dying and bereaved) ameliorates the effect(^{211,119}). Rituals can help, particularly for children(^{120}). Deaths with hospice care are sometimes (not always(^{121})) associated with better outcomes than deaths in hospital in bereaved people. Some evidence suggests that deaths in hospice care are associated with lower mortality rates in the bereaved(^{121}). Death of a child in hospital is associated with more symptoms for parents than the death of a child at home(^{123}).</td>
</tr>
<tr>
<td><strong>Pre-bereavement caregiver strain</strong></td>
<td>Strain affects health of caregiver before and after bereavement(^{74,112,114,125}). Although successful caregiving can be helpful, caregiving benefits might also be associated with high amounts of grief(^{127}). Health consequences not only owing to burden and responsibilities but also to personal neglect of one's own health, nutrition, physical and emotional needs(^{12}). Death might on occasion be judged a relief for patient and bereaved(^{128}).</td>
</tr>
<tr>
<td><strong>Type of lost relationship (eg, child vs spouse)</strong></td>
<td>Findings of a few studies show that kinship relationship moderates type of effect on health(^{129,130}). Loss of a child (adult) associated with more intense and persistent grief and depression than loss of spouse(^{111,132}).</td>
</tr>
<tr>
<td><strong>Quality of relationship with deceased</strong></td>
<td>Earlier claims that poor relationships (eg, ambivalence, dependency) lead to difficulties in bereavement, some benefits from good relationships(^{95}), but findings not consistent concerning positive or negative outcomes and marital quality with respect to dependency, closeness, harmony, etc(^{122,135}).</td>
</tr>
<tr>
<td><strong>Ongoing conflicts, concurrent work and legal difficulties; poverty or economic decline</strong></td>
<td>Concurrent stressors affect bereavement outcome, eg, financial hardship that compounds difficulties in adjustment. If bereavement is accompanied by a drop in economic resources, or insufficient income, effects of bereavement might be exacerbated(^{72,136}). Poor eating habits and loss of weight compared with married people(^{41}).</td>
</tr>
</tbody>
</table>
Risk and Protective Factors (Stroebe, Schut, & Stroebe, 2007)

Some protective factors identified (e.g., optimism, perceived control over daily activities, high self-esteem, secure attachment style in relationships with others) could prevent the intensification of depression in bereavement. Pre-bereavement depression probably associated with high risk of intensification of depression in bereavement. Findings of most studies show early (childhood or adolescent) bereavement to be a risk for later (adulthood) mental and physical health issues. Also noted are: cortisol concentration differences, information processing biases, different sibling relationships. Adequacy of remaining parent care and personal characteristics of child are important. Findings of some, but by no means all, studies show religion helps.

Socioeconomic status: findings of some studies suggest that health outcomes of bereavement are not related to socioeconomic status (see also economic resources below). Some reports of poorer health in lower socioeconomic groups probably indicate non-bereavement-specific patterns. Relative mortality is similar across education and income groups but absolute differences compared with married people are greater in lower social strata. Gender: widowers are relatively more vulnerable than widows; mothers are affected more than fathers. Age: young people are reported to be more vulnerable in some studies; curvilinear relations also noted. Ethnic group: similarities in grieving recorded between black and white people; however, anger and despair are lower in black populations, and high rates of psychiatric disorders and mortality are seen in both black and white bereaved people (patterns of comparative sex differences are less clear). Differing ethnic groups also have unique features of grief.
## Risk and Protective Factors (Stroebe, Schut, & Stroebe, 2007)

<table>
<thead>
<tr>
<th>Interpersonal or non-personal resources and protective factors</th>
<th>Social support, cultural setting</th>
<th>Economic resources</th>
<th>Professional intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social support helps bereaved and non-bereaved individuals alike, but bereaved people with higher support are not comparatively better-adjusted than are those with low support, compared with non-bereaved counterparts.</td>
<td>Social isolation compounds difficulties in adjustment. Cultural and social embedding probably affects bereavement outcome.</td>
<td>Material resources (money; services) might buffer against extra stresses, but in general, effects of bereavement are broadly similar across income groups.</td>
<td>See table 3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Coping styles, strategies, processes</th>
<th>Grief work, appraisal processes</th>
<th>Emotion regulation</th>
</tr>
</thead>
</table>
| Grief work, sharing, and disclosure are not as predictive of outcome as has been previously claimed. Avoidance is not necessarily so detrimental, but rumination is associated with poor outcomes, whereas positive (re)appraisal is associated with good outcomes. | Regulation (confrontation or avoidance; positive and negative appraisals) in the grieving process is likely to be beneficial.
Risk factors identified in Hong Kong

- Dependency on the deceased
- Loneliness (emotional and social loneliness)
- Perceived Traumatic effect of the death
Assessment of Outcomes in Bereavement
Experiences of Grief

**Affective**
- Depression, despair, dejection, distress
- Anxiety, fears, dreads
- Guilt, self-blame, self-accusation
- Anger, hostility, irritability
- Anhedonia—loss of pleasure
- Loneliness
- Yearning, longing, pining
- Shock, numbness

**Cognitive**
- Preoccupation with thoughts of deceased, intrusive ruminations
- Sense of presence of deceased
- Suppression, denial
- Lowered self-esteem
- Self-reproach
- Helplessness, hopelessness
- Suicidal ideation
- Sense of unreality
- Memory, concentration difficulties
Experiences of Grief

**Behavioural**
- Agitation, tenseness, restlessness
- Fatigue
- Overactivity
- Searching
- Weeping, sobbing, crying
- Social withdrawal

**Physiological-somatic**
- Loss of appetite
- Sleep disturbances
- Energy loss, exhaustion
- Somatic complaints
- Physical complaints similar to deceased
- Immunological and endocrine changes
- Susceptibility to illness, disease, mortality
Health Consequences of Bereavement (Stroebe, Schut, & Stroebe, 2007)

Increased risk of mortality:

- mainly related to broken heart (psychological distress due to the loss, such as loneliness and secondary consequences of the loss, such as changes in social ties, living arrangements, eating habits, and economic support)
- for widowers, increased risk with alcohol consumption and the loss of their sole confidante
- chance of death in the early months are higher
- widowers (compared with married same-sex counterparts) are at relatively more excessive risk of mortality than widows (compared with married same sex counterparts)
- odd ratio vs rate: 5% of widowers vs 3% of married men in the 55 years and older age category dying in the first 6 months of bereavement. (OR=1.66)
Health Consequences of Bereavement (Stroebe, Schut, & Stroebe, 2007)

**Higher Physical Morbidity**
- more likely to have health problems
- higher rates of disability, medication use, and hospitalization than non-bereaved counterparts
- more likely to have medical consultations, but in one study indicated high intensities of grief reduced the use of health services
- increase of activity-limiting pain and moderate to severe current pain among recently bereaved persons
- associated with weight loss
Health Consequences of Bereavement (Stroebe, Schut, & Stroebe, 2007)

Higher Psychiatric Morbidity

- increase in depressive symptoms in bereaved populations
- 25-45% have mild levels of depressive symptoms, and 10-20% show clinical levels
- PTSD
Health Consequences of Bereavement (Stroebe, Schut, & Stroebe, 2007)

Additional medical implications:
- impaired memory performance,
- nutritional problems
- work and relationship difficulties
- difficulties in concentration
- decrease in social participation
Trajectories of Grief

Chronic Grief (about 16%)
- Depressed improved Group (about 11%)
- had poorest quality marriages
- higher on ambivalence towards the spouse in the pre-loss stage
- about 75% of this group reported experiencing intense yearning (painful waves of missing the spouse) as well as pangs of intense grief in the earliest months of bereavement
- better able to gain comfort from talking about and thinking about the spouse
- had relatively lower scores on avoidance and distraction, as well as having fewer regrets
- but less likely to make sense of or find meaning in the spouse’s death

Resilient Group (about 46%)
- about 75% of this group reported experiencing intense yearning (painful waves of missing the spouse) as well as pangs of intense grief in the earliest months of bereavement
- they also ruminating, or going over and over what had happened
- better able to gain comfort from talking about and thinking about the spouse
- had relatively lower scores on avoidance and distraction, as well as having fewer regrets
- but less likely to make sense of or find meaning in the spouse’s death

Common Grief (about 11%)
- had poorest quality marriages
- higher on ambivalence towards the spouse in the pre-loss stage
- mostly on those with a seriously ill spouse
- less frequently talking and thinking about the spouses
- reported the lowest levels of comfort from memories of the spouse
- but higher perception of pride in coping ability

Abnormal Grief?

Defined by the norm

It is “normal” for Bereaved persons have “abnormal” behaviours as bereavement itself is an “abnormal” experience ....
Barriers

Diversified Domain: Biological, psychological, emotional, and spiritual
Individualized responses
Unsettled conclusion: absent of grief = recovery?
Timing of assessment
Source of information: self-report, clinical assessment and by proxy
Insider experience vs expressed experience
Cross cultural standard
Qualitative vs Quantitative
Normality Vs Abnormality of Grief

Abnormal Grief (Worden, 1982)
- Chronic Grief
- Delayed Grief
- Exaggerated Grief
- Masked Grief

Pathological Grief (Gort, 1984)
- Chronic grief
- Inhibited Grief
- Delayed Grief
- Atypical Grief

Complicated Grief

Grief complicated by other factors

Traumatic Grief

Prolonged Grief

Major Depressive Episode related to Bereavement

Adjustment Disorder related to Bereavement

Persistent Complex Bereavement-Related Disorder

DSM 5

ICD 11
3 major proposals in DSM-5 related to bereavement

1. Removal of exclusion in major depressive episode
2. Removal of exclusion in adjustment disorder
3. Inclusion of a new diagnosis which is bereavement-specific


Amy Chow, University of Hong Kong

12th Australian Palliative Care Conference
3 major proposals in DSM-5 related to bereavement

1. Removal of exclusion in major depressive episode
2. Removal of exclusion in adjustment disorder
3. Inclusion of a new diagnosis which is bereavement-specific
Earlier Versions (DSM III, APA, 1980)

- Major depressive episode first introduced
- Not being diagnosed with MDE “if the symptoms are better accounted for by bereavement”
- Bereavement Exclusion (BE)

http://kidsandmeds.umwblogs.org/files/2010/10/41Lc8JOrQL._SL500_AA300_.jpg

12th Australian Palliative Care Conference
Earlier Versions (DSM IV, APA, 1994)

10 Defined time frame as 2 months

E. The symptoms are not better accounted for by Bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than 2 months or are characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation.

Major Depressive Disorder

Diagnostic Criteria

A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.

Note: Do not include symptoms that are clearly attributable to another medical condition.

1. Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad, empty, hopeless) or observation made by others (e.g., appears tearful). (Note: In children and adolescents, can be irritable mood.)

2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation).

3. Significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day. (Note: In children, consider failure to make expected weight gain.)

4. Insomnia or hypersomnia nearly every day.

5. Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).

6. Fatigue or loss of energy nearly every day.

7. Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).

8. Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others).

9. Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.
B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

C. The episode is not attributable to the physiological effects of a substance or to another medical condition.

Note: Criteria A–C represent a major depressive episode.

Note: Responses to a significant loss (e.g., bereavement, financial ruin, losses from a natural disaster, a serious medical illness or disability) may include the feelings of intense sadness, rumination about the loss, insomnia, poor appetite, and weight loss noted in Criterion A, which may resemble a depressive episode. Although such symptoms may be understandable or considered appropriate to the loss, the presence of a major depressive episode in addition to the normal response to a significant loss should also be carefully considered. This decision inevitably requires the exercise of clinical judgment based on the individual’s history and the cultural norms for the expression of distress in the context of loss.¹

D. The occurrence of the major depressive episode is not better explained by schizoaffective disorder, schizophrenia, schizophreniform disorder, delusional disorder, or other specified and unspecified schizophrenia spectrum and other psychotic disorders.

E. There has never been a manic episode or a hypomanic episode.

Note: This exclusion does not apply if all of the manic-like or hypomanic-like episodes are substance-induced or are attributable to the physiological effects of another medical condition.
In distinguishing grief from a major depressive episode (MDE), it is useful to consider that in grief the predominant affect is feelings of emptiness and loss, while in MDE it is persistent depressed mood and the inability to anticipate happiness or pleasure. The dysphoria in grief is likely to decrease in intensity over days to weeks and occurs in waves, the so-called pangs of grief. These waves tend to be associated with thoughts or reminders of the deceased. The depressed mood of MDE is more persistent and not tied to specific thoughts or preoccupations. The pain of grief may be accompanied by positive emotions and humor that are uncharacteristic of the pervasive unhappiness and misery characteristic of MDE. The thought content associated with grief generally features a preoccupation with thoughts and memories of the deceased, rather than the self-critical or pessimistic ruminations seen in MDE. In grief, self-esteem is generally preserved, whereas in MDE feelings of worthlessness and self-loathing are common. If self-derogatory ideation is present in grief, it typically involves perceived failings vis-à-vis the deceased (e.g., not visiting frequently enough, not telling the deceased how much he or she was loved). If a bereaved individual thinks about death and dying, such thoughts are generally focused on the deceased and possibly about “joining” the deceased, whereas in MDE such thoughts are focused on ending one’s own life because of feeling worthless, undeserving of life, or unable to cope with the pain of depression.
Eligibility

= Quality \times Persistence \times Intensity

5 out of 9
• Depressed Mood
• Loss of Interest
• Weight Change
• Sleep Change
• Psychomotor Change
• Fatigue
• Worthlessness
• Indecisiveness
• Thoughts of death

Consecutively for 2 weeks

Nearly Everyday

Impairment of Functioning
3 major proposals in DSM-5 related to bereavement

1. Removal of exclusion in major depressive episode
2. Removal of exclusion in adjustment disorder
3. Inclusion of a new diagnosis which is bereavement-specific


Amy Chow, University of Hong Kong

12th Australian Palliative Care Conference
Earlier Versions (DSM IV, APA, 1994)

• Bereavement Exclusion in Adjustment Disorder

  Bereavement is generally diagnosed instead of Adjustment Disorder when the reaction is an expectable response to the death of a loved one. The diagnosis of Adjustment Disorder may be appropriate when the reaction is in excess of, or more prolonged than, what would be expected. Adjustment Disorder should also be distinguished from other nonpathological reactions to stress that do not lead to marked distress in excess of what is expected and that do not cause significant impairment in social or occupational functioning.

  (APA, 1994, p.626)

• Intensity or duration of the symptoms might quality the diagnosis of AD even induced by bereavement
Adjustment Disorder and Bereavement

Elimination of the bereavement exclusion with respect to Mood Disorders, has led to the decision to also eliminate this exclusion for Adjustment Disorders. As a result, the loss of a loved one may qualify as an event that precipitates a mood or adjustment disorder. Now that bereavement is accepted as a qualifying event, there is also a need for a diagnosis to characterize an individual who is having clinically significant distress as a result of the death of a loved one. This matter has been the subject of considerable research on abnormal mourning which has been named, in some circles,
Current Version (DSM 5, APA, 2013)

- Bereavement Exclusion being removed
- New sub-category: Related to Bereavement

[Website](http://www.absolutelyautism.com/2012/02/09/the-new-dsm-5/)
Adjustment Disorders (APA, 2013, p. 286-287)

Diagnostic Criteria

A. The development of emotional or behavioral symptoms in response to an identifiable stressor(s) occurring within 3 months of the onset of the stressor(s).

B. These symptoms or behaviors are clinically significant, as evidenced by one or both of the following:

1. Marked distress that is out of proportion to the severity or intensity of the stressor, taking into account the external context and the cultural factors that might influence symptom severity and presentation.

2. Significant impairment in social, occupational, or other important areas of functioning.

C. The stress-related disturbance does not meet the criteria for another mental disorder and is not merely an exacerbation of a preexisting mental disorder.

D. The symptoms do not represent normal bereavement.

E. Once the stressor or its consequences have terminated, the symptoms do not persist for more than an additional 6 months.
Adjustment Disorders  (APA, 2013, p.286-287)

Specify whether:

309.0 (F43.21) With depressed mood: Low mood, tearfulness, or feelings of hopelessness are predominant.
309.24 (F43.22) With anxiety: Nervousness, worry, jitteriness, or separation anxiety is predominant.
309.28 (F43.23) With mixed anxiety and depressed mood: A combination of depression and anxiety is predominant.
309.3 (F43.24) With disturbance of conduct: Disturbance of conduct is predominant.
309.4 (F43.25) With mixed disturbance of emotions and conduct: Both emotional symptoms (e.g., depression, anxiety) and a disturbance of conduct are predominant.
309.9 (F43.20) Unspecified: For maladaptive reactions that are not classifiable as one of the specific subtypes of adjustment disorder.
Diagnostic Features

The presence of emotional or behavioral symptoms in response to an identifiable stressor is the essential feature of adjustment disorders (Criterion A). The stressor may be a single event (e.g., a termination of a romantic relationship), or there may be multiple stressors (e.g., marked business difficulties and marital problems). Stressors may be recurrent (e.g., associated with seasonal business crises, unfulfilling sexual relationships) or continuous (e.g., a persistent painful illness with increasing disability, living in a crime-ridden neighborhood). Stressors may affect a single individual, an entire family, or a larger group or community (e.g., a natural disaster). Some stressors may accompany specific developmental events (e.g., going to school, leaving a parental home, reentering a parental home, getting married, becoming a parent, failing to attain occupational goals, retirement).

Adjustment disorders may be diagnosed following the death of a loved one when the intensity, quality, or persistence of grief reactions exceeds what normally might be expected, when cultural, religious, or age-appropriate norms are taken into account. A more specific set of bereavement-related symptoms has been designated persistent complex bereavement disorder.

Adjustment disorders are associated with an increased risk of suicide attempts and completed suicide.
Eligibility

=  

Quality  \xmark  Persistence  \xmark  Intensity

Marked Distress

Impairment of Functioning

Depends on the nature of event: can be brief or in persistent form

Exceeds what normally be expected
3 major proposals in DSM-5 related to bereavement

1. Removal of exclusion in major depressive episode
2. Removal of exclusion in adjustment disorder
3. Inclusion of a new diagnosis which is bereavement-specific


Amy Chow, University of Hong Kong

12th Australian Palliative Care Conference
Complex Persistent Bereavement Disorder *(APA, 2013, 789-790)*

Persistent Complex Bereavement Disorder

**Proposed Criteria**

A. The individual experienced the death of someone with whom he or she had a close relationship.

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

1. **Persistent yearning/longing** for the deceased. In young children, yearning may be expressed in play and behavior, including behaviors that reflect being separated from, and also reuniting with, a caregiver or other attachment figure.

2. **Intense sorrow and emotional pain** in response to the death.

3. **Preoccupation** with the deceased.

4. Preoccupation with the circumstances of the death. In children, this preoccupation with the deceased may be expressed through the themes of play and behavior and may extend to preoccupation with possible death of others close to them.
Complex Persistent Bereavement Disorder (APA, 2013, 789-790)

C. Since the death, at least six of the following symptoms are experienced on more days than not and to a clinically significant degree, and have persisted for at least 12 months after the death in the case of bereaved adults and 6 months for bereaved children:

**Reactive distress to the death**

1. **Marked difficulty accepting** the death. In children, this is dependent on the child’s capacity to comprehend the meaning and permanence of death.
2. Experiencing **disbelief** or emotional numbness over the loss.
3. Difficulty with **positive reminiscing** about the deceased.
4. Bitterness or anger related to the loss.
5. **Maladaptive appraisals about oneself** in relation to the deceased or the death (e.g., self-blame).
6. Excessive **avoidance of reminders** of the loss (e.g., avoidance of individuals, places, or situations associated with the deceased; in children, this may include avoidance of thoughts and feelings regarding the deceased).
Complex Persistent Bereavement Disorder (APA, 2013, 789-790)

Social/identity disruption

7. A desire to die in order to be with the deceased.
8. Difficulty trusting other individuals since the death.
9. Feeling alone or detached from other individuals since the death.
10. Feeling that life is meaningless or empty without the deceased, or the belief that one cannot function without the deceased.
11. Confusion about one's role in life, or a diminished sense of one's identity (e.g., feeling that a part of oneself died with the deceased).
12. Difficulty or reluctance to pursue interests since the loss or to plan for the future (e.g., friendships, activities).

D. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.
E. The bereavement reaction is out of proportion to or inconsistent with cultural, religious, or age-appropriate norms.
Specify if:

**With traumatic bereavement:** Bereavement due to homicide or suicide with persistent distressing preoccupations regarding the traumatic nature of the death (often in response to loss reminders), including the deceased’s last moments, degree of suffering and mutilating injury, or the malicious or intentional nature of the death.
Eligibility

Quality

Persistence

Intensity

1 out of 4
• Persistent Yearning
• Intense Sorrow
• Pre-occupation with the deceased
• Pre-occupation with the circumstances of the death

At least for 12 months (Adults); for 6 months (Children)

More days than not; to a clinical significant degree

6 out of 12
(Reactive Distress)
• Difficulty Accepting
• Disbelief
• Difficulty +ve reminiscing
• Bitterness
• Maladaptive Appraisals
• Excessive Avoidance

(Identity Disruption)
• Death Reunion
• Difficulty Trusting
• Detached
• Meaningless
• Diminished Self-Identity
• Reluctance to pursue interests

Impairment of Functioning
The Controversies in Bereavement Care

5. Timing
Pre-death Care

Premature anticipatory grief

Finishing the unfinished businesses in particular the relational ones
Feed when demanded

Inspirations from the wisdom of breast-feeding:

- Need of continuous assessment
- Times with upsurges in outcomes
  - Subsequent Temporary Upsurges of Grief (STUG Reactions) in accordance to Precipitants (Rando, 1994)
    - Cyclic Precipitants (Anniversary or Festive Effect etc..)
    - Linear Precipitants (Graduation, marriage..)
    - Stimulus-cued Precipitants (News of similar deaths….)
Anticipatory Anniversary Effects and Bereavement: Development of an Integrated Explanatory Model

AMY Y. M. CHOW
Department of Social Work and Social Administration, University of Hong Kong, Hong Kong, China

Anniversary effects have been previously noted in bereavement, but there is little empirical support for this observation. This article reports on the development of an anniversary effects model with intrapersonal, interpersonal, and environmental determinants based on a literature review of anniversary reactions. A secondary analysis of a cross-sectional study of Chinese bereaved persons in Hong Kong was undertaken, and anticipatory bereavement anniversary effects were observed rather than the bereavement anniversary effects reported in the literature. Based on a further literature review, the first model was amended to form an integrative model of anticipatory anniversary effects. The revised model integrated concepts of appraisal and coping, as well as postulating their relationship to anniversary reactions.

**Anticipatory Anniversary Effect**

---

**FIGURE 4** Integrated model of anticipatory anniversary effects.

**Chow, A. Y. M.** (2010). Anticipatory anniversary bereavement effects and Bereavement: Development of an integrated explanatory model. *Journal of Loss and Trauma, 15*(1), 54-68.
Process model of Bereavement Care

Pre-death

Prevention of Traumatization

Post Death

Anticipatory Anniversary Work

Moment of Death

Anticipatory Grief Work

Assessment and Bereavement Intervention
Question and Answer
If grief is the price we pay for love, we, as health care professionals, may make the price more bearable...

Thank you

chowamy@hku.hk