An update on bereavement science

& what it tells us about the needs of palliative care carers

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IN GRIEF …
WHAT IS NORMAL? AND WHAT IS PATHOLOGICAL?

“I am stretched on your grave … “
The Voice Squad
The disclaimer ....
The BIG questions

- When does “normal grief” become pathological?
- What is going on with the DSM criteria?
- Can we prevent some negative bereavement outcomes for palliative care caregivers?
Grief, depression & “the bereavement exclusion”

DSM 5 Controversy #1
The case of “the bereavement exclusion”

In DSM IV…

- Problems of bereavement were classified within the depressive disorders
- Defined grief as "an expectable and culturally sanctioned response to a particular event"

BUT

- “The bereavement exclusion” meant no diagnosis of major depression could be made for two months after a person was bereaved (had previously been 12 months)
The case of “the bereavement exclusion”

Changed for DSM V…

- Diagnosis of a major depressive disorder in a bereaved person can be made after only two weeks of symptoms.
In support of the bereavement exclusion

In removing the so-called bereavement exclusion, the DSM-5 would encourage clinicians to diagnose major depression in persons with normal bereavement after only 2 weeks of mild depressive symptoms. Unfortunately, the effect of this proposed change would be to medicalize normal grief and erroneously label healthy people with a psychiatric diagnosis. And it will no doubt be a boon to the pharmaceutical industry, because it will encourage unnecessary treatment with antidepressants and antipsychotics, both of which are increasingly used to treat depression and anxiety.

Grief, Depression, and the DSM-5
Richard A. Friedman,
...eliminating the bereavement exclusion means essentially this: the death of a loved one -- a common precipitant of major depression----will no longer be a "disqualifying" factor in diagnosing MDD, within the first few weeks after bereavement. This emphatically does not mean that we should be starting everyone with bereavement-related MDD on antidepressants! Some depressed and bereaved patients will heal and recover with "tincture of time"; some will benefit from cognitive, supportive or grief-oriented psychotherapies. More severely depressed, grieving patients--those, for example, with melancholic features or pronounced suicidality--may require concurrent medication and psychotherapy.

No, indeed: we must not "medicalize" normal grief. But neither must we "normalize" major depression, simply because it occurs in the context of bereavement.

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Grief vs depression

Commentary provided by the APA focuses on…

- Risks of failing to make a diagnosis of MDD
- Those vulnerable to MDD are at increased risk during bereavement
- Treatments are effective for both and should not be delayed
- More nuanced guidance is now available to help clinicians make the distinction between grief and depression\(^1\)

\(^1\) Major Depressive Disorder and the “Bereavement Exclusion” Fact Sheet APA 2013.
Is it grief or depression?

**Grief**
- Painful feelings come in waves, mixed with positive feelings, often memories of the deceased
- Self-esteem usually preserved

**Depression**
- Mood and ideation are almost constantly negative
- Corrosive feelings of worthlessness and self-loathing are common
Or grief AND depression?

- The two may be comorbid
- The syndrome associated with grief is still *specific and different*
Prolonged grief disorder  
~ PGD a brief history

DSM 5 Controversy #2
PGD – a brief history

The rationale for PGD as a specific diagnostic category:

- Clinically identifiable subgroup of around 10% of bereaved have persistent anguish / distress with significant impairment
- Their other health outcomes appear to be worse
- “Chronic grieving” – stuck – disconnected from others. May feel that to move on is disloyal to the deceased
- They may not be appropriately diagnosed as depressed, and grief symptoms appear to not respond as well to antidepressants
- However – grief intensity has been shown to improve with effective pharmacological treatment of comorbid depression
PGD, PTSD

Horowitz – identified the PTSD syndrome in 1974 and at that time recognised its links with grief

PTSD/PGD are both considered “stress-response symptoms” – part of a family of failure to adapt problems
PGD a brief history

PGD has elements that relate to both **Trauma** and **Separation**

- **Trauma** –
  - Leads to patterns of avoidant behaviours - numbness
  - **Problem**: Intrusive thoughts and memories

- **Separation** –
  - Patterns of over-involvement with the deceased and loss of self-identity
  - **Problem**: Yearning - can be defined as intrusive *wishes*
Theoretical models – attachment theory

- Attachment theory – the biological requirement for close and secure interpersonal relationships
- Attachment figures – proximity is sought and separation is resisted
- They provide the secure base from which competence, autonomy and exploration are facilitated
- Loss of an attachment figure is a massive disruption of the foundations for interpersonal relationships and causes disbelief, painful emotions, numbing, intrusive thoughts, inhibition of the exploratory system
Problems of bereavement

- Failure to *fully* integrate the loss into memory
- Unable to acknowledge the loss, revise life goals, regain capacity to explore, and make new social connections
- Result is a persistent inability to engage in life and relationships

The failure of the normal memory processing of the trauma is likely to be the basis of the connection between bereavement problems and PTSD
By 2009 the main research groups had achieved a consensus on a diagnostic framework for complications of grief


In Brayne, Carol. PLoS Medicine 6 (8): e1000121
Proposed diagnostic criteria
Separation distress
symptoms of PGD

The bereaved person experiences at least one of the following symptoms daily or to a distressing or disruptive degree:

• Intrusive thoughts related to the lost relationship

• Intense feelings of emotional pain, sorrow, or pangs of grief related to the lost relationship

• Yearning for the lost person
Cognitive, emotional, and behavioral symptoms of PGD

The bereaved person must experience 5 (or more) of the following symptoms daily or to a distressing / disruptive degree:

- Confusion about one's identity
  (eg role in life, diminished sense of self, feeling a part of oneself has died)
- Difficulty accepting the loss
- Avoidance of reminders of the reality of the loss
- Inability to trust others since the loss
- Bitterness or anger related to the loss
- Difficulty moving on with life (eg making new friends, pursuing interests)
- Numbness (absence of emotion) since the loss
- Feeling that life is unfulfilling, empty, and meaningless since the loss
- Feeling stunned, dazed, or shocked by the loss
Other criteria

Impairment

The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (e.g., domestic responsibilities).

Duration

Duration at least six months from the onset of separation distress
The criteria for PGD have now been extensively validated, including for…

- Different cultures
- Various kinship relationships to the deceased
- Different causes of death and settings of care
PGD – a brief history

The subset of bereaved people who meet the criteria for PGD appear to respond to specific treatments, especially:

- Interpersonal CBT-based psychotherapy
- Exposure-based therapy – based on treatments for PTSD
- Evidence also supports online delivery of specific PGD interventions
Medicalisation of normal grief – high risk of false positives

Bereavement PLUS depression?
Or bereavement = depression?

A continuum of symptomatology or a distinctive condition?

One bereavement disorder or one of many?

Some community consternation occurred as well…
PGD – a brief history

And so when the moment finally arrived …

PGD was **NOT** included in the DSM 5.

Instead, a new, modified category, “*Persistent Complex Bereavement-Related Disorder*”

- Placed in an appendix with recommendation for further research
- Symptom duration required for a diagnosis increased to 12 months, with continuous symptoms
DSM 5 – the reaction

DSM 5 Controversy #3
Critique of DSM 5

Under sustained challenge from *two* directions

- From the some of the psychiatric establishment (NIMH) – pushing for a new pathophysiologically-based disease framework ~ the RDOC

- From some of the psychological establishment, challenging perceived overmedicalisation and “diagnostic creep” – and fiercely disputing the view that all mental disorders result from biological dysfunction
Critique of DSM5

Statement by the US National Institute of Mental Health, just prior to release of DSM 5…

“While DSM has been described as a “Bible” for the field it is, at best, a dictionary, creating a set of labels and defining each. The strength of each of the editions of DSM has been “reliability” – each edition has ensured that clinicians use the same terms in the same ways. The weakness is its lack of validity. Unlike our definitions of ischemic heart disease, lymphoma, or AIDS, the DSM diagnoses are based on a consensus about clusters of clinical symptoms, not any objective laboratory measure. In the rest of medicine, this would be equivalent to creating diagnostic systems based on the nature of chest pain or the quality of fever.”
Bereavement. Still an issue for the clinician.

“A clinician evaluating a bereaved person is at risk for both over-and under-diagnosis, either pathologizing a normal condition or neglecting to treat an impairing disorder.”

Bereavement. Still an issue.

Evidence about the natural history in palliative care confirms this problem in practice

At 6 months following a death in a palliative care inpatient unit:

Severe depression 15%  Complicated grief 40%

Risk assessment by staff at 1 month after bereavement:
For CG: sensitivity 55% - specificity 63%
For severe depression: sensitivity 27% - specificity 86%

Positive predictive value: 27% for depression, 23% for CG

The proportion who received bereavement services at 6 months
CG +ve 47% Depression +ve 64%

Risk factors - preloss

- Negativity / pessimism
  - A stable personality trait
  - Use of fundamentally different coping strategies
- Insecure attachment style
- Social supports
- Severity of life stressors – beyond the cancer diagnosis
- ?Age

Strong correlation between pre-loss symptomatology and post-loss
Natural history

Many unknowns …

- Prevalence of PGD syndrome in a palliative care population and its longer term sequelae
  → good longitudinal studies are needed

- Prevalence of related complications of grief eg PTSD and the specific risk factors for these

- The relationship between pre-loss symptoms and longer term outcomes

All somewhat complicated by flux in the diagnostic framework…
Management – the questions

- Prevention – is it possible?
  Yes there is *some* evidence for this – equivocal – using CBT-based preventive approaches

- Treatment – is it effective?
  Yes – treatment has both short and longterm benefits, which increase over time
  Exposure based therapies seem to be the most valuable – reinforcing the links to the trauma model for PGD
Treatments for PGD

- Exposure based therapy – derived from PTSD treatment
  - Imaginal and in vivo exposure
  - “Revisiting” the deceased loved one

- Some therapies also include a phase of cognitive restructuring
  - Focusing on dysfunctional thoughts eg guilt

- Online therapy
  - Self-confrontation using writing exercises
  - Ten weeks – ten assignments – email feedback from therapist within 24 hours of each assignment
PGD – exposure based therapy

- A *hard* treatment – but more effective than interpersonal therapy – which is helpful with the restoration phase but may not deal with the significantly impaired memory processing of the trauma component

- High attrition rates

- Better outcomes if concurrently treated with antidepressants
Where to next?

Can we regard bereavement distress of caregivers as a *palliative care outcome*?

This assumes that distress could be influenced by potentially modifiable events eg:
- Preparation for death
- Sense of control and decision-making
- Quality of end of life care
- Communication that is appropriate for a person in trauma

Can we develop interventions that affect peritraumatic stressors for individuals?

Eg. Routine offer of debriefing after death

Do we need to develop specific communication strategies that may be appropriate in the context of trauma?

Are there sentinel events that may have a higher association with trauma?
- Delirium – prolonged terminal phase – mode of death
Complicated grief …

… its complicated!

Not to be confined to a single syndrome or disorder.

PGD – only one element of the complications of grief?

Key message for the clinician

- Look at distress and function
- There are effective treatments for PGD, so refer
Acknowledgements

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The end.