

Working with the Bereaved

Practical Strategies for Individual & Group Work

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Disclosure

- Sue Morris receives royalties for two self-help books about grief published in the U.K.

Overview of the Workshop

- The nature of grief
- Risk factors for poor bereavement outcomes
- Different types of grief
 - Spouse-loss
 - Child-loss
 - Parent-loss
- Individual and group strategies based on CBT

My Role

- Director of Bereavement Services, Dana-Farber Cancer Institute since 2010
 - Department of Psychosocial Oncology & Palliative Care
 - Harvard Medical School Teaching Hospital
 - Outpatient academic medical center
 - Approximately, 2800 deaths of adult patients each year

My Role

- I developed the first institutional bereavement program at DFCI and also at Boston Children's
- Adopted an education, guidance and support model based on cognitive-behaviour therapy principles
- Completed my PsyD given lack of reciprocity between Australia and the USA

Introductions

- Who are you?
- What is your role?
- How much bereavement experience have you had?

My Approach

- I studied clinical psychology and adult mental health
 - Informed by cognitive-behaviour therapy model (CBT)
 - Interested in grief and loss in graduate school
- I learned very early on that I could not ‘fix’ a bereaved person’s problem
- My aim is to help the bereaved take control of their grief rather than letting their grief control them
- I conceptualize bereavement care as a preventative model of care and use a ‘tool-box’ approach

My Approach

- Two influential articles:

Kavanagh, D.J. (1990). Towards a cognitive-behavioural intervention for adult grief reactions. *British Journal of Psychiatry*, **157**, 373-383.

Holmes, TH. & Rahe, RH. (1967). The social readjustment rating scale. *Journal of Psychosomatic Research*, *11*, 213-218.

Prevention

A Cognitive Perspective

- A loss through death:
 - Is an adverse external event over which there is no control
 - Changes the bereaved's belief system about themselves and the world resulting in changes in their emotions and behaviour
- Cognitions play a central role in reconciling the experience and facilitating the process of adaptation
(Malkinson, 2007)

Exercise #1

- What aspects of working with bereaved clients do you find challenging?

Supporting the Bereaved

- Can be both extremely rewarding and challenging because:
 - Grief touches us all at some stage
 - It forces us to challenge the strongly held ‘fix it’ mentality of the medical profession and to face our own mortality
 - We often worry about ‘saying the right thing’
 - We need to approach the bereaved and not avoid, especially as initial support tends to be quickly withdrawn and replaced with an impatience for them to ‘return to normal’

Bereavement in Context

- Death of a loved one is believed to be the most powerful stressor in everyday life (Holmes & Rahe, 1967)
- Bereaved individuals are at increased risk of:
 - depression, suicide, cardiovascular problems, and substance abuse (Stroebe, et al. 2007)
- 10-20% bereaved estimated to experience suffering requiring professional intervention (Prigerson, 2004)

Bereavement in Context

- Oncology research indicates that:
 - bereaved family members of adult cancer patients who die in hospitals are more likely to suffer from PGD than bereaved family members of patients who die at home with hospice (Wright, et al 2010)
 - bereaved family members of cancer patients who die in the ICU are more likely to suffer from PTSD than bereaved family members of patients who die at home with hospice (Wright, et al 2010)

Grief at a Glance

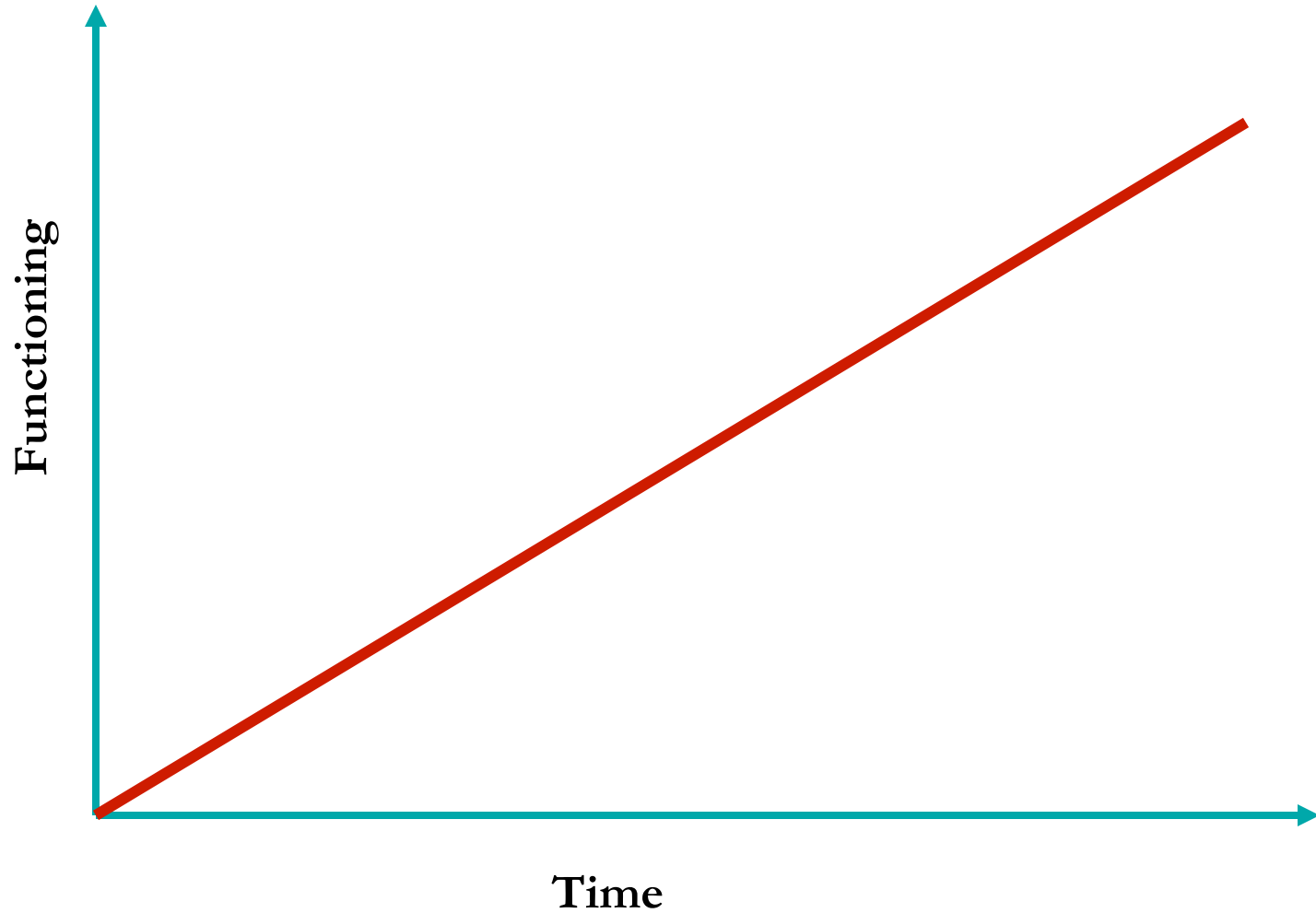
- Grief is defined as the *anguish* experienced after significant loss, usually the death of a loved one (APA, 2007)
- Intense physical and emotional reactions
 - often described as paralyzing
 - sense of being on automatic pilot in first weeks to months
- Characterized by a deep sadness and an intense *yearning* to be with their loved one again
- Grief is a normal response to loss – it's not an illness with a prescribed cure
- One of the hardest things for bereaved individuals is 'not knowing' what to expect

Understanding Grief

- Grief occurs within the context of our society:
 - technology driven
 - fast paced
 - task-focused
 - sense of control
 - “fix-it” mentality

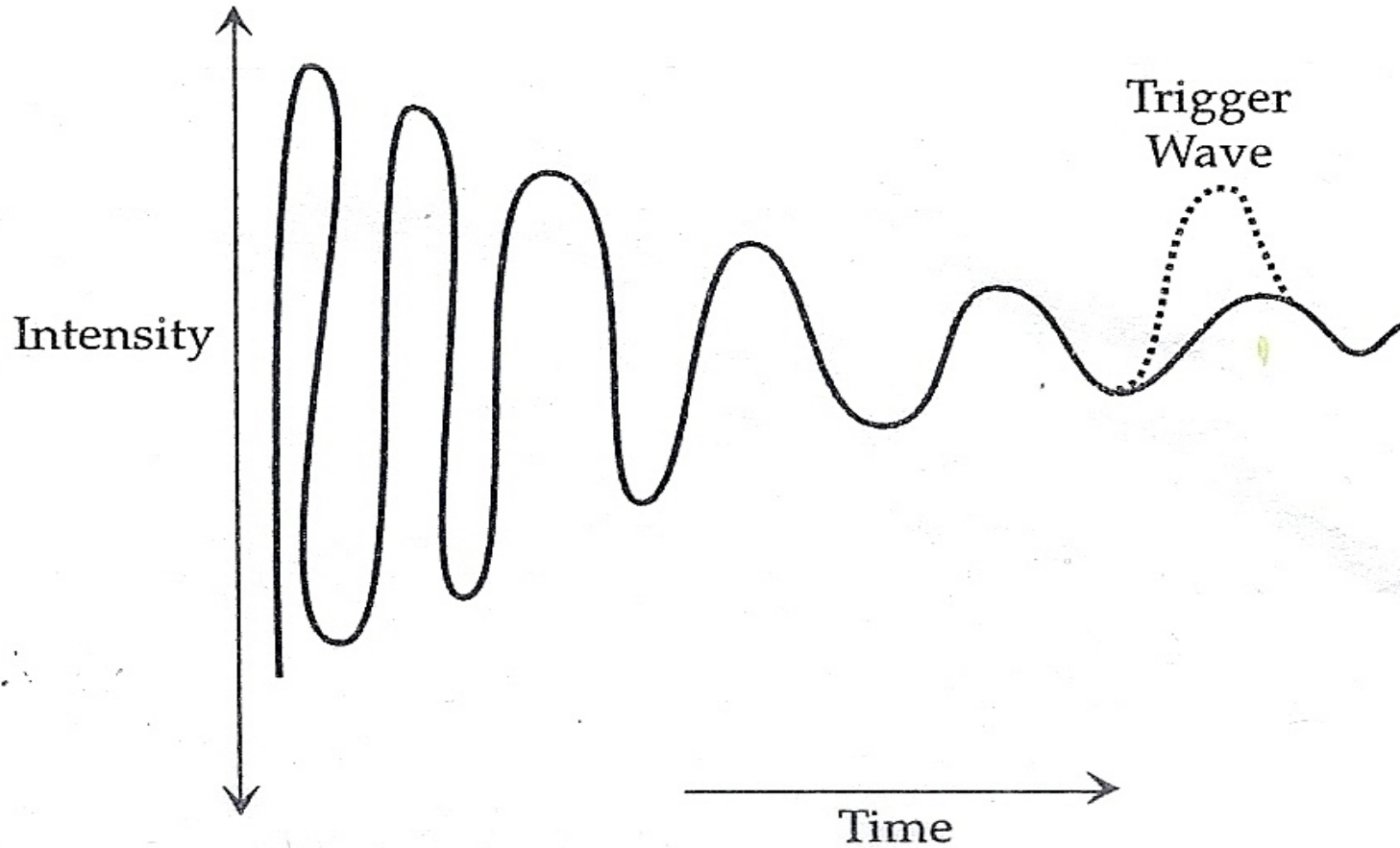
I thought I'd be better by now

Expectations of Progress

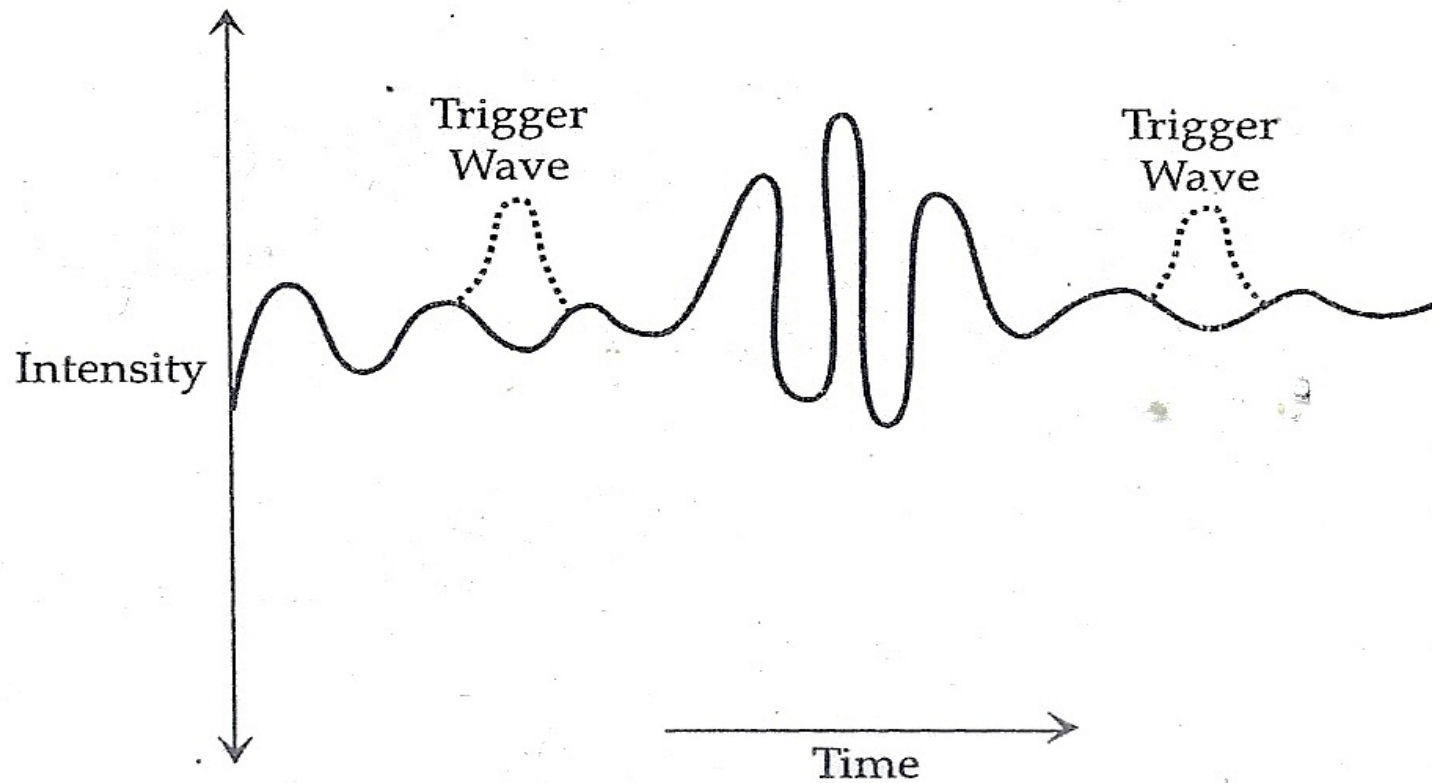


The Wave of Grief

Strategy to Promote Realistic Expectations of Progress



The Wave of Grief



Exercise #2: Understanding Grief

- Hand-writing exercise
 - Used in Session 2 of bereavement support groups
 - Adapted from *Six Simple Weeks*, Cole & Johnson (2001)

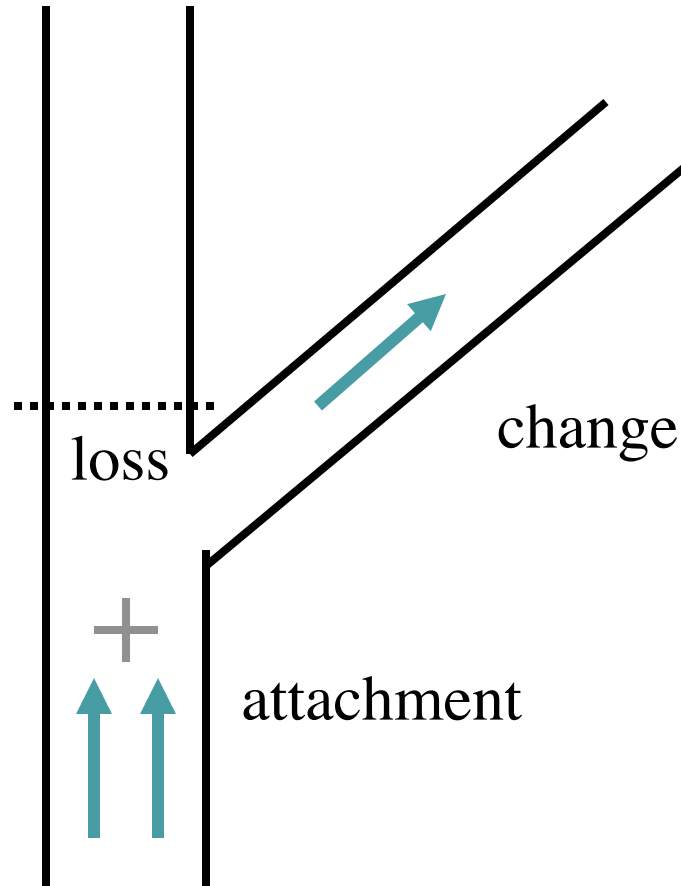
Central Psychological Factors

- Attachment
 - especially important in the death of a child
- Loss
 - many losses including practical roles to hopes and dreams
- Change
 - the more change, the greater the adjustment
- Control
 - lack of regarding the death itself and the grieving process
- Expectations
 - larger the gap between expectations and reality, the greater the adjustment

CHANGE

ISOLATION

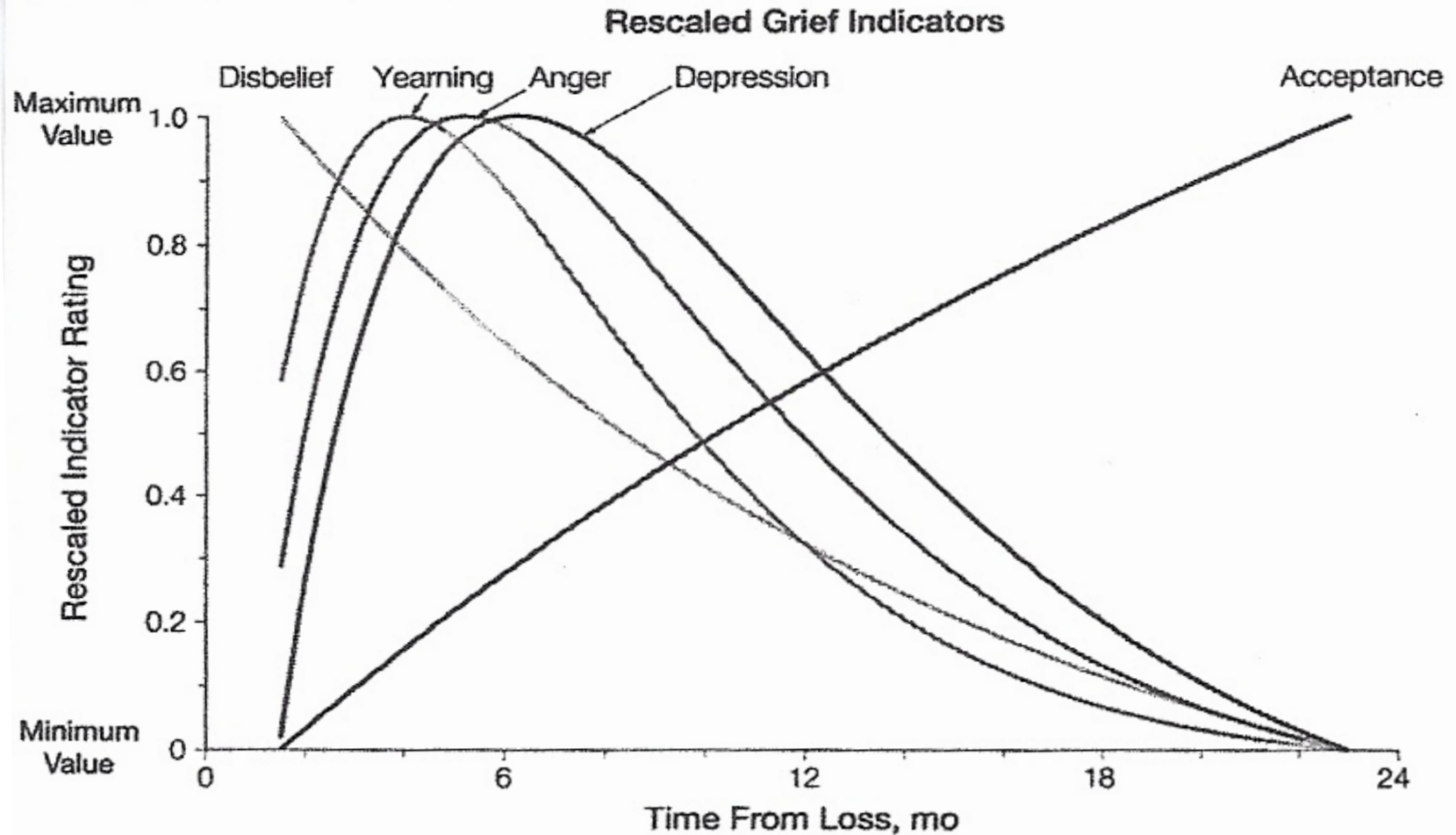
Navigating a Different Path



Normal Bereavement

- Intense emotions even though considered ‘normal’
 - Yearning for the deceased
 - Period of adjustment
 - Wave-like pattern
 - Intensity slowly subsides usually by six months with triggers that result in an intensification of emotion *
- * Research based largely on spousal loss

Maciejewski et al (2007) *JAMA*



Prolonged Grief Disorder

- Characterized by yearning and at least 5 out of 9 disabling symptoms including: difficulty accepting the loss, numbness, and avoidance of reminders of the reality of the loss
- Clinical impairment in social and occupational functioning
- Diagnosis not made until 6 months post-death (ICD) though PGD did not make DSM-5 (Prigerson, et al 2009)
- New category for further study in DSM-5 is ‘Persistent Complex Bereavement Disorder’

Major Depression

- Characterized by depressed mood and loss of interest, feelings of worthlessness, guilt, and hopelessness, whereas in bereavement focus is more on the loss
- Symptoms cause clinically significant distress or impairment in functioning
- DSM-5 – removal of the ‘bereavement exclusion’ where previously, clinicians were advised to refrain from diagnosing major depression with the first two months following the death of a loved one

Risk Factors

- ???

Risk Factors for Poor Bereavement Outcome

- Hx of psychiatric disorders
- Hx of childhood separation anxiety
- Lack of or poor social support
- Hx of abuse or neglect in childhood
- Concurrent stresses
- Previous losses
- High initial distress
- Lack of preparation for death
- Unexpected Dx and unanticipated death
- Death of a child
- Highly dependent relationship with the deceased
- Conflict with the deceased/unresolved issues
- Witnessing a difficult death

Exercise #3

- What does a grieving person need?
 - Think about someone whose loved one has recently died
 - What is it like to sit with them?
 - What do you think might help them?

What does a Grieving Person Need?

- To have the death and their loss acknowledged
- To be able to tell their story over and over
- To express their thoughts and feelings
- To try to make sense of what has happened
- To build a new life without the deceased physically present

The Experience of Grief

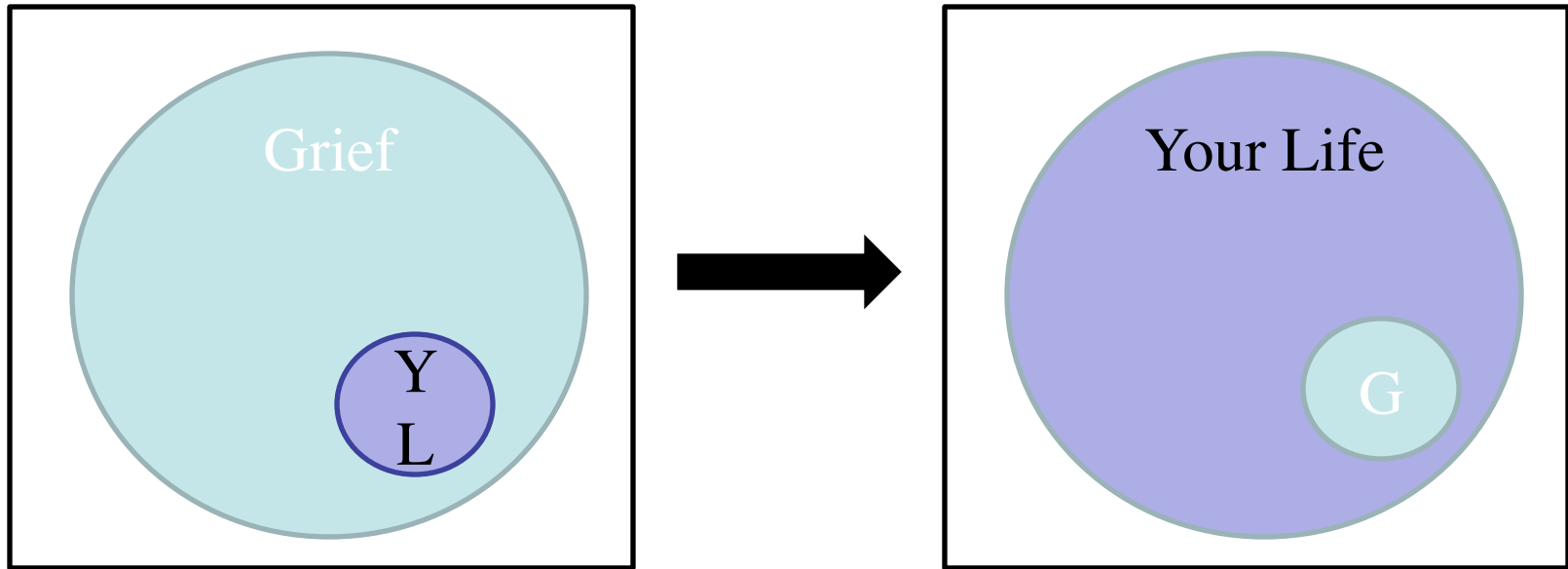
- Spouse-loss
- Janet's story – DVD

How to Help the Bereaved?

- Overwhelmed
- Little control
- Uncertain about their experience
- Unrealistic expectations
- Conflicting advice

- What is our role?

Aim to Increase Sense of Control



Cognitive Behaviour Therapy Framework

- The way we think, affects the way we feel and behave
- Importance of our expectations – how we think things *will* be
- If our expectations don't match reality, a discrepancy or gap exists
- The larger the gap, the greater the adjustment that needs to be made on the part of the bereaved

CBT Approach to Help the Bereaved

- Education, guidance and support model (Morris & Block, 2015)
- Information about grief and what to expect
- Strategies to increase their sense of well-being
 - Routine
 - Increase pleasant events
 - Social connections
- Strategies to increase their sense of control
 - Planning for ‘firsts’
 - Decision-making strategies
 - Challenging unhelpful thinking
 - Graded exposure to difficult situations

Barriers to Healthy Grieving

- Lack of acknowledgement of death
- Disenfranchised grief
- Distressing feelings – guilt, regret, anger
- Difficult memories associated with witnessing death
- Decisional regret
- Unanswered questions – ‘not knowing’
- Unresolved differences or conflict
- Avoiding certain places or people
- Having difficulty making decisions

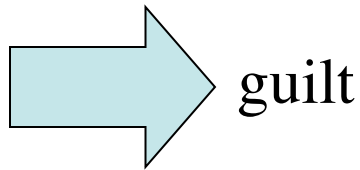
Goal of CBT with the Bereaved

- To help the bereaved reconcile the death of their loved one in some way so that they can begin to take control of their life again
- Focus is on their cognitions, emotions and behaviour concerning the death of their loved one **and** building a new life for themselves

CBT Framework and Grief

- Need to understand the bereaved individual's:
 - cognitions – their self talk, their expectations
 - emotions – guilt, anger, sadness, anxiety, regret
 - behaviour – what they are doing, avoiding?

E.g. *I should have been there when she died*



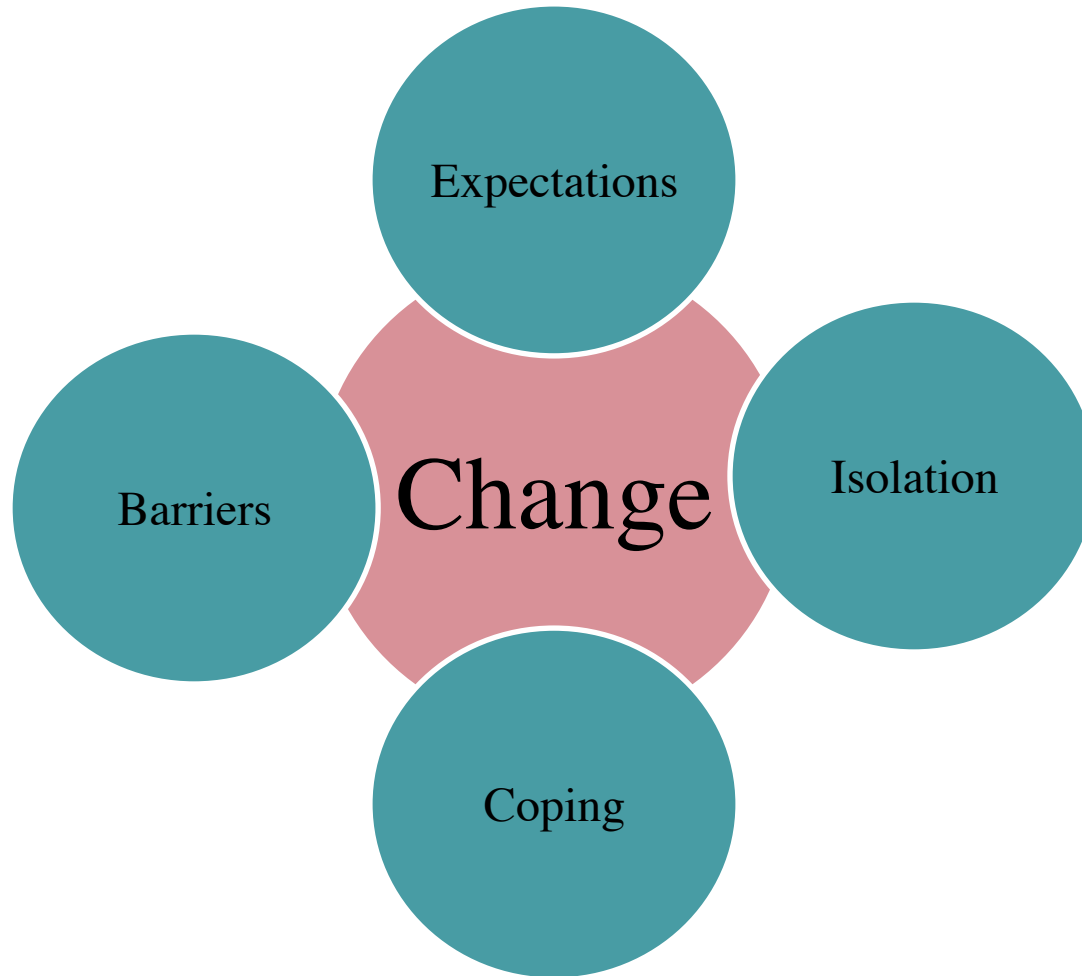
CBT Framework and Grief

- Identify the gap:
 - How big is the gap between what they expected and what actually happened?
 - The larger the gap – the more adjustment that needs to be made
 - Implement strategies to reduce the gap
- Assess how much their life will change

First Meeting

- Encourage them to tell their story
 - important intervention
 - regrets, things left unsaid
- Gain an understanding, related to both the death and their progress, of their:
 - cognitions e.g. *I should be stronger; I won't be able to cope*
 - emotions e.g. *anger, guilt*
 - behaviour e.g. *avoidance, alcohol use*
- Identify barriers and gaps
 - amount of change in their life
 - discrepancy between expectations and reality

First Meeting



First Meeting

- Provide information

- to normalize their experience
- set realistic expectations about progress e.g. wave
- emphasize importance of *routine*, *self-care* and *social connections*
- recommend check-in with doctor
- screen for suicidal ideation
- organization and/or community-based resources

CBT Strategies to Help the Bereaved

1. Tell their story
2. Understand their experience
3. Develop realistic expectations about ‘progress’
4. Permission to grieve
5. Increase sense of control over their grief
6. Increase sense of well-being
7. Challenge unhelpful thoughts
8. Tackle difficult or new situations
9. Maintaining a connection

CBT Strategies

Second or Subsequent Meetings

- Invite them to bring in photos or mementos
- Let them tell more of their story and reflect on first session
- Introduce strategies to increase their sense of control
- Suggest ways that they might develop a connection based on memory and legacy
 - use technology – DVDs, photo books, playlists
 - asking others for stories of their loved one
 - create new traditions – special Holidays, birthdays

Case Study - Jack

- Challenging unhelpful thoughts that were keeping him stuck

Jack's Story

- Peggy, Jack's wife of 44 years was diagnosed with pancreatic cancer. Peggy had wanted to die at home with hospice but she had to be admitted to hospital where she died. See handout.
 - A (event) – Peggy died in the hospital
 - B (unhelpful thought) – *I let Peggy down. I failed her. I feel so guilty that I couldn't care for her at home and let her die there in peace.*
 - C (feelings/behaviour) – guilt/withdrawing

Challenging Unhelpful Thoughts

- Jack began to challenge his thinking using Qns 1, 2 & 5 and eventually was able to tell himself:

There's nothing to suggest that I failed Peggy. I tried my best but the disease got the better of us in the end. I wish things could have been different, but I know I did all I could. Peggy would say that going to the hospital was the best decision at the time given the limited choices we had.

The Experience of Grief

- Child-loss
- Mark's story – DVD

Grief and Children

- Like adults, children grieve
- Great website www.dougy.org
- The way they express their grief will depend on:
 - The nature of the relationship the child had with the deceased person
 - The child's age and developmental level

Suggestions to Help Children

- Use language that child can understand
 - avoid terms such as ‘asleep’, ‘lost’ as they are confusing
- Share family’s beliefs with children in ways they can understand
- Ease child’s fears
- Include children in plans for special days
- Speak to their school teachers and counselor
- Seek community support – counseling, peer support groups, grief camps

Suggestions to Help Children

- Creative artwork; memory photo books
- Journals
- Encourage them to participate in creating new family rituals and traditions
- Find ways to honour and remember the deceased as time goes on
- Anticipate significant dates at school and in years to come

Grief and Adult Children

- Missed opportunities
 - Now and in future e.g. weddings, grandchildren, graduations
- Role reversal with other parent
- Planning for firsts
 - especially in years to come
- Coping with new relationships that surviving parent might have

Grief and Adult Children

- Depending on age of adult child, grief can be very isolating, especially if peers have not yet lost parents
- Support groups can be beneficial as tackle isolation and carves out grief time
- Encourage sharing of stories - invite others to share stories of parent; focus on legacy – see handout

My Conclusions

- Bereavement care is a preventative model of care
- Assess the “change” and “isolation” factors
- CBT strategies, drawing on the depression and anxiety literature, can help bereaved individuals reconcile the death and build a new life for themselves, utilizing a “tool-box” approach.

Questions & Discussion

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