Bereavement & Loss

Principles & Practice of End of Life Care

Agreement for our time together

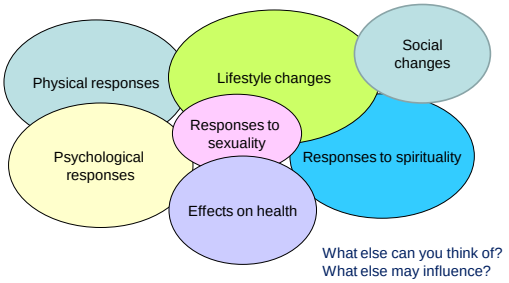
- Confidentiality
- Respect Difference
- Emotive subject/self-care

Learning outcomes

- Comprehend the various dimensions of loss affecting patients, carers & families.
- Recognise the process of anticipatory grief.
- Have increased knowledge of contemporary bereavement theory.
- Develop a critical awareness of indicators of vulnerability or coping in bereavement.
- Increase confidence in supporting people in bereavement & when to refer on.
- Appreciate impact on health professionals of working with loss, death & grief.

Any questions?

Impact of facing end of life for patient & family



What else can you think of?
What else may influence?

Anticipatory Grief

Grief occurring prior to the death

- Serious illness & imminent death gives rise to a complex range of emotional experiences for the dying person, their family & friends.
- During the period of anticipation family often begin mourning & the patient may grieve for their own losses.
- Therefore attention to this is necessary to the successful development & provision of palliative/family focussed support and care.

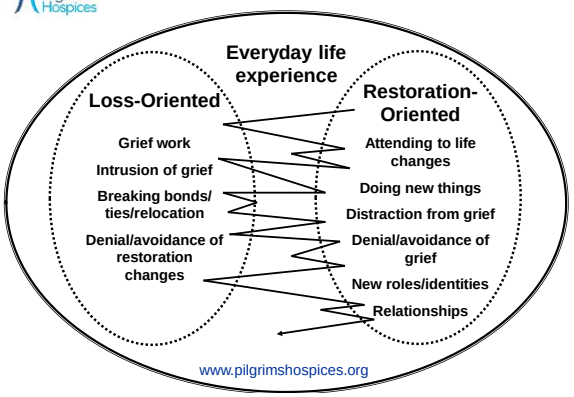
Could support be offered pre - bereavement?

Pre - bereavement support

- Those identified as vulnerable pre bereavement to be offered early referral to appropriate member of MDT
- Early referral can improve bereavement outcome

DUAL PROCESS MODEL

(Stroebe & Schut 2001)



Dual Process Model

Stroebe & Schut (2001)

- Model of coping
- Meaningful for professionals and bereaved alike
- Oscillation (moving back & forth) between confronting grief and dealing with/adjusting to life without the deceased
- Complication identified when someone stuck in one orientation
- Universal model – applicable to culturally varied patterns

Check out - Handbook of Bereavement Research: Consequences, Coping and Care (2001) Stroebe, Stroebe, Hansson, Schutt)

Range of Response to Loss

RRL Model

Adapted from Machin (2010)

Aim to help turn vulnerability towards finding resilience.

Continuing Bonds Theory

Silverman & Klass (1996)

Death ends a life not a relationship

- The bereaved remain psychologically and emotionally connected to the deceased
- The connection developing and changing over time.
- Relationships continuing
- Connections provide solace, comfort and support easing the transition from past to future.

Bereavement assessment

- Grief is natural response to loss
- Many people find inner resources & support from family & close friends
- May seek help to just to check their reactions are normal

However

- Some people are more vulnerable & have greater difficulty in adjusting to life without the person who has died
- May be at increased risk of physical & mental health problems
- Need to consider both indicators of coping/resilience & indicators of risk/vulnerability

What are the risks to health?

- Can be increased risk of physical & mental illness
- Possible increase in heart problems & immune system
- Studies have shown link to increase in mortality rates
- Exacerbation of existing illness
- Increase in smoking, alcohol & drugs
- Increase in use of health services
- Depression

What Factors can Influence Bereavement?

- Events & circumstances leading to death
- Meaning of relationship with deceased
- Personal vulnerability or coping skills
- Previous losses
- Concurrent life events
- Health history (alcohol or drug abuse)
- Availability of social support & financial resources

What guidance is available?

NICE – Quality statement 14

- People closely affected by a death are communicated with in a sensitive way & are offered immediate & ongoing bereavement, emotional & spiritual support appropriate to their needs & preferences.

(NICE 2011 modified Oct 2013)

How do we do this?

Levels of Bereavement Support

(NICE Guidance 2004)

Most people manage without professional help Information about bereavement & support to be offered	1
Some people may require more support May be provided by bereavement volunteers, self help, faith, social groups	2
Minority of people will require specialist interventions May be provided by mental health, specialist counselling & bereavement services	3

How do we measure?

What do you currently do?

Back to NICE …..

Outcome

- People closely affected by a death feel that information and support was available to them around the time of death and afterwards, which was appropriate for them and offered at the right time.

(NICE 2011 modified Oct 2013)

VOICES Survey (2014)

- National survey of bereaved people (VOICES) *(ONS 2015)*
- 3 out of 4 rate overall quality of EoLC as outstanding, excellent or good
- However 1 out of 10 rated poor
- Also revealed wide differences
  - Some identifying lack of support around feeding
  - Some felt not given opportunity to ask questions
  - Interestingly 7 out of 10 felt hospital was right place to die (despite only 3% stating wish to die in hospital)
- Can be used as a baseline to measure progress

What about us?

Effects of working with loss can lead to accumulative grief

Effects of Working with Loss

When our experience of loss & bereavement has not been recognised, this can lead to:

- Physical exhaustion – 'Burnout'
- Progressive loss of energy & purpose
- Insensitivity and lack of concern for colleagues & patients
- Negative self concepts
- Loss of self esteem
- Dissatisfaction with job

How do we take care of ourselves?
Will leave this for Martyn!

A few tips (adapted from Machin 2010)

Ensure best practice & outcome in EoLC by:

- Unconditional respect for people (empathy)
- Create safe environment
- Careful listening & sensitivity
- Develop communication skills
- Allow for restoration & reflection
  - For the patient this may include complementary therapy
  - For us, this may mean good opportunities for debriefing & supervision

'Space & safety will enhance the ability to think, decide & act.'

References & Further Reading

- Machin, L. (2010). Loss responses at the end of life: A conceptual reflection. *End of Life Care.* Vol 4(1):46-52.
- Link to Keele University & research by Linda Machin http://www.keele.ac.uk/mappinggrief/theoriesofgrief/
- NICE – Quality statement 14 - care after death bereavement support: https://www.nice.org.uk/guidance/qs13/chapter/quality-statement-14-care-after-death-bereavement-support?print=true
- Payne, Horn & Relf (1999) *Loss & Bereavement.* Buckingham. Open University Press.
- Relf, M., Machin, L. and Archer, N. (2010) *Guidance for bereavement needs assessment in palliative Care.* Help the Hospices, London. (www.helpthehospices.org.uk)

"For the majority of people, grief although psychologically painful and distressing, is a normal process reflecting both the strengths and values of human attachments and the capacity to adapt to loss and adversity"

Raphael et al (2002)