



It's your life,
and that's what matters.

Understanding the current bereavement landscape: an update

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June 2018

Contextualising the session

- Bereavement is an integral aspect of palliative care
- We bring both a personal and professional aspect to our understanding of grief and bereavement which are entwined.
- Loss, change and the associated grief are central to life and as such are not illnesses or symptoms to be cured.
- Grief can be activated by any loss and change not just bereavement
- We have the capacity not to be crushed by loss and change – resilience is part of our human heritage

The changing landscape



Aims for the session

- Summarise the bereavement research evidence and policy
- Briefly give an overview of different grief perspective, including complicated grief
- Introduce the Range of Response to Loss and consider it's impact for practice
- Share some of the current developments which are being explored and researched

• Much of this work is drawn from ideas formulated and researched by Dr Linda Machin (2014) Working with loss and grief a theoretical and practical approach – acknowledgement and thanks for agreement to share this work

Policy

- NICE Guidance for Supportive and Palliative Care (2004)*: assessment of need
- When a Patient Dies (2005), England & Wales
- Living & Dying Well (2008), Scotland
- N. Ireland Strategy for Bereavement Care (2009)
- End of Life Care Strategy (2009)
- Ambitions for palliative and end of life care: a national framework for local action 2015-2020
 - Ambition 6
- A guide to commissioning bereavement services in England (2017) <http://nationalbereavementalliance.org.uk/wp-content/uploads/2017/07/A-guide-to-commissioning-bereavement-services-in-England-Web.pdf>

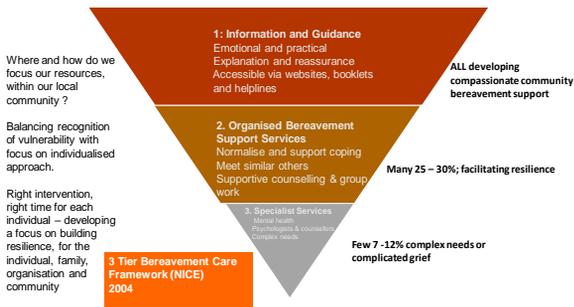
*revision currently being undertaken will not include the bereavement framework, National Bereavement Alliance (2017) published amended version based upon service data.

Why assess need?

- Belief that offering support proactively to those who are more vulnerable can minimise health risks (NICE 2004)
- Helps us to make more objective decisions and make best use of resources
 - No measurable benefits for universal interventions
- To clarify type of support needed – increasing evidence that offering therapy to those who are resilient may be harmful (Schut and Stroebe 2005).
- Assessment – by talking to people about their experiences - can be a helpful intervention
- EAPC (2015) bereavement taskforce – Delphi study 25% used formal assessment framework / tool

Summary of current research evidence

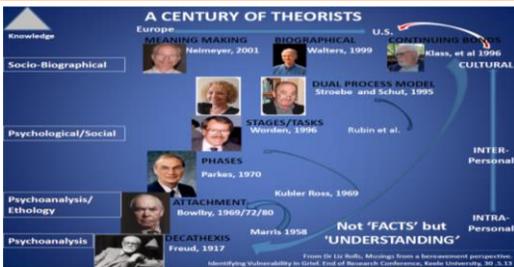
- Outreach to all not advised
 - To clarify type of support needed – increasing evidence that offering therapy to those who are resilient may be harmful (Schut and Stroebe 2005).
- Information & sign-posting to facilitate self-referral
- Offer support to those where indicators of lack of resources to manage grief
 - Belief that offering support proactively to those who are more vulnerable can minimise health risks (NICE 2004)
- Recognise complicated grief & offer intervention
- High-risk people show modest benefits
- Self-referrers show good benefit
- Those clearly symptomatic show good benefit
- Challenge; Developing a public health approach, enabling peer support and ensuring community capacity is built



Models of grief

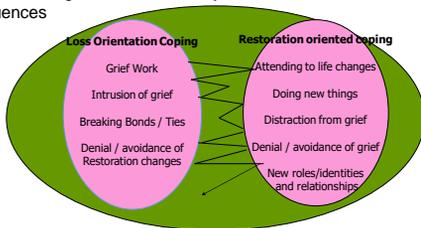
- Kubler-Ross – Stages
- Parkes - Phases
- Klass et al – Continuing Bonds
- Stroebe & Schut – Dual Process Model
- Martin & Doka – Intuitive & Instrumental
- Machin – Range of response to loss

A century of theorists



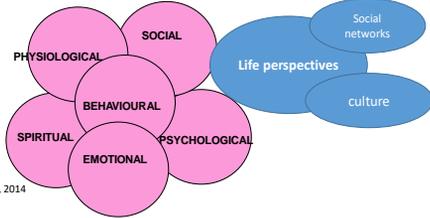
Dual Process Model: Stroebe and Schut 1995

To face **or** avoid grief all the time may have serious mental health consequences



Bereavement support isn't just about the psychological and emotional impact

How do you ensure services are meeting a variety of need?



Adapted from Machin, 2014

Remember it's not just an individual who is impacted: cultural and personal context

An intra and inter personal experience



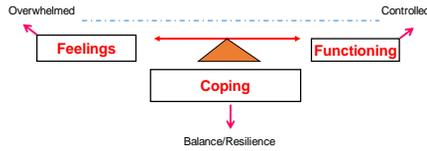
Adapted from Machin, 2014

The Range of Response to Loss model as a new and evolving theory for practice (Machin, 2009; 2014)

We bring individual differences to challenging life events but there are patterns in human response to loss

The Range of Response to Loss model developed as a framework for capturing individual difference and patterns

The Range of Response to Loss model (Machin 2001)



Reactions and responses to grief (Machin 2014)

Primary grief reactions

- Feelings: sadness, despair, guilt, anger etc.
- Sense of: disbelief, powerlessness, injustice etc.
- Thoughts: confused, contradictory, rumination etc.
- Behaviour: passive, over-active etc.

Coping responses

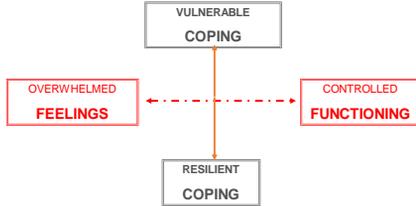
- regulating emotion
- adjusting to changed relationships
- adjusting to changed social realities
- making sense of the loss etc.

Conceptual comparisons between the RRL model and other key theories of grief (Machin, 2009)

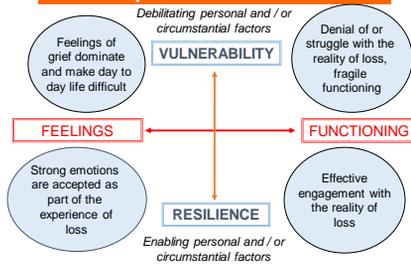
RRL (Machin 2001)	Feelings -Overwhelmed	(Resilient) Coping	Functioning - controlled
Attachment theory (Ainsworth et al 1978)	Anxious / ambivalent attachment	Secure attachment	Avoidant attachment
Stress theory (Horowitz 1997)	Intrusion		Avoidance
Dual Process Model (Stroebe and Schut 1999)	Loss orientation	Oscillation	Restoration orientation
Personality related (Martin and Doka 2000)	Intuitive grief – expressed emotionally	Blended grief – expressed emotionally and cognitively	Instrumental grief – expressed cognitively

The Range of Response to Loss model (Machin, 2009 2014)

Two dimensional model:
core grief reactions & coping responses



The RRL model as a template for practice (Machin 2009; 2014)



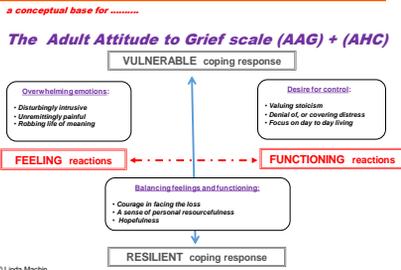
Vulnerable response (Machin, 2014)

- Avoids facing issues of impending loss
- Does not demonstrate use of inner and external resources – totally overwhelmed, no control
- Cannot acknowledge the current emotional and social impact of the illness – lacks insight
- Does not feel hopeful that strength or meaning may come.

Listening to the story of grief (Machin, 2009)

Narrative process	Range of Response to Loss		
	Overwhelmed	Resilient	Controlled
Tell me about events?	Detailed story, emphasising awfulness	Coherent story including positive & negative aspects	Minimum detail with emphasis on facts
Impact on you?	Grief described as engulfing – self as victim	Loss seen in wider context of personal resourcefulness	Desire for control & bravery dominate & pain minimised
How are you managing?	Lack of hopefulness & sense of meaninglessness	Hopefulness combined with sense of meaning & personal strength	Diversion from pain & sense of meaning found in courage & fortitude

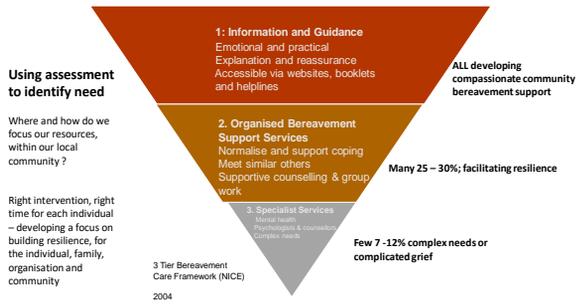
The Range of Response to Loss model



The Adult Attitude to Grief as a tool for practice

- 2. For me, it is difficult to switch off thoughts about the person I have lost
- 5. I feel that I will always carry the pain of grief with me
- 7. Life has less meaning for me after this loss
- 4. I believe that I must be brave in the face of loss
- 6. For me, it is important to keep my grief under control
- 8. I think it's best just to get on with life after this loss
- 1. I feel able to face the pain which comes with loss
- 3. I feel very aware of my inner strength when faced with grief
- 9. It may not always feel like it but I do believe I will come through this experience of grief

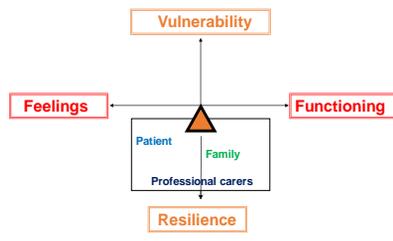
- Assessment/review/outcome – qualitative interpretation of the scores alongside the qualitative comments
- The AAG as an intervention in prompting the 'story' of loss
- Using the AAG assessment as a guide to intervention
- Reflective exploration of responses to the scale for self, as practitioner, and in supervision



Matching interventions to need



The RRL – what does it mean for the family context? (Machin, 2014)



Prolonged grief disorder (DSM-v)

A. Event: bereavement

B. Core features – separation distress

- Unbidden memories, intrusive thoughts
 - Intense emotional pain, sorrow
 - Distressingly strong yearning, longing
- At least one experienced several times daily or to a distressing or disruptive degree

Prolonged grief disorder (2)

c. Cognitive, emotional & behavioural symptoms (5 or more)

- Empty, confused, feeling that part of self died
- Trouble accepting loss as real
- Avoidance of reminders
- Loss of trust in others
- Extreme bitterness, anger
- Extreme difficulty moving on with life
- Pervasive numbness, detachment or withdrawal
- Life empty, bleak
- Stunned, dazed, shocked

Prolonged grief disorder (3)

- D. Duration (lasting at least 6 months from onset)
- E. Impaired social, occupational or other areas of functioning
- F. Exclusion – not due to effects of a substance or general medical condition
- G. Not accounted for by PTSD, generalized anxiety disorder or depressive disorder

Prigerson H, Horowitz, M, Jacobs, Parkes et al (2009)

Using the RRL framework and AAG in practice

- Assessment
 - Telephone
 - 1:1
 - Family
- As a tool to frame initial conversations
- As a means of monitoring and exploring change (outcome)

References

- Department of Health (2008) End of Life Care Strategy. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/146431/End_of_life_strategy.pdf (accessed 18 June 2018).
- Guddin, MB., Murphy, L., Keegan, O., Monroe, B., Reverte MALI, Benkel, I. (2015) Bereavement care provision in Europe: a survey by the EAPC bereavement care taskforce. *European Journal of Palliative Care* 22(5)
- Machin, L. (2009) *Working with loss and grief: a theoretical and practical approach*. London: Sage.
- Machin, L. (2014) *Working with loss and grief: a theoretical and practical approach (2nd edition)*. London: Sage.
- National Council for Palliative Care (2016) Each Community is Prepared to Help: Guidance on Ambition Six. Available at: http://www.ncpc.org.uk/sites/default/files/1448%20ncpc_strand_6_ART_NC.pdf (accessed 8 June 2018).
- National End of Life Care Programme (2011) When a person dies. Available at: <http://bsauk.org/uploads/834766631.pdf> (accessed 8 June 2018).
- National Institute for Clinical Excellence (2004) Supportive and Palliative Care for Adults with Cancer. Available at: <https://www.nice.org.uk/guidance/CS64> (accessed 8 June 2018)
- Prigerson, HG., Horowitz, M., Jacobs, SC, ParkesCM., Asian, M. Goodwin, K et al (2009) Prolonged grief disorder: psychometric validation of criteria proposed for DSM-V and ICD-11 sourced from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2676163/> *Journal of General Internal Medicine* 24(10):1012-1017
- Sim, J. Machin, L. and Bartlam, B. (2013) Identifying vulnerability in grief: psychometric properties of the adult attitude to grief scale *Quality of Life Research*
