

# Meaning Reconstruction and Chronic Illness: A practice discussion



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*Leah B.Lewis, PhD.*

# Overview

- ❖ Introduction
- ❖ Chronic illness and grief
- ❖ Chronic illness and identity
- ❖ Quick review grief models with chronic illness
- ❖ Meaning Reconstruction in grief counselling and therapy
- ❖ Meaning Reconstruction and chronic illness
- ❖ Example - End Stage Renal Disease, context and symptoms
- ❖ Some techniques

Check in

Who is in the room?

# Who am I?

- ❖ Counsellor with graduate training in counselling psychology and arts therapies
- ❖ Doctoral studies: meaning reconstruction and end stage renal disease
- ❖ Informed by personal experience
- ❖ Currently teaching in a counselling masters program
- ❖ Private practice, including chronic illness

# Chronic Illness

**Chronic diseases** are long-term medical **conditions** that are generally progressive. Some examples of **chronic diseases** include heart **disease**, End Stage Renal Disease, diabetes, HIV, Multiple Sclerosis, and **chronic** respiratory problems (e.g. COPD). At present, these are the major cause of disability and death globally.

# Chronic Illness and loss

- ❖ Physical
- ❖ Relational - modified
- ❖ Repeated loss cycles - physical, mental health
- ❖ Secondary loss - ie. comorbid conditions, fertility, job/career, freedom etc...
- ❖ Pain, medical procedure

# Chronic Illness and Identity (Charmaz)

- ❖ Life interruption
- ❖ Modification of life narrative - 'preferred person'
- ❖ Family and relationship - ie. caregiver experiences
- ❖ Mental health and social isolation
- ❖ Medical spaces

# Chronic Complex Illness

- ❖ Informed by social context and engagement
  - ❖ Context
  - ❖ Supports - access, relationship, family
  - ❖ Medical team
  - ❖ Medical procedure
  - ❖ Pain experience
  - ❖ Patient agency and role in care - Patient engagement and health outcomes.

# Chronic illness and complicated grief

- ❖ Medical procedure is repetitive, hospitalization
- ❖ Diagnostic change
- ❖ Health regression
- ❖ Pain experience
- ❖ Morbidity

# Meaning Reconstruction: Narrative approaches in grief therapy

- ❖ Quick review of grief models - stage based
  - ❖ Kubler-Ross
  - ❖ Bowlby - attachment

# Kubler-Ross 5 phase model

- ❖ Denial: Initial shock of loss
- ❖ Anger: Aggressive reaction
- ❖ Bargaining: The 'if only' phase
- ❖ Depression
- ❖ Acceptance: Full integration
- ❖ Note: We move back and forth between and through these states. Some occur simultaneously.

# Bowlby's attachment model

- ❖ Discussed grief and part of attachment psychology - the phenomenon by which a human attaches to another thereby experiencing security and comfort within the relationship - via its reversal, or 'detachment'.
  - ❖ Numbness
  - ❖ Yearning or searching
  - ❖ Disorganization and despair
  - ❖ Reorganization

# Some questions re stage based models

- ❖ Have evolved somewhat, but generally fail to capture the day to day of grief
- ❖ Limiting to humans' inherent need to apply meaning to experience
- ❖ Focusing on negative aspects and 'getting through' them - client is passive
- ❖ Grief is not linear, nor does it follow a strict path
- ❖ Not universally accessible - ie. cultured experiences of grief
- ❖ Applied best as part of integrative practice

# Newer models?

## Meaning making and loss

- ❖ Dual Process Model
- ❖ Meaning Reconstruction Model
- ❖ Both are dynamic models, not relying on stages or phases, focusing on integrating loss - instead therapy focuses on experiences and relationships and how these inform the grief experience

# Dual Process Model (Stroebe and Schut)

- ❖ Attempts to integrate pre existing concepts - ie. acknowledges that attachment concepts are present in grief processing.
- ❖ Critiques previous models as lacking identification of grief related stressors
- ❖ Defines grief as an 'oscillation' between...
  - ❖ Loss orientation
  - ❖ Restoration orientation

# Loss orientation

- ❖ Speaks to attempts to deal with elements of the loss itself
- ❖ Rumination - reviewing the experience of the loss itself, yearning, emotional response (crying), predominantly negative affect
- ❖ Expects that more positive affect integrates over time (humour, revisiting loving memory, feelings of gratitude etc.)
- ❖ A waxing and waning between avoiding and approaching (confronting) loss - in other words, we must engage with loss in order to process it fully
- ❖ Creates new meaning over time in relationship to loss experience

# Examples of loss orientation in chronic illness

- ❖ Acute illness, hospitalization, procedure
- ❖ Health loss - ie. transplant fails, diabetes-related amputation
- ❖ Health news - life span, co-morbid diagnosis
- ❖ 'Facing this next stage of my illness feels too hard to bear.'

# Restoration orientation

- ❖ Focuses on 'secondary' experiences of loss rather than the direct loss - shaping coping strategies
- ❖ Comes about as a result of the direct loss
- ❖ Example; a dialysis patient cannot attend a family reunion due to necessary treatments -
- ❖ 'I'm chronically ill in a society that demands health and fitness'.
- ❖ Includes a redefining or renegotiating how one engages with the world. May entail learning new skills.

# Restoration Orientation - examples in chronic illness

- ❖ Family/caregiver stress
- ❖ Career modification/attendance
- ❖ Travel and leisure

# Oscillation

- ❖ Central to the DPM is the two orientations are dynamic, oscillating back and forth as the loss is negotiated and integrated
- ❖ Individual will fluctuate between the two, experiencing acute feelings of loss along with avoiding acute feelings in favour of restoring new perceptions and behaviours

Loss orientation:  
direct experiences



Restoration  
Orientation:  
secondary experiences

# Cognitive elements of DPM

- ❖ Acknowledges the meanings and assumptions present in 'good' versus 'bad' adaptation
- ❖ The fluctuation between both orientations speaks to an confrontation/avoidance that occurs between positive and negative affect - fosters tolerance
- ❖ Requires a true visiting of both orientations in order to achieve full integration of loss. I.e. too much sadness becomes depressive or too much focus on positive elements of the relationship can lead to denial of loss and need for change

# Meaning Reconstruction Model

(Neimeyer)

- ❖ Postmodern understanding of grief and loss
- ❖ Meaning-driven model - ie. not based on stages
- ❖ Views grief and loss as cultured
- ❖ Grief processing is informed by
  - ❖ Context
  - ❖ Relationships
  - ❖ Engagement with grief experience
- ❖ Accommodation and Assimilation
- ❖ Coherence and Incoherence -

# Meaning-Reconstruction

- ❖ Constructivist - our experiences are grounded in our own context, 'truth' is subjective
- ❖ Narrative-driven - therapy is a storied process,
- ❖ Interpersonal - requires engagement, relationship is relevant
- ❖ Resists linear models of grief processing - passive
- ❖ Acknowledges that complex/traumatic grief is informed by ongoing incoherence - lack of sense making

# Meaning Reconstruction

- ❖ Human beings are inherently meaning-driven
- ❖ Meaning is derived and applied through experiences, relationships
- ❖ MR seeks to move from an incoherent dysregulating experience of loss to a coherent integration

# Assimilation

- ❖ Anticipated loss
- ❖ Not considered to be complicated or traumatic
- ❖ Loss integration makes sense over time, is coherent

# Accommodation

- ❖ Occurs when loss is more complex, or traumatic
- ❖ Loss experience difficult to make sense of, is incoherent
- ❖ Integration takes a long time, or never occurs
- ❖ Requires an intentional reconstruction of the meaning associated with the loss
- ❖ Requires repeated 'revisiting' of the narrative - reconstruction is often ongoing

## Chronic illness example: End Stage Renal Disease

- ❖ Failure of the kidneys to operate adequately enough to support human life
  - ❖ Regulate potassium, phosphate, lactate, calcium and other chemistries
  - ❖ Release of volume - Pee!
- ❖ Functioning less than 15%

# Treatments

- ❖ Dialysis
- ❖ Transplant - Usually lasts 10-15 years

# MH and ESRD

- ❖ QoL for ESRD Patients is one of the most impacted of all chronic conditions
- ❖ Higher rates of
  - ❖ depression
  - ❖ anxiety
- ❖ suicidal thinking
  - ❖ withdrawal
  - ❖ resistance
  - ❖ refusal

# Identity and ESRD

- ❖ Otherness - peripheral identity
- ❖ Social Isolation -
- ❖ Abandonment of the 'preferred person'
- ❖ Caregiver dynamic - vicarious experiences
- ❖ Pain -
- ❖ Body autonomy -

# ESRD: An ongoing grief

- ❖ Requires a repeated 'revisiting' - will never assimilate, fully integrate
  - ❖ Freedom, life movement
  - ❖ Procedure - body space is dictated, pain
  - ❖ Increased hospitalizations, support procedures (site maintenance, surgery)
- ❖ Intimacy and the body
- ❖ Long term complex chronic illness and development

# Other complex chronic conditions

- ❖ Diabetes
- ❖ HIV
- ❖ Multiple Sclerosis

# Complex Chronic Illness as complicated grief

- ❖ Tensions between illness and preferred person identities
- ❖ Recycling health
- ❖ Comorbid conditions
- ❖ Never fully assimilates, loss experience is ever-present
- ❖ Meaning requires intentional reconstruction

## Relevance of meaning-driven grief counselling and psychotherapy to wellness and chronic illness (Lewis)

- ❖ Medication compliance
- ❖ Medical team communication, relationship
- ❖ Disclosure of change
- ❖ Adherence to appointments

# Narrative techniques in illness counselling

- ❖ *Externalization* - client is not the disease, the disease is the disease...
- ❖ *Unique outcomes* - pieces of the client's experience (narrative) that contradict the problem experience - these act as entry points to reconstructed perspective
- ❖ Journaling, writing, images
- ❖ *Preferred story focus* - move away from illness saturated narrative
- ❖ *Client as agent of change* -
- ❖ *Despair is sedative* -
- ❖ Validation of illness-related depression -

# Externalization

- ❖ What is your relationship with your illness?
- ❖ How does your illness define you?

# Unique Outcomes

- ❖ Think of a time when your illness has less presence for you, takes up less 'space'.
- ❖ Describe the experience.

# Journaling, Visual Journaling

- ❖ Write a letter to your illness
- ❖ Name your illness
- ❖ Draw your illness - what colour, what shape?

# Themes in therapy

- ❖ Chronic illness can inform a complicated grieving - is bonding
- ❖ Involves accommodation
- ❖ Reconstruction of relationship to illness
- ❖ Illness acceptance
- ❖ Patient agency
- ❖ Autonomy

Thank you for your time

Questions?