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Trauma and adherence issues: making sense of what seems not to make sense

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The Complexities of Coping: Non-Adherence as a Survival Strategy

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In relation to this presentation I declare that I have no conflict of interest

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Overview

- Acknowledge links between non-adherence and adversity/trauma
- Explore the counter-intuitive idea that non-adherence is a survival strategy
- Think about how we can adapt healthcare delivery to fit with complex needs

Factors that influence adherence

- Shock/adjustment
- Emotional/psychological state
- Trauma (past or current)
- Alcohol, drugs, chemsex
- Comorbidities
- Cognitive problems
- Experience of side effects
- Previous experiences of Tx
- Family history of illness/Tx
- Illness representations
- Quality of healthcare relationships

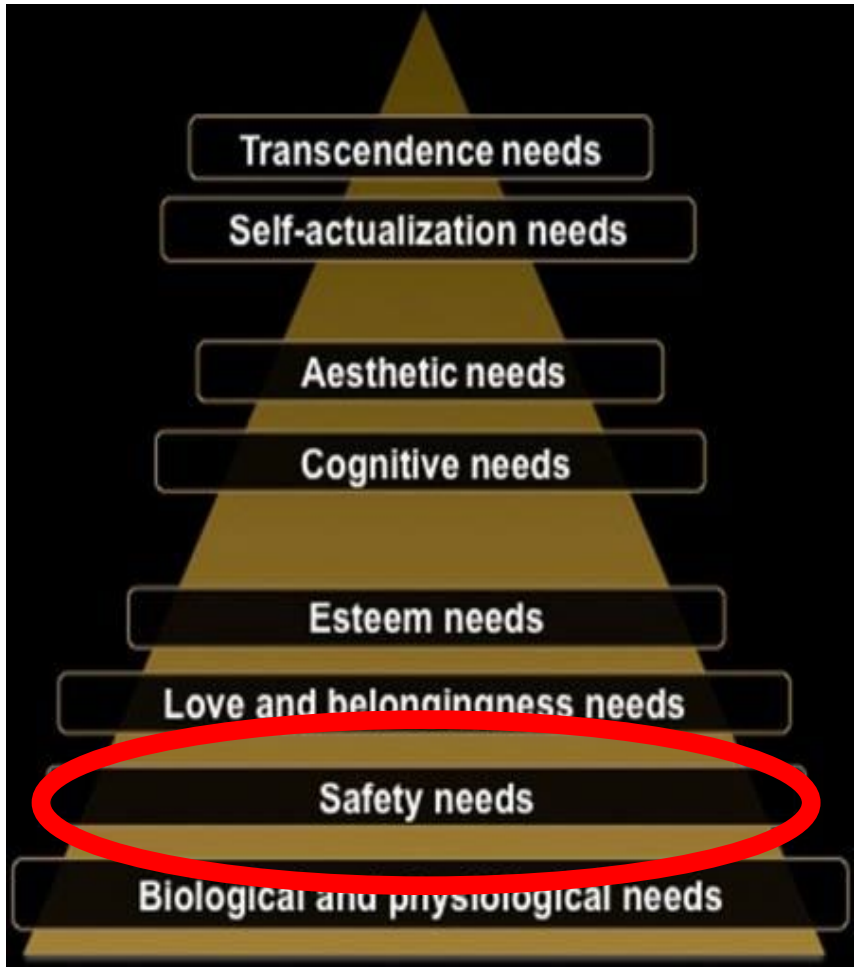
- Attachment/early relationships
- Cohort issues
- Social and cultural contexts
- Current relationships

Linking non-adherence to adversity: the evidence

- *Not all people with complex histories have adherence issues*
- **However, adherence issues do tend to be underpinned by psychosocial complexity and disadvantage**
- Gonzalez et al (2011)
- Graham et al (2015)
- Le Grand et al. (2015)
- Nightingale et al. (2010; 2011)
- Randhawa et al., (2018)
- Watkins Hayes (2014)

Relating adherence to unmet needs

The more needs that are met – the more likely Tx adherence



Maslow's (1970) revised hierarchy of needs – (adapted by Baroso et al 2017)

Adverse histories: threat systems & expectations

- Trauma sensitises the threat system
  - Survival mode
  - Emotional versus rational reasoning

- Trauma in attachment relationships: people who are not cared for
  - Don’t learn how to care for themselves or self-soothe
  - Monitor the world/people for threat
  - Anxiety drives expectations (e.g people who care for me hurt, neglect, dismiss, punish……. me)
  - Find ways to keep themselves safe – draw on in adulthood

Bowlby 1969. 1973, 1980; Ainsworth & Bowlby, 1991; Howe, 2005

The impact of adverse histories

Psychological/emotional issues

- High levels overwhelming trauma-related distress
- Anxiety
- Low mood
- Low self-esteem
- Anger
- Emptiness/numbness
- Worthlessness
- Helplessness and hopelessness

Adaptive coping (conscious and unconscious)

- Avoidance
- Denial
- Distraction
- Dissociation
- Social withdrawal
- Alcohol and drugs
- Self- harm (range of functions)
- Control
- Eliciting care

Ainsworth & Bowlby, 1991; Bowlby, 1969. 1973, 1980; Howe, 2005; Warner, 2009; Warner & Rutter 2020

Non-adherence as a survival strategy

- **HIV – condition as a threat -** The power of fear and shame
  - **ART – constant trauma trigger**
    - Taking the tablet - Psychological, emotional, physiological distress
    - Shame – ART presence in the home
    - Denial – “if I don’t take it and am well – maybe I don’t have it?”
    - Distraction & dissociation – distress & suicidal ideation
    - Compounding worthlessness
    - Learned helplessness – safety in familiarity
    - Hopelessness – escaping a dark future

AVOIDANCE = ESCAPE

managing distress in the short term prioritsed over the long term risks

Non-adherence as a survival strategy

- **Care relationships as a threat**
  - Issues around trust
  - Power as inherent to the medical model – feeling ‘done to’
  - Care as unfamiliar – therefore anxiety provoking
  - Social withdrawal
  - Control
  - Aggression

EMOTIONAL BRAIN IN CHARGE

RESPONSES OFTEN HARD WIRED & UNCONSCIOUS

Delivering healthcare

- Adherence difficulties – how does the healthcare professional fit into this picture?
- Are we perfect robots that deliver perfect care?
- Principle of do no harm – how does that apply in reality?
- What affects our behaviour?
  - The urge to save
  - Our own sense of failure?
  - Pressure from systems to ‘perform’ (shame and blame)
  - Strong emotional responses
  - Attachment patterns at play

Delivering healthcare

- **The role of fear** (Chapman, 2018)
  - There is evidence that fear can be an effective tool in behaviour change
  - However,
    - can be stigmatising for already marginalised populations
    - Locates responsibility in the individual rather, ignores need for systemic, legislative or regulatory change
    - "many personal changes in health-related behavior are difficult, requiring physical discomfort, perseverance, sacrifice, and sometimes major lifestyle change, which is often limited by structural impediments such as poor access to safe environments, cost, and work and family constraints"
    - ***Fear can elicit 'unhelpful' coping***
- **Rewards as Incentives?** (Stephens, 2014)
  - Impact on relationship boundaries
  - Short term vs long term – disempowering?
  - Whoever pays the piper plays the tune
- **Is it ever ok to nudge?** (Johnstone, 2017)
  - Manipulation by power?
  - Who's decision constitutes what is 'right'?

So what can we do?
The *how* as well as the what

- **Communication and the importance of language**
  - Give space and acknowledge concerns- May just need time to process
  - Listen and try to understand the person in their context– sometimes the reasons are very clear
  - Ask permission to discuss adherence, and address any concerns about discussing
  - Open questions
  - Visible language
  - Give required information BUT be aware of the power of language
    - "shoulds, oughts and musts"
    - subtle coercions unintended veiled threats/inducing fear ("maybe you should see another nurse/consultant") or unintended dismissiveness ("you'll be fine")

Warner, 2009; Warner & Rutter 2020

So what can we do?
The *how* as well as the what

- **Clinical responses**
  - Try to adapt to any concerns – normalise and validate
  - Don't make adherence sole focus of consultations
  - Create a safe base
  - Proactive, structured, consistent contact
  - Collaborative care plans
  - Explore values and goals
  - Discuss with MDT, involve in-house mental health professional
  - Explore you own emotional responses (reflective practice)
  - Ask yourself - who's needs are you meeting????
  - If you feel yourself nudging – *label it!*

Warner, 2009; Warner & Rutter 2020

Thank you for listening

Questions, reflections, ideas welcome

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