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# Why we need to think about trauma in HIV services

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# Overview of session

- Define trauma
- Think about the many ways in which trauma is relevant to PLWHIV
- Think about why it is important that HIV services have an understanding of the impact of trauma
- How can services help people affected by trauma

**Disclaimer – take care of yourselves**

# What is trauma?

- Diagnostic and Statistical Manual of Mental Disorders – 5<sup>th</sup> Edition (DSM-5; 2013)

## CRITERION A

- *The person was exposed to: death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence (direct indirect)*

Trauma= Fear + Helplessness

Can a potentially life threatening illness count as a traumatic event?

# What is trauma?

- **CRITERION B: Re-experiencing**
  - Intrusive thoughts, Nightmares, Flashbacks, Emotional distress and/or Physical reactivity after exposure to traumatic reminders
- **CRITERION C: Avoidance**
  - Avoiding trauma-related reminders or trauma-related thoughts and/or feelings
- **CRITERION D: Negative thoughts and feelings**
  - Overly negative thoughts (self and world), exaggerated blame (self or others), negative affect, loss of positive affect, reduced interest, feeling isolated
- **CRITERION E: Arousal**
  - Irritability, aggression, hypervigilance (monitoring for threat) heightened startle response, sleeping and concentration difficulties

# What is trauma?

## Criterion F

- Symptoms last for more than 1 month.
  - (Presents similarly to Acute Stress Disorder – short term response to a traumatic event)

## Criterion G

- Symptoms create distress or functional impairment (e.g., social, occupational).

## Criterion H

- Symptoms are not due to medication, substance use, or other illness.
- **RESILIENCE IS THE NORM**

# How does trauma work?

- Many complex cognitive, emotional , physiological and behavioural processes involved
- Several theoretical viewpoints – e.g.
  - Horowitz (1975, 1976)
  - Shattered Assumptions – Janoff Bulman (1983)
  - Brewin et al (1996; 2010) – Information Processing and Dual Representation Theory
  - Foa et al (1989) – Fear Networks
  - Ehlers and Clark (2000)– Cognitive Model of PTSD
- *Cumulative aspect – ‘the kindling effect’*

# Trauma and HIV

- HIV diagnosis can be traumatising
- People living with trauma may find it more difficult to manage a chronic condition (poorer health outcomes)
- People with a history of trauma are more vulnerable to HIV infection



# Prevalence of Trauma in the HIV Population

- There is strong evidence that there is higher prevalence of mental health problems amongst people living with HIV compared with the general population (WHO, 2008).
- PTSD 33% more prevalent in HIV population (National Institute for mental health)
- PTSD prevalence rates – 10-74% - compared to 8% general population (Applebaum et al 2015)

# Traumatic impact of HIV diagnosis

- **Shock** – highly stressful event
- **Fear of death**
  - ‘a heavy history’
  - Previous direct exposure to HIV-related death
  - Lack of up to date treatment knowledge
- **Fear of loss**
  - Health, relationships, employment, future.....
- **Fear of stigma, discrimination and isolation**
  - Including internalised stigma and self-directed shame
- **Fear of onward transmission** (partners, or mother to child)
- **Source of transmission** can enhance the trauma

# Influence of history and context

- **Long term survivors**
  - Fear of death was very realistic
  - Multiple traumatic bereavements
  - Physical trauma of side effects of early medications
  - Rejection by society
  - Loss of significant others and survival guilt
- **Newly diagnosed people**
  - Very little information – no frame of reference
  - Less of a sense of community?
- **Asylum seekers**
  - High rates of trauma
  - Loss of family, friends and familiar base
  - ongoing insecurity about status

# Influence of history and context

- **Older age**
  - Fears about going into care
  - Concerns about managing increasing co-morbidities
  - Dementia
- **Gender and sexuality**
  - Motherhood
  - Gender-based violence
  - LGBT related issues – e.g. persecution
- **Community**
  - Social norms and expectations
  - Attitudes
  - Religious frameworks

# Traumatic impact of HIV-related ill health

- **Extreme ill health at time of diagnosis**
  - Unknown cause
  - ICU admission
  - Cognitive impairment
- **On going management of HIV – chronic stressor**
  - Constant fear of people finding out
  - Non-consent disclosures
  - Stigma and discrimination
  - Fear of missing medication doses – resistance
  - Hypervigilant research – with a ‘fear filter’

# Historical Trauma

- HIV diagnosis can exacerbate existing trauma
- HIV high prevalence in already marginalised groups (e.g. people with mental health issues, LGBT, asylum seekers)
- Historical trauma (mental health issues)
  - puts people at more risk of being infected with HIV
  - May increase risk of onward transmission
- Abuse in early life – particularly is by caregivers – can affect engagement with healthcare professionals
- Historical trauma may mean people have less helpful coping strategies after diagnosis/managing HIV

# The complexities of 'unhelpful' coping

- **External coping**
  - Risk behaviours-sex, drugs, rock and roll
  - Historical trauma can manifest in relational issues –
    - Insecure template for relationships
    - exposure to unfulfilling relationships – chaotic, abusive
    - Distressing = familiar = safe
- Hep C, other STD's – compound the trauma via things such further concealment – shame
- Generally not looking after health – HIV, co-morbidities, or just general wellbeing (e.g. smoking, drinking, drug use)– impact on overall health outcomes

# The complexities of 'unhelpful' coping

- **Internal coping**
  - Rumination
    - Doesn't solve the problem, just keeps mind on it – low mood
  - Hypervigilance
    - Constantly monitoring for threat
  - Self criticism
    - Feeds negative feelings, more unhelpful coping, further self criticism
- **Avoidance** (part of the trauma presentation)
  - Avoiding any reminders of the traumatic event, including own thoughts
  - Withdrawal
    - Isolation and not processing the trauma
- **Dissociation**



# Trauma and Adherence

- Fear of side effects
- Chaotic lifestyle
- Medication as a trigger for overwhelming trauma memories and emotions
- Supporting a sense of denial
- Not taking ART may serve a function
  - Self punishment and/or self harm
  - Sense of control
- Worthlessness
- Hopelessness
- Lack of trust of health care professionals/system – affecting engagement
- **HOWEVER** – can also increase adherence

# Vicarious Trauma/Secondary Traumatic Stress

- Dealing with a population with complex psychosocial needs – impact on healthcare professionals
  - Overwhelmed
  - Distressing emotional responses
  - Negative thoughts about people/situations/world
  - Trying to avoid certain people/situations
  - Irritability/anger
  - High work stress levels
  - Loss of empathy
  - Fear – from role pressures
  - Work stress affecting sleep
  - Things outside of work reminding you of work
  - Periods of sick leave
  - Helplessness
  - Hopelessness?

# What is trauma?

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# What Can HIV Services Do?

- Show compassion and give space
- Delivery of up to date information
  - Make sure people have been able to take information in (dissociation)
  - Provide written info, info sources, checking in regularly
- Get to know the signs of trauma – trauma screening questionnaire?
- Signpost as necessary
- Seek consultation and/or supervision
- Be aware of power dynamics – impact of our ‘status’
- Be consistent – across the team
- Take care of ourselves and each other
- Don't force ‘de-briefs’

# Psychological first aid

- Empathy and compassion
- Listen
- Re-assure
- respond

# Post Traumatic Growth

- **HIV diagnosis can:**
  - Help people find a community
  - Access support
  - Perspective shift – changing life choices
- **The care team can:**
  - Function as a ‘safe base’ for those with difficult histories
  - Help a person learn how to develop; and manage relationships
  - Help people learn to care for themselves
  - Aid an overall recovery



**Thank you for listening**

**Questions?**

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