



Sussex Community
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Intentional ART Non-Adherence: How Can Providers Respond?

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Excellent care at the heart of the community

Declarations of Interest

- Declaration of interests relating to this presentation
- I have none to declare

Introduction

- Ultimately as health care providers, our aim is to promote a healthy lifestyle, to deliver high quality care and to enable people to live long and healthy lives
- Adherence is an important outcome measure because non-adherence to ART increases morbidity and mortality and health service costs, as well as the risk of resistance and onward transmission
- So how do we approach and manage those patients who choose to opt out of treatment, otherwise known as Intentional Non-Adherence ?

Medication Adherence

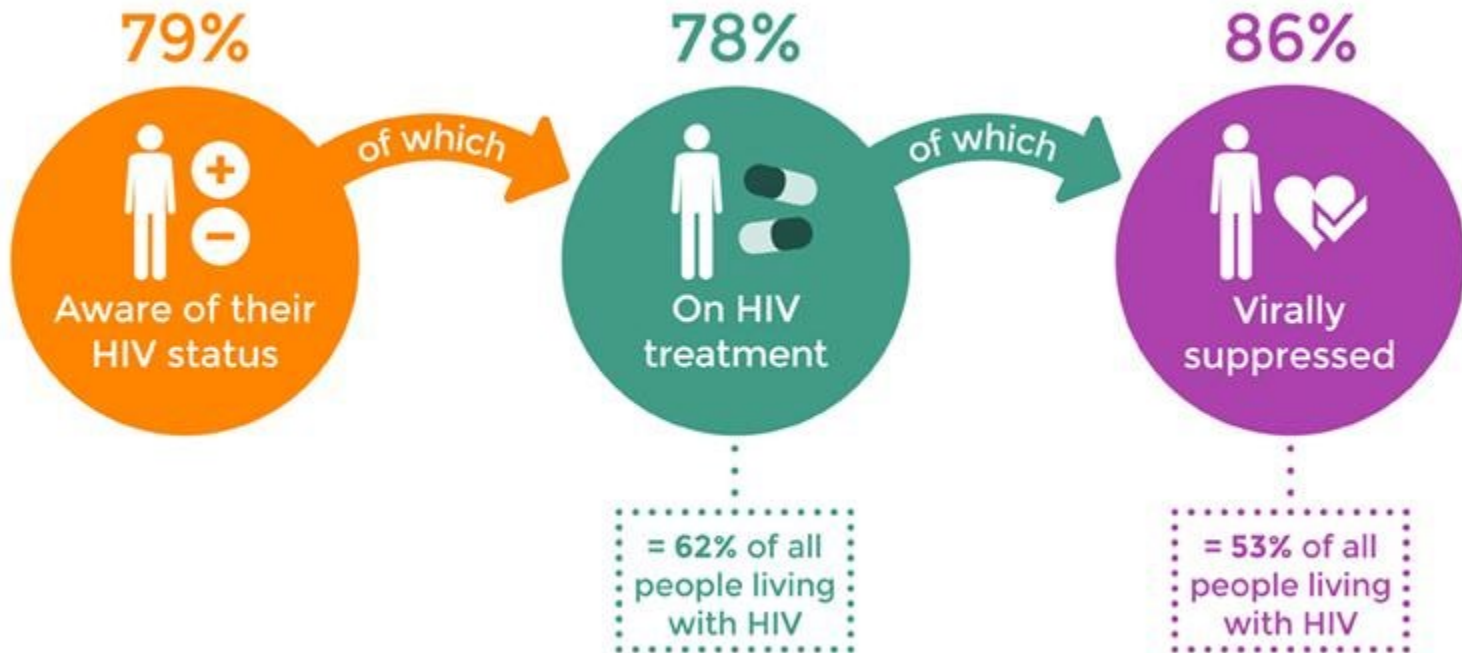
- Non-adherence falls into two categories: intentional and unintentional (NICE, 2009).
- Unintentional non-adherence is when a patient unintentionally struggles to take their tablets due to barriers that are beyond their control, for example forgetfulness or drug and alcohol issues.
- Intentional non-adherence is when a patient intentionally decides to stop their treatment.

Medication Adherence

- In order to better understand adherence to treatment we need to consider the factors that influence a patient's choice to stop treatment
- Applying this approach in practice requires a holistic, empathetic and no blame approach encouraging discussion around intentional non-adherence and any doubts or concerns patients have about treatment (NICE, 2009).

Statistics

Global progress towards the 90 90 90 targets 2018 (all ages)



Source: UNAIDS Data 2019

Statistics

- An estimated 4% of 102,000 people diagnosed with HIV in England are not taking ART (Brown *et al.*, 2017).
- A caseload review identified reasons why patients opt out of ART (intentional non-adherence) or struggle with adherence. Barriers to adherence were identified

Methodology was carried out in my previous post at Liverpool University Hospitals Trust and case studies are taken from the caseload in my previous post

Methodology

- A comprehensive caseload review was undertaken to identify and explore why some HIV positive patients decide to stop ART
- Participants reflected on past cases to identify key components of a best practice model
- 14% of caseload had a detectable viral load
- Of those with a detectable viral load, 40% had opted out of treatment

Barriers to Intentional Non Adherence

- Associating tablets with HIV related stigma-daily reminder
- Adoption of personal belief systems such as religion, alternative therapy, traditional medicine, conspiracy theorists
- Slow progressors who feel well
- Lack of trust in health care professionals
- Denial



Barriers to Intentional Non Adherence

- Fear of side effects & medication toxicity
- Medication fatigue
- Invincibility/optimistic bias
- Depression/ low self-esteem
- Social isolation with no incentive for good health and well-being



Barriers to Intentional Non Adherence

- Cyclical periods of good/poor health coinciding with starting/stopping ART
- Desire to survive but not with HIV
- The need to exercise control
- Punishment to significant others
- A desire to die



Control Issues

- We cannot underestimate the need for control
- For some people, choosing not to take life sustaining treatment is about regaining some control similar to the complex nature of eating disorders such as anorexia and bulimia
- Brown (1990) discusses the control paradox: *Power struggles in therapeutic relationships are disastrous as they force people who feel out of control to cling more desperately to the only control they have*
- In other words the more practitioners try to take power away or enforce their opinions on someone, the more the patient's symptoms and behaviours are likely to escalate

Our Responce

- The 'right to die' is a highly emotive topic
- Respecting someone's choice to die is complex.
- Liberty and autonomy, or self-government, are sources of human dignity too.
- The General Medical Council (GMC) discusses personal beliefs and medical practice. They state: *You must respect a competent patient's decision to refuse an investigation or treatment, even if you think their decision is wrong or irrational. You may advise the patient of your clinical opinion, but you must not put pressure on them to accept your advice.*

Mental Capacity

- Assessing a patient's mental capacity is important when someone is refusing treatment
- Capacity' means the ability to use and understand information to make a decision, and communicate any decision made
- A person lacks capacity if their mind is impaired or disturbed in some way, and this means the person is unable to make a decision at that time.

The language we use

- Compliance relates to a more paternalistic or even autocratic relationship, in which someone is seen as either following instructions (compliant) or disregarding them (non-compliant)
- Being labelled 'non-compliant' by health professionals becomes a barrier to empathising with a patient's perspective. It prevents us understanding why the patient is unable or unwilling to adhere to lifestyle changes, medication regimens or advice. It places responsibility for a perceived failure to optimise health outcomes on the patient, and assumes that health professionals know best (Chapman, 2018)

The language we use

- Concordance is an indicator of the quality of decision-making in healthcare. It depends on patients being well-informed
- A concordant relationship promotes self-management of health; it is based on trust, enabling patients to discuss with the health professionals providing care how other aspects of their life influence, and are influenced by, health and health interventions. It is a partnership to achieve the best health and wellbeing outcomes (Chapman, 2018)

Role of the practitioner

- Help patients to develop strategies to incorporate lifestyle changes or medications into their routines
- Support significant others
- Supporting and managing change of mind
- Shifting emphasis from medication to other pressing issues



Role of the practitioner

- Robust MDT working & communication
- Advanced communication skills-listening skills
- Resilience and Patience (don't show frustration)
- Realistic expectations



Role of the practitioner

- Maintain engagement (home visits/phone/clinic appointments)
- Flexible approach to tailored care
- Advocacy
- Timely referrals to palliative care (1 year before anticipated death)



Role of the practitioner

- Prepare to adjust your communication style to meet your patients needs
- Ask about prior experiences of medication to identify any problems
- Respond openly and honestly to questions about medication/side effects
- Provide motivational support but do not be disappointed with non-adherence; try to understand it and respect your patients decision

Case study 1

- Ben 22 yr. old
- Vertical transmission-positive since birth
- Told he was HIV positive at 15 yrs.
- Struggled with acceptance and adherence since
- Power struggle between Ben and his mum
- Stopped taking his ART
- Multiple MDT discussions and interventions used
- Mental capacity discussed in MDT
- Specialist doctors and nurses found it hard to accept his decision
- Died at 22 years of age from end stage HIV on the ID ward
- Reflection-what could we have done better?



Case study 2

- Peter 30yrs old
- Decided he would rather die
- Couldn't accept diagnosis
- Stopped taking ART
- HIV Specialist team respected and accepted his decision
- Referral to Palliative care team
- DNR in place and Advanced care planning
- Visited for two years often just to listen and maintain engagement
- In November 2018 he suddenly decided he did not want to die and started ART
- Present day Viral load < 30 and CD4 count above 200
- Peter is happy and has come to accept diagnosis



Case study 3

- Paula 38yrs old
- Hoarder
- Intermittent engagement for 5 years
- Religious belief that God had healed her
- Taking ART was showing a lack of faith-stopped ART
- Admitted to hospital with CD4 count of 11
- Discharged 3 days later-clinically dying
- Admitted to Marie Curie Hospice Jan 2018 for end of life care
- Started taking ART whilst in hospice as became frightened of imminent death
- Now undetectable with CD4 count over 200



Conclusion

- Trust is the most important factor in patient satisfaction and adherence to care; health professionals need to develop a concordant relationship with their patients
- It is vital to understand the psychological reasons and issues which lead to someone choosing to opt out of ART so we are better able to help our patients on their journey (Grant and Hong, 2011)
- Our duty of care remains the same with patients who choose to stop ART.
- Care should remain high quality

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