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Intentional ART Non-Adherence: How should health professionals respond?

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Introduction

- 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, mortality and health service costs, as well as the risk of resistance and onward transmission

- This presentation will explore how we approach and care for those patients who choose to opt out of treatment, otherwise known as Intentional Non-Adherence

Medication Adherence

- In order to better understand adherence to treatment we need to consider the factors that influence a patients 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).

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.

Living with HIV in the UK

- In 2019, it was estimated that there were 105,200 people living with HIV in the UK.
- 94% of these people are diagnosed, and therefore know that they have HIV.
- 98% of people diagnosed with HIV in the UK are on treatment, and 97% of those on treatment are virally suppressed which means they can’t pass the virus on.
- That leaves approximately 3% of people diagnosed that aren’t virally suppressed

UK HIV Statistics | National AIDS Trust

Aidsmap-May 2022

- Recently at BHIVA conference UKHSA’s Dr Brown warned that this estimate was a "somewhat rosy picture".
- She pointed out that there is an assumption that once diagnosed and linked to care, people *stay* in care – and that if they do stay in care, continue taking treatment and remain virally suppressed.
- Brown said that a worst-case scenario could mean that up to 20% of people with HIV in England might in fact have an unsuppressed viral load and therefore both be in danger of progressing to end stage HIV and of transmitting HIV

Caseload Review

- A comprehensive caseload review with the HIV community team (SCFT) was recently undertaken in 2022 to identify and explore why some patients with HIV decide to stop ART
- 45% of the caseload were identified as having adherence issues and needing intense support around this specific issue
- 25.49% of the caseload had a detectable viral load
- Of those with a detectable viral load, 9.8% had chosen to opt out of treatment. Otherwise known as Intentional non adherence

Barriers to Intentional Non Adherence

- Associating tablets with HIV-daily reminder
- Adoption of personal belief systems such as religion or alternative therapy
- Patients who feel well
- Lack of trust in health care professionals and medicine-potentially due to serious drug interactions
- Denial

Barriers to Intentional Non Adherence

- Fear of side effects & medication toxicity –especially based on early experience of ART

- 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. As soon as we become a patient we experience a loss of control.
- Choosing not to take life sustaining treatment is about regaining some control similar to the complex nature of eating disorders such as anorexia.
- 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 stop life sustaining treatment 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

- Always document capacity in these situations

- 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 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 HCP 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)

Trauma Informed care

- The Five Principles of Trauma-Informed Care are; safety, choice, collaboration, trustworthiness and empowerment.
- Trauma-informed care shifts the focus from “What’s wrong with you?” to “What happened to you?”
- A trauma-informed approach to care recognises that health care professionals need to have a complete picture of a patient’s life situation — past and present — in order to provide effective health care services with a holistic approach.
- Adopting trauma-informed practices can improve patient engagement, treatment adherence, and health outcomes.

https://www.kingsfund.org.uk/blog/2019/11/trauma-informed-care

Role of the practitioner

- Help patients to develop strategies to incorporate lifestyle changes or medications into their routines

- Support significant others
- Supporting change of mind but not coercing
- Shifting emphasis from medication to other pressing issues such as deprivation or housing issues

Role of the practitioner

- Robust MDT working & communication with GP and other relevant health services
- Advanced communication skills-listening skills
- Patience (don’t show frustration)
- Realistic expectations

Role of the practitioner

- Maintain engagement (home visits/phone/clinic appointments)
- Flexible approach to tailored care

- Advocacy
- Carry out advanced care planning with your patient
- 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

Best practice guidance

NHIVNA Best Practice

Barriers to adherence and intentional non-adherence: a guide for nurses

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Background

BHIVA Standards of Care 2018

Microsoft Edge
PDF Document

Case study 1

- Mike - Heterosexual man-61 years old
- Diagnosed with HIV in 1999
- Wife died from MS
- Has a 21 yr old daughter
- Father died 4 years ago and left money to Mike so no need to work
- History of non adherence –not been <30 for the last 2 years
- Mikes rational for not taking his ARV medication is that he ‘feels so well’ and considers himself to have an ‘excellent quality of life’. He has a regular morning routine and takes the tablet out and ‘just looks at it’ and then doesn’t take it.

Case study 1

- Mike is clinically unwell with Viral load of 102,015 copies/ml and CD4 count of 16 (3%)
- Skin is in poor condition, poor circulation and low BMI
- Multiple conversations with consultant and CNS about the importance of taking ART and that without ART will die
- Mike engages very well with Mel (CNS) and trusting relationship-sends her photos of his cooking
- Future initiatives-advanced care planning and weekly visits with Mel CNS
- The team will continue to walk alongside Mike on his journey, respect his wishes and be there when needed

Case study 2

- Paula - 38yrs old
- Hoarder-couldn’t get into her house to offer her care
- 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 with package of care however no access into house due to hoarding situation
- Urgent admission into the Hospice 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)

- Respect your patients choice even if you don’t agree or understand

- Our duty of care remains the same with patients who choose to stop ART.

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