NHIVNA Best Practice

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

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Background

Since the identification of HIV in 1983, the HIV field has changed dramatically and HIV is no longer classed as palliative but as a long-term condition. HIV continues to be an important public health issue in the UK. Although diagnosis can be traumatic we can now offer people hope. If patients are diagnosed early and antiretroviral therapy (ART) is initiated their prognosis is extremely good. Treatment outcomes for people with HIV are amongst the best in the world. Ultimately as healthcare professionals, our aim is to promote a healthy lifestyle, to deliver high-quality care and to enable people to live long and healthy lives. So how do we approach and manage patients who choose to opt out of treatment (intentional non-adherence) or struggle with adherence?

A new report published by Public Health England (PHE) showed that the UK is one of the first countries to meet the UNAIDS 90-90-90 targets [1], highlighting that prevention efforts are working in the UK. In 2015 it was estimated that there were 101 200 people with HIV in the UK, of whom 13% were unaware that they were living with HIV [1]. New estimates revealed that in 2017, 92% of people living with HIV in the UK have been diagnosed, 98% of those diagnosed were on treatment, and 97% of those on treatment were virally suppressed. Of all people living with HIV, 87% have an undetectable viral load and are unable to pass on HIV to other people, widely known as 'Undetectable equals Untransmissible' or 'U=U' [2]. However the authors estimate that there are still almost 3600 people diagnosed with HIV who have detectable viral loads.

Non-adherence to medication means either not taking the prescribed treatment or taking it incorrectly. Patients with complex care needs often suffer from combinations of multiple chronic conditions, mental health problems, drug interactions and social vulnerability, which can lead to healthcare service overuse, underuse or misuse [3]. HIV remains a stigmatised and under recognised condition that disproportionately affects already vulnerable populations. Men who have sex with men, transgender women, black African men and women, and people who use drugs continue to be disproportionately represented among people with HIV.

We are producing these guidelines as failure to adhere to ART and poor engagement with care is associated with poorer health outcomes and a higher risk of onward transmission. The need for guidelines and innovative approaches to engage those hard-to-reach populations cannot be overstated. Ultimately, nursing interventions lead to new or improved resources that drive costs down and advance nursing care and optimal patient outcomes [4].

As HIV specialist nurses we have vast experience of working with patients with complex care. Our aim is to improve health, wellbeing and quality of life for patients who are difficult to reach, non-attenders or those who have defaulted from care, aligning with British HIV Association (BHIVA) care standards 2018 [5]. By optimising adherence to ART we prevent deterioration of health and prevent onward transmission of HIV.

BHIVA Standards of Care 2018

The third set of quality standards of care for people with HIV in the UK were produced in 2018 by BHIVA in partnership with many other HIV care providers, HIV agencies and people with HIV [5].

The standards were developed against a background of enormous improvements in clinical outcomes for people with HIV, the impact of virological suppression with effective ART and prevention interventions such as pre-exposure prophylaxis (PrEP).

An ageing population of people with HIV and comorbidities (a consequence of ageing) bring additional challenges and complexity to the provision of quality HIV care.

The standards provide a reference point for the provision of care, which will provide a framework for care commissioners and policy decision makers. The standards also provide people with HIV with information about the level and quality of care they should expect. Importantly for providers of HIV services, the standards also include what care should be provided, why it should be provided and how patient outcomes can be measured and audited, this will in turn measure care outcomes and facilitate continued service development.

Keywords

Adherence, intentional non-adherence, barriers to adherence, HIV, ART, people with HIV

Aim

This guidance is aimed at nurses and healthcare professionals who work within the field of HIV, supporting people with HIV who may struggle with adherence or choose to stop taking their ART. The aims of this guidance are:

- to identify reasons why people with HIV opt out of ART (intentional non-adherence) or struggle with adherence; and
- to identify key components of best practice that will equip nurses to help these people.

Evidence

The authors conducted a caseload review to identify reasons why patients opt out of ART or struggle with adherence; barriers to adherence were also explored. Four Clinical Nurse Specialists (CNSs) reflected on past cases to identify key components of a best practice model. Opting out of treatment is different to struggling with adherence. As HIV CNSs we deal with many complex patients who struggle with adherence but ultimately desire to be undetectable. Choosing to opt out of ART brings new challenges in terms of how to best manage and support these patients and still ensure that high-quality care is provided. Of the caseload of complex patients (*n*=60), 14% had a detectable viral load, see Figure 1a. Of the 14% who were detectable 40% had chosen to opt out of ART, see Figure 1b.

There are many barriers to adherence and some patients may have multiple barriers:

- Associating tablets with HIV-related stigma
- Adoption of personal belief systems such as religion, alternative therapy, traditional medicine, shamanism and conspiracy theories
- Slow progressors who feel well
- Long-term nil by mouth, absence of swallow reflex, dysphagia
- Lack of trust in health professionals
- Denial
- Invincibility
- Poor mental health
- Social isolation with no incentive for good health and wellbeing
- Cyclical periods of good/poor health coinciding with starting/stopping ART
- Past or present trauma
- Poor ability to exercise control
- Punishment to significant others
- Erratic lifestyle/travellers/migrants
- Negative influence of partner, family, friends and social media
- Homelessness, rough sleeping, sofa surfing, shared accommodation
- Poor literacy skills/English as a second language
- Cognitive impairment
- Sensory disturbance, e.g. neuropathy, visual impairment or sight loss

As well as barriers to adherence it is important to briefly discuss challenges to engagement. Failure to engage with care is associated with poorer health outcomes and a higher risk of onward transmission. Until we engage effectively with patients we cannot help them with adherence. Challenges to engagement include those shown in Figure 2.

Key components of best practice

The key components of best practice are to engage complex, underserved and 'hard-to-reach' patients with HIV; to optimise adherence to ART and prevent onward transmission of HIV. The aims are also to support and respect a patient's decision and facilitate high-quality end-of life-care in certain circumstances.

The General Medical Council (GMC) discusses personal beliefs and medical practice. They state:

> *'You must respect a competent patient's decision to refuse treatment, even if you think their choice is wrong or irrational. You may advise the patient of your clinical*

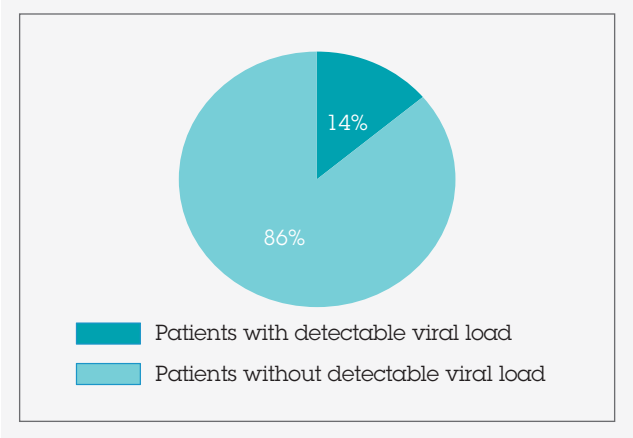

Figure 1a: Proportion of caseload of complex patients with a detectable viral load

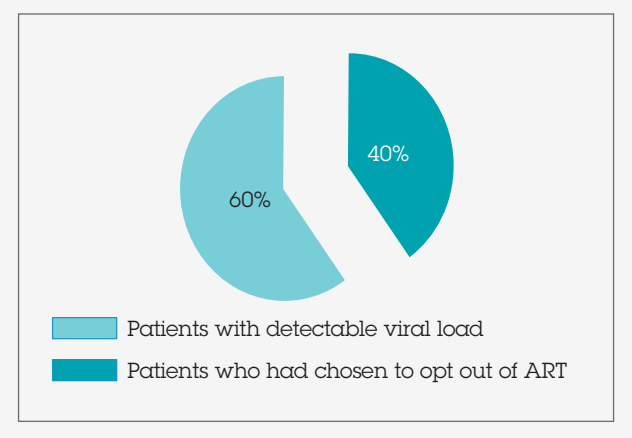

Figure 1b: Proportion of caseload of complex patients with detectable viral load choosing to opt out of ART

Figure 2: Challenges to engagement with adherence

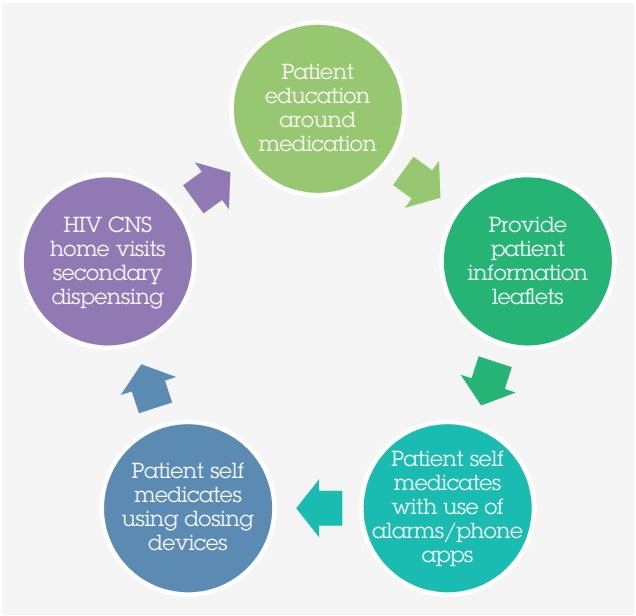

Figure 3: First-line adherence support. CNS: clinical nurse specialist

opinion, but you must not put pressure on them to accept your advice [6].'

Assessing capacity is vital for adherence. Capacity is 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 [7].

The language used, combined with advanced communication skills are key elements when discussing the importance of adherence, especially when questioning a patient about non-adherence. Often there may be a disparity between a patient saying they are 100% adherent and monitoring blood results that would suggest otherwise.

Advanced communication skills include listening skills, formulating appropriate responses, open-ended questioning, managing silence and acknowledgement so that patients feel heard.

The word 'compliance' relates to a more paternalistic and autocratic relationship, in which someone is 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 places responsibility for perceived failure to optimise health outcomes on the patient, and assumes that health professionals know best [8]. 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. It is a partnership to achieve the best health and wellbeing outcomes [8].

External factors can also impact on a patient's decision-making on engagement in care, including adherence to treatment, and may in some cases lead to a patient deciding to opt out of treatment even after the consequences have been discussed at great length and on many occasions.

Optimisation of ART and ensuring that it is taken as directed is one of the roles of an HIV specialist nurse. Patient education is crucial ensuring that patients are well informed about their medication. Patients with comorbidity requiring medication may have an additional pill burden prescribed by their GP. Medication can be provided in blister packs via the dispensing pharmacy however, the reasons patients struggle with ART adherence may also affect their adherence to GP prescribed treatments and this should be considered when discussing adherence and providing secondary dispensing. The community HIV CNS may also play a role in secondary dispensing of ART [9]. Figure 3 suggests first-line adherence support for patients.

Conclusion

Through reflection and clinical practice the key components, shown in Figure 4, were identified as best practice when managing patients who struggle with adherence or choose to opt out of ART.

Adherence is an important outcome measure for healthcare because non-adherence increases morbidity, mortality and health service costs, as well as the risk of resistance and onward transmission. However moving the emphasis from adherence to trust and patient satisfaction cannot be overstated. Trust is the most important factor in patient satisfaction and adherence to care. We need to develop a concordant relationship with our patients. Advance communication skills have particular relevance in promoting adherence or supporting those who decide to opt out

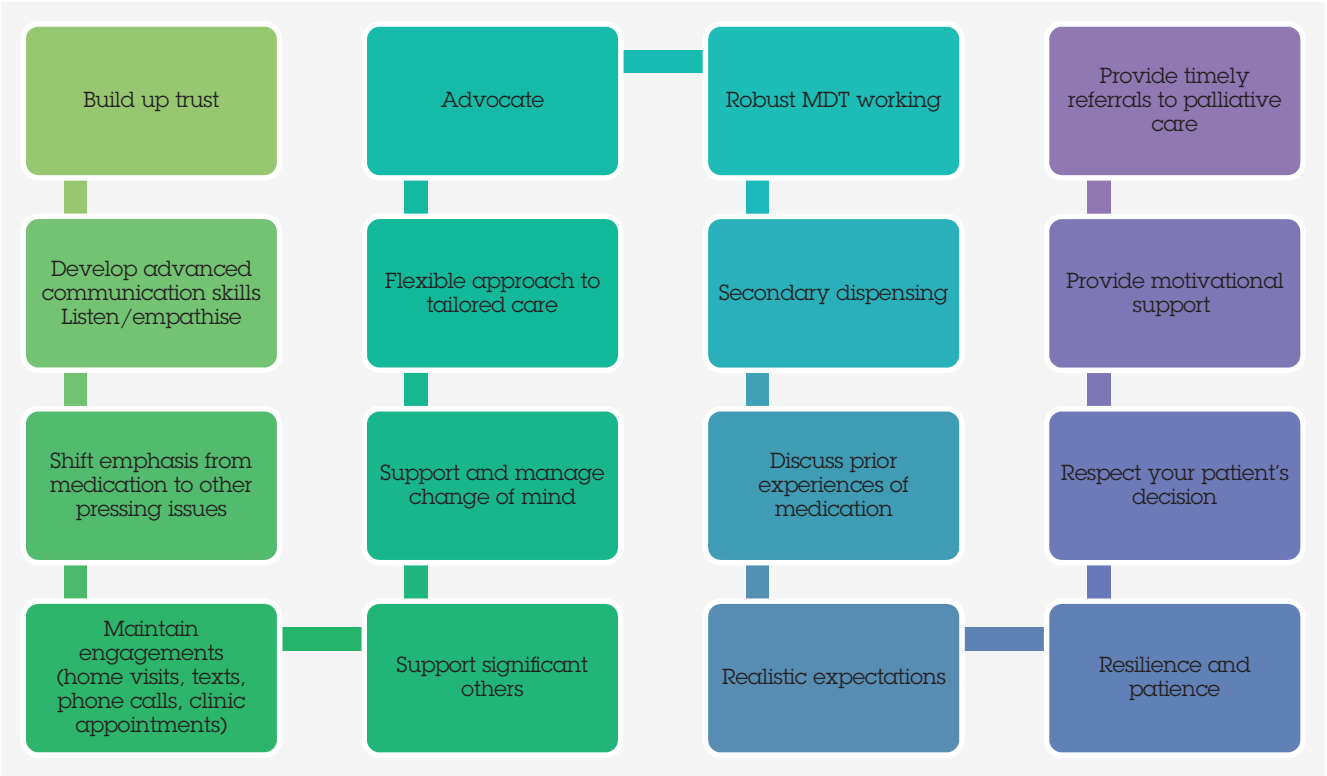

Figure 4: Key components of best practice to manage patients of intentional non-adherence and those who struggle with adherence. MDT: multidisciplinary team

of treatment. A multidisciplinary team wrap-around approach to support adherence may include occupational therapy, NHS specialist pharmacy services, memory clinics, and the Royal National Institute of Blind People. To conclude, it is vital to understand the psychological reasons and issues that lead to someone choosing to opt out of ART so we are better able to help our patients on their journey or to achieve congruence, to walk with someone on their journey objectively without being emotionally involved [10].

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Conflicts of interest

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