

# What adherence support do patients require from an HIV Service?

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## Background

High levels of adherence to anti-retroviral therapies (ART) are necessary for the long term health of those with HIV and the prevention of onward transmission of infection. Lifelong adherence poses substantial challenges to many individuals for a multitude of reasons; effective support from HIV services is therefore essential. Understanding what constitutes effective support is important for service development. The aim of our study was to understand what aspects of care are important to patients in supporting their adherence to ART.

## Method

This qualitative study involved two care centres – a Sexual Health clinic and an Infectious Diseases unit - in a provincial city. Semi structured interviews were conducted with a purposive sample of 23 HIV positive patients. Participants were recruited to ensure coverage across a range of characteristics including: age; gender; ethnicity; sexual orientation; duration of diagnosis; care centre and difficulty with adherence.

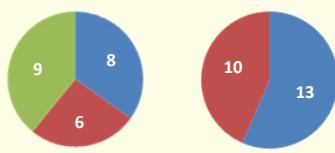
Data were analysed using a modified framework analysis approach.

## Results

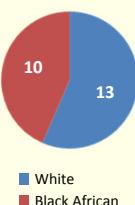
### Overview of participants

Age: Range - 18-58 years; Mean = 42

Gender/orientation



Ethnicity



### Themes identified

Four themes were identified that captured the important elements of adherence support (see below). A cross-cutting thread which ran through all themes was the care relationship between patients and the HIV service. This provides important insights into why the mechanisms identified as adherence support were defined as such.

#### 1. Being prepared for treatment

Even those who were diagnosed late and needed to start almost immediately valued a small amount of preparation time to enable them to adjust psychologically and to contribute to decisions about treatment. Many expressed the importance of having a sense of control:

*"It's like putting myself in the driving seat if you like ... because I'm going to take the tablet, so it's nice to be able to choose as well"* (Helen)

#### 2. Being supported to take the treatment

The respondents identified a range of problems relating to the mechanics of pill taking and side-effects. Support from staff was most helpful when it was based on listening to individual concerns and working collaboratively to find an acceptable solution:

*"So [the HIV CNS] ... bless her ... tried and tried and tried for me, and she got to this regime that two of these tablets were dissolvable ... for a person that does not like taking tablets ... and all of a sudden these are forced on you, it's hard"* (David)

Respondents valued staff support in helping them to develop a pill taking regime which was compatible with their routines and lifestyle. Those with a daily routine favoured an events-based approach, whilst those who lacked a fixed daily routine, perhaps because they were shift workers, used a timing based approach, supported by reminder systems.

#### 3. Providing a responsive service

Participants valued contact with staff outside of clinic visits, particularly in the early days of treatment and at times of uncertainty: ready access to advice helped them to deal with problems and become more confident in managing their treatment. Participants also appreciated being contacted at home by the service to check how they were managing with their treatment or simply to see how they were, particularly if their mood was low. This was an important source of emotional support, especially for those who were socially isolated:

*"She [the HIV CNS] would call me just to ask if I am OK. Just to talk to someone who is thinking of you ... it helped me"* (Gloria)

#### 4. Supporting engagement with the service

Many of the respondents placed high value on clinic attendance. One important aspect was the degree of confidence they had in the service and the expertise of the staff who cared for them. Another was the attitude of staff, and the respectful and individualised care they received. Continued attendance was important for those who had problems with treatment: either in enabling those who stopped treatment to restart or in helping them to keep going:

*"The whole staff here have dealt with me as though I was a human being ... and so I thought if I'm being treated properly, I'll keep going back. If you keep going back they're going to give you more pills. So I keep going back to get more pills"* (Steve)

## Conclusion

**This study identified essential components of adherence support and provided insights into their importance from the perspective of the patient. Changes in commissioning will necessitate changes in the way services are delivered. These findings can be used to inform service developments to ensure optimal adherence support.**