


# The Experience of Antiretroviral Treatment for Black West African Women who are HIV Positive and Living in London: An Interpretative Phenomenological Analysis

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**Abstract** Antiretroviral therapy (ART) offers a powerful intervention in HIV but effectiveness can be compromised by inadequate adherence. This paper is a detailed examination of the experience of medication in a purposively selected group of people living with HIV. In-depth interviews were conducted with 10 HIV positive, West African women of black heritage living in London, UK. This group was of interest since it is the second largest group affected by HIV in the UK. Interviews were subjected to interpretative phenomenological analysis, an idiographic, experiential, qualitative approach. The paper details the women's negative experience of treatment. ART can be considered difficult and unrelenting and may be disconnected from the women's sense of health or illness. Participants' social context often exacerbated the difficulties. Some reported an improvement in their feelings about the medication over time. These findings point to some intrinsic and social motivators which could act as spurs to adherence.

**Keywords** Qualitative · Medication · Adherence · Stigma

## Introduction

Morbidity and mortality associated with HIV infection can be dramatically reduced by effective ART [1] as can the risk of onward transmission to uninfected sexual partners [2]. However, full benefit of treatment relies on both prompt uptake of a clinically indicated offer and high levels of adherence (90–95 % of doses taken) in the long term [3]. These behaviours are necessary not only for efficacy but also to prevent viral resistance and the exhaustion of treatment options [4]. Despite this, existing research suggests that adherence to treatment may frequently fall short of the necessary threshold, with some studies reporting only 50–70 % of doses taken [5, 6].

HIV is highly prevalent in Sub-Saharan Africa, and diaspora communities from Sub-Saharan Africa in the UK have disproportionately high rates of HIV infection [7]. Following men who have sex with men (MSM), men and women of black African heritage make up the largest group affected by HIV in the UK [7]. It is therefore worthwhile exploring the experiences and behaviours of people from Sub-Saharan Africa living with HIV both in their home countries and abroad in order to more fully understand their experiences both in terms of living with HIV and adhering to ART.

Several authors have examined the experiences of those living with HIV in Sub-Saharan Africa, both in terms of barriers and facilitators to taking treatment. One such paper discussed the notion that adherence to ART is in fact higher in Africa than in resource rich settings [8]. These authors argued that this was the case because people starting ART were sicker at treatment initiation and experienced tangible benefits over time. In contrast, people with HIV in the UK are encouraged to start treatment before symptoms emerge [9] and many do not experience discernible benefits from

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starting ART. For those living in Africa, the need to meet family responsibilities was found to be a major motivator to remain adherent to their treatment. Conversely, Adewuya et al. [10] looked at adherence for those living with HIV in Nigeria and found psychopathology and low levels of social support were significant correlates of low levels of adherence.

There are a number of papers exploring the lives of people of black African heritage living with HIV in countries outside Africa. Doyal and Anderson [11] used qualitative methods to look at the experiences of African women living in London with HIV, and found that issues around gender and migrant status were as important as their HIV status. Living in the UK granted women access to treatments they would not have had in Africa but, consistent with other work [12], this came at the price of living far away from home. The same authors also explored the lives of heterosexual African men living with HIV in London [13] and reported that men found it hard to accept their HIV status, which was considered an assault on manliness. Men were also likely to be isolated, living away from friends and family. For many people of black African heritage living with HIV in London, issues such as housing, lack of money and concerns about immigration status, confidentiality, stigma and difficulties accessing healthcare may be more pressing than considering and dealing with their seropositive status [12, 14].

Several authors have focused on the impact of HIV-related stigma for people of black African heritage living with HIV outside Africa [12, 15]. One strong qualitative paper spoke to key figures within healthcare about African people living with HIV in the UK [14] and found that despite the availability of effective ART since 1996, African patients, especially men, still tended to access care late and that patients reported pathways to care as being overly complex. African participants living with HIV in the Netherlands [15] felt stigmatised through social and physical distance, words, and silence. This had various consequences, including a deleterious effect on adherence. For some, keeping their HIV status secret was more important than adhering to medication. Flowers et al. [12] found that stigma could lead to additional problems for people of black African heritage living with HIV in London, including lack of social support and isolation. Accessing support services runs the risk of revealing one's HIV status. In a close-knit community where HIV is highly stigmatised, as is the case for many African communities, this may not be a risk worth taking, potentially impacting negatively on adherence [12].

There is less work looking specifically at the challenges that people of black African heritage living with HIV face in adhering to their medication. One review [16] looked at 24 qualitative papers on adherence in HIV, and although

some of these authors concentrated on particular sub-groups of participants, only Sankar et al. [17] focused on participants of African origin. These authors used discourse analysis to examine the influences informing the behaviour of the participants and found that although the physician's voice commonly served to facilitate adherence, influential social voices—such as those who suggested the medicines do not work or are toxic—acted as barriers to adherence. This paper is concerned with external discourses informing the behaviour of the participants and could be usefully complemented by work focused on the personal, lived experience of the participants.

A wealth of interventions aiming to improve adherence to ART have been undertaken. A recent review [18] has found some encouraging results with multi-component interventions to improve adherence to ART. However, effects are often small and short lived. There also appears to be a dearth of interventions focusing specifically on people of black African heritage living with HIV and the particular challenges they may face with adherence.

In order to develop effective interventions to promote adherence, we need to address the right barriers and fully utilise facilitators. This constitutes a complex area worthy of more detailed examination, especially in a population who is under-researched but over-represented within HIV care. There is a strong case to suggest that experiential qualitative approach is warranted to increase understanding of patients' beliefs about treatment for HIV [18].

Previous research [5] has suggested that patient beliefs about the necessity of being on ART impact both uptake and adherence to ART. It is logical to suggest that personal beliefs, circumstances and emotions will impact upon each person's ability to adhere in different ways. For these reasons, we have employed Interpretative Phenomenological Analysis (IPA) [19] to provide an in-depth exploration of the experience of treatment in a group of women of West African heritage living with HIV in London with documented difficulties with adherence to ART. Indeed, Skinta et al. [20] have demonstrated that IPA can be used extremely effectively to uncover the nuances and details within the lifeworlds of a small group of people living with HIV, as we aim to do in this paper. IPA is an idiographic, experiential, psychological methodology which provides a detailed analysis of convergences and divergences in individuals' accounts of their lived experience.

IPA was selected over other qualitative methods since it is particularly well suited to health psychology research [21], and is an experiential method [19]; as we have seen, there is a need for more experiential work to help unpack complex individual experiences of barriers and facilitators to ART. Given the potential for nuanced and multi-layered findings within the topic, we believe that IPA was a stronger choice than other experiential qualitative methods

such as grounded theory [22, 23], narrative analysis [24] or descriptive phenomenology [25]. IPA is well suited to subjects that are multifaceted and equivocal; it allows the researcher to focus in on a particular phenomenon, rather than a whole life story, and it allows space for idiographic variation, rather than searching for essential structures or basic theory. A detailed description and interpretation deriving from an IPA reading of these women's experiences will enable the reader to explore the lifeworlds of these women and understand the barriers they face in adhering to ART, together with factors that have helped improve adherence. Although exploratory, these types of findings can, as part of a broader repertoire of approaches, act to inform the development of interventions, for example by helping to calibrate quantitative instruments and by offering content material to constructs in interventions which involve vignettes and narratives.

## Method

All authors contributed equally to the design of the study.

### Sampling

Participants for this study were part of a larger cohort selected for a thematic analysis. This group was recruited from the specialist NHS HIV outpatient clinics at two London hospitals. Criteria for selection to this larger sample were that patients must be of Black African or Caribbean heritage, living in the UK, English or French speakers, and to be currently being treated with ART for HIV. Further to this, participants were deemed, following study of blood results and notes, as well as consultations with healthcare professionals, to have some evidence of adherence difficulties with their medication. The first and third author worked closely with clinicians at the participating hospitals to look for spikes in viral load within potential participants' blood results, as well as reviewing potential participant notes to look for discussions about adherence difficulties. Further to this, clinicians suggested potential participants who they believed to be struggling with adherence.

For this paper, we conducted a more detailed examination of how personal factors come into play within a more closely designated group. From the larger cohort, we selected 10 West African, English speaking women for this study. The principles of IPA require working with small, homogeneous samples [19]. Smaller samples allow for greater idiographic detail to be uncovered. Whilst the larger, thematic study gives a wider illustration of the topic, we have narrowed down on one key group. Our small

sample enables us to explore the experiences of this group in great detail.

It may be argued that a smaller sample results in a loss of generalizability. However, it is not suggested that one can make specific generalisations from IPA studies in the same way that one can from traditional, quantitative psychology studies. Instead, the interpretation of accounts in a study will present a particular perspective as accurately and with as much resonance as possible. Sandelowski argues that: "the real business of case studies is particularisation, not generalisation" [26, p. 527]. Hence, in-depth case study work of this nature can complement broader, traditional quantitative work by adding texture and resonance to the existing picture but also by problematizing some assumptions in quantitative work and leading researchers to expand their construct base.

Of course, there may be important information about facilitators to adherence to be gleaned from people living with HIV who are adherent to their medication. However, there is existing, high quality qualitative literature which compares excellent and sub-optimal adherers to ART [27]. In this instance, we were interested in providing a new dimension to the picture by looking in-depth at the idiographic experiences of non-adherers. In addition to this, since IPA works with a principle of homogeneity to order to ensure that the phenomenon in question is foregrounded [19], a decision was made to explore the experiences just of those who appeared to have difficulties with adherence. This decision to focus on a sample of West African women was also guided by IPA's principle of homogeneity and a desire to respect demographic differences of gender and heritage. Future researchers may wish to focus on the experiences of men. Details of participants can be found in Table 1.

Approval for this study was granted by the City and East London Research Ethics Committee. Informed consent was taken in a session prior to interview, in which the procedure was explained to participants and any questions about taking part were answered.

### Interviews

An interview schedule comprised of open questions addressing views on treatment was drawn up. Interviews took place in consulting rooms at the two hospitals and were audio recorded before being transcribed verbatim. The interviews were conducted by the first and third authors. The interviewers emphasised that the participants were the experts on the topic of ART, and used open ended questions to encourage participants to speak candidly about their experiences. Any interesting or unexpected leads established by the participants were followed up by the

**Table 1** Demographic information for the participants

Name	Age	Marital status	No. of children	Country of origin	Years in UK	Job status	Date of diagnosis
P1	42	Separated	3	Sierra Leone	7	Unemployed	2006
P2	43	Single	1	Nigeria	16	Student	2001
P3	56	Single	0	Ghana	56	Unemployed	1999
P4	32	Cohabiting	2	Nigeria	10	Employed	2003
P5	44	Widow	2	Nigeria	13	Employed	2002
P6	46	Married	6	Nigeria	6	Unemployed	2005
P7	42	Single	2	Nigeria	14	Employed	2003
P8	42	Divorced	3	Ivory Coast	10	Employed	1996
P9	40	Single	1	Nigeria	8	Employed	2003
P10	30	Cohabiting	0	Guinea	6	Employed	2008

interviewers. The interviews themselves lasted between 23 and 70 min (mean = 47 min).

### Analysis

The analytic process followed the guidelines for IPA [19]. Interviews were transcribed by a professional transcribing service, and then checked for accuracy by the first author. Each transcript was first analysed in its own terms. The transcript was read a number of times. Notes of descriptive, linguistic and conceptual features were recorded in one margin. These notes were then transformed into themes capturing the experience in a nuanced, detailed and yet succinct manner. Themes were clustered into groups, bearing in mind intrapersonal patterns of convergence and divergence, and given super-ordinate theme titles. Once this was complete for each transcript, further interpersonal patterns of divergence and convergence were then traced across the sample, which resulted in a master table of themes for the group.

The first two authors took the lead on analysis. Initial analytic work by the first author on the first three transcripts was checked by the second author who, by independently reading the transcripts, refined, modified and deepened the thematic schema. Once the two authors reached consensus on the early transcripts and moved on to subsequent interviews the second author's role shifted more to auditor, checking claims were warranted from data presented.

The master table of themes for the group provided the springboard for the first draft write up, but analysis was continually refined and honed during the writing process. Thus, analysis of the participants' experiences continued during the writing up of the study, as certain themes and quotations revealed themselves to be more potent in uncovering the stories of the participants [19]. All authors contributed to the final write up of the findings. IPA involves a double hermeneutic in order to make sense of

the participant's sense making around their own experience [19]. Thus the themes in the results section are evidenced by extracts taken from participant's transcripts followed by interpretations of those extracts from the authors. Those interpretations stay close to the respondent's words and offer a combination of empathic and reflective reading. This also provides a further layer of validity as the reader of the paper is themselves enabled to check the viability of the unfolding account in the light of the evidential base and the interpretative narrative.

### Results

Analysis revealed three master themes, which tell the story of difficult adherence and how it may improve over time. In the first theme, we can see that all of the women struggled with different aspects of the medication, making adherence challenging. In the second, it is shown that experience of medication can improve as time goes on. Finally the third theme explores spurs to adherence. This table of themes is reported in Table 2:

#### The Negative Experience of Medication

Nine of the 10 of the participants talked about the experience of taking the medication as being a negative force in their lives. These experiences broke down into four sub-themes, which were: An aversive regime; Disconnect between treatment and feeling of health; Feeling trapped in a monotonous life sentence; and Social context exacerbates the difficulties.

##### *An Aversive Regimen*

Most of the women found their medication regimen extremely onerous. A number commented on the sheer difficulty of having to take so much medication:

**Table 2** Table of themes

Master themes	Negative experience of medications	Temporal improvement in the experience of medication	Spurs to adherence
Sub-themes	An aversive regimen		Intrinsic motivators
	Disconnect between treatment and feeling of health		Relational motivators
	Feeling trapped in a monotonous life sentence		Sense of collaborative agency over the medication
	Social context exacerbates the difficulties		

Before in the night I used to take 20-something tablets and then in the morning, around 8, and it was too much, too much. (P7)

P7 is overwhelmed by the large a number of tablets, a sentiment echoed by P1:

When they bought the medication to give me loads in a cup maybe 13, 15, I say I don't want to drink this medicine, it's too much.

Many of the participants noted features of the appearance of the tablets which distressed them. P3 comments on their colour:

They are orange and blue, they're not the regular colour you would expect so for me, I am seeing something that just looks unreal really.

For P3, the colours of the tablets are a signal that something out of the ordinary is going on. The tablets are impossible to ignore. It may be that P3 is thinking that the loud colour, almost a warning siren to the outside world that stigmatised ill health is happening here. P9 seems to feel suspicious of the tablets due to their unusual appearance:

Everything, the size, the colour. If it was just this innocent, white tablet common size that you get with paracetamol.

P9 unfurls a moral taxonomy. Paracetamol are small and white and therefore innocuous. By contrast the ART tablets seem to be imposing and sinister. While this most directly implicates a quality of the treatment, it may also point to a perception of a judgement on the condition. The tablets for HIV are big and bright and an obvious sign to the patient and to others of what is frequently considered a shameful illness.

A number of women talk about the uncomfortably large size of the tablets:

When you have three tablets to take at the same time you are scared and especially when it is big, you are very scared because when you take it sometimes you

feel it on your chest and it is like you're going to throw up. (P4)

We can see here how pervasive the dread of the tablets is. While the fear is a physical one, it also feels emotional. Perhaps the bigger the tablets are, the bigger the problem they seem to represent; three big tablets signify one very large enemy. Similarly for P3:

The tablets are big, they are ugly and they're not easy to take.

Again the word ugly suggests an emotional as well as a physical reaction to these tablets. After all, who would expect a tablet to be beautiful? For P3, ART has become personalized.

Frequently, the aversive features of the tablets lead to physical difficulties in taking them. Participants have had to find strategies to help them overcome this:

If I take my tablet I have to put something in my mouth immediately to take away the taste in my mouth, otherwise I will be feeling sick like I want to throw up. (P4)

The physical act of taking the tablets is invasive, disturbing and disgusting. The act of swallowing ART is physically repellent to P4, while P2 describes ritualistic behaviour to deal with the repulsion of swallowing the tablets:

Just be going around looking at, go in, go eat again and come back, make sure that there is good there and I don't like taking one I just it take it all once and I will have my drink.

The procedure is elaborate and involved, ensuring the body is forearmed with good food to withstand the invasion of the noxious substance. The preparations need to be carried out carefully but the ingestion of the tablets is then done as quickly as possible.

So great is the aversive conception of ART that, for P3, the very anticipation of the pills makes her feel sick:

Sometimes it's just overcoming the thought of taking them before you can take them and get rid of them.

The anticipation of disgust becomes disgust in itself. The thought of the tablets seems to create more of an issue for P3 than the tablets themselves. The term ‘get rid of them’ is interesting; the tablets are taking on the mantle of an aversive entity, perhaps in part becoming a symbol of the condition they are intended to alleviate.

Participant 9 powerfully summarizes the problem:

I felt that the medication put me off. The number, the size, the smell, different things and at times I just don't want to think about it.

P9 reminds us the different aversive features of the tablets can all come together producing an obnoxious gestalt. And P9 also here explicitly links this to the important consequence; the regimen is so unpleasant that patients try to avoid having to think about it. It is not surprising then that non-adherence happens, either as a deliberate avoidance or as result of forgetting something so unpleasant.

#### *Disconnect between treatment and feeling of health*

A number of participants pointed to a problematic gap between the treatment they were undergoing and their personal sense of being well or ill:

It's just taking the tablets I hate, because sometimes there is an improvement and sometimes there is not. (P2)

P2 feels a disconnect between the unrelenting routine of the medication and the erratic outcome of her blood results. P2 believes she is taking the tablets correctly, and yet the results do not reflect this. One can see how this experience of the medication would contribute to a sense of confusion and lack of faith in ART. Meanwhile, for P3:

I was taking them regularly and then suddenly they stopped working for some reason.

P3 had to switch to a new combination when a previous one failed. We can feel confusion and sense of injustice from P3, as she believed she was doing all she could with a combination she was quite happy on; and yet the blood results then gave a different story. This hits her hard:

I really felt it because I knew I was taking them regular and it was only two tablets a day and then to find out I had that resistance and I had to find another cocktail, that was really sad.

P4 also experienced some difficulties with medicines not controlling the virus. However for her, the emphasis appears to be more on a lack of any sense of agency or control:

My doctor then change it and then I had another medication after some time the medication failed and I was asked to change medication again.

P4 presents herself as entirely passive in this extract; these are all things that happened to her, rather than things in which she took an active part. Her doctors make the decision; her medication is the thing that fails; she does as she is asked. One can see how together, these experiences result in a feeling that since the medications do not work (for her), there may be less reason to be engaged and less opportunity to feel in control of the situation.

#### *Feeling Trapped in a Monotonous Life Sentence*

A number of the women experienced being on ART as monotonous and relentless:

They will tell you that you have to take it. It's the words ‘for life’ I hate, I can't stand it. (P2)

‘For life’ has echoes of the most severe prison sentence. Of course the tablets are also *for life*, in the sense of, to preserve life, which serves to remind her of the seriousness of her predicament. P2 also feels the routine is something that has been imposed upon her by an external force, ‘they,’ who force her to ‘take it’ in the way one may be forced to submit to an unavoidably heavy life burden.

P10 says:

It's just like, me, another me going around the house, really, at least you control your partner in some way, but this thing you have to be carrying everywhere.

P10's medication is a burden from which she can never escape. She anthropomorphises it in a striking fashion, seeing the medication as ‘another me.’ However, it is the medications that have the upper hand, wresting essential control away from P10.

P5 vividly describes the sense of exhaustion and ennui that arise from being trapped by this life sentence of medication:

You know the side effect of it, you still can't be bothered because you have to do it every day, you get tired. It's not like two times a week.

The unrelenting toll means that she cannot always bring herself to take them correctly. As a result of this sense of being trapped and the consequent exhaustion and depression, P5 explicitly invokes a desire for a break from the medication:

Let me take a break because after all I am still going to be on it for the rest of my life.

P4 echoes the fantasy of a positive break from the turgid routine:

Sometimes I just want to treat myself, I don't want to take this medication today.

This extract suggests that a day away from medication is a treat to be savoured.

Several of the women suggested that not adhering to their tablets was a way to try to escape the feeling that the regime is a repressive life sentence. P9 seems to hint at deliberately 'forgetting' her tablets in order to escape the monotony, saying:

Makes me think, it gets too much in my face... so at times I forget.

P3 points to how the nature of non-adherence can itself become habitual:

One week became two, two weeks became three and so forth and it was just easier not to take anything.

This extract accurately captures a growing sense of inertia as time slips away, making it easier to be in denial about the need to take the tablets P5 vividly captures the process:

Let me get my freedom not taking it. So I put it in one corner and I carried on living my daily life without taking my tablets.

Hiding the tablets away in a 'corner' gives her an occasional liberation from the unrelenting regimen.

### *Social Context Exacerbates the Difficulties*

For P6, the weekends can be a barrier to adherence:

The time I usually forget is weekends. Like maybe 30 min after, I say, 'Oh my medication!' Then just sneak in and take my medication, that's it.

P6 is married with six children, so it could be that the demands of family life at the weekend make it harder for her to keep to her medication routine.

Relatedly, P9 says:

Initially people were living with me so because of the crowd I couldn't take it.

The crowd suggests a distancing from the people who share her house, giving a sense of how isolated P9 feels in her condition. She still feels unable to be open about her medication and therefore take it properly.

The inhibition extends to the work environment:

I don't want to be popping pills everywhere and if you're popping pills at work all the time people look at you, are you alright? (P9).

P9 sees the tablets as something that should be hidden rather than something that can be openly taken and explained in front of colleagues. This is echoed by P2 who says:

In a way you look like a drug addict.

This emphasises the sense of shame she perceives in relation to her condition and the treatment for it.

P5 talks about how difficult it can be to remain adherent in the face of family circumstances, in this case, her husband dying of cancer:

I have to run around my girls now, my husband is diagnosed bowel cancer lying in the hospital, can't stand this. And still you want me to carry on remember about taking the pills?

These family pressures make the struggle to remain adherent in the face of the already challenging sense of a life sentence that much harder.

The reverse social context may also be a problem. P8 reports the impact of losing her partner:

He left me last year, I was really pissed off, I was really down. I stopped taking my medication completely, the virus was up and down.

We can see here how the breakdown of a relationship can become a barrier to adherence.

### **Temporal Improvement in the Experience of Medication**

Four of the women do express that there has been an improvement in the experience of taking the tablets, demonstrating how adherence can be a temporally dynamic process. P10 talks about how, over time, her attitude towards the tablets has normalised, so that they no longer feel threatening:

But the way I see it right now, it just like any normal (laughs) medication. Sense of the speaking, they just like paracetamol to me, so it's become natural for me to have them anywhere I go, yeah.

Use of the word 'normal' here suggests that previously, P10 had seen HIV medications as being 'other.' However, as time has gone on, the medications have become much more every-day, 'natural' things to keep in close proximity to her at all times.

P9 says:

Treatment's working, I'm using it. It's working for me so I've been able to overcome some of my [...] I

<sup>1</sup> [...] indicates editorial elision.

take it and I guess my body seems to be tolerating it fine, so it's better than before definitely.

P9 seems to be outlining a very pragmatic relationship with her medication. She is using it, and it is working and this is an improvement over time. Similarly for P1 an improvement in her condition seems to lead to a more positive attitude towards the medication:

Before I used to put it a lot in my mind – I'm HIV positive, oh God, how can I be – but now I am ok. Don't worry about your sickness, it's undetectable, don't worry, you are fine, you are fine, just be taking your medication. Since that time, the fear has gone.

The effectiveness of the medication has had a direct impact on P1's feelings of fear, helping her to accept her condition and feel less concerned about it.

P4 reported a positive experience with the tablets she is currently taking:

So far, so good, the one I'm taking now is fine, because they are not too big and I have time to take them at home.

We can see here P4's emphasis on the practical aspects of ART. If the tablets are easy to swallow and do not interfere with her day too much, P4 feels satisfied with taking them.

### Spurs to Adherence

Amidst the negative portrayal of the experience of ART medication, six of the 10 women discussed several facilitators which helped them keep to the treatment regime. This theme broke down into three sub-themes: Intrinsic motivators; Relational motivators; and Sense of collaborative agency over the medication.

#### *Intrinsic Motivators*

Both P2 and P8 recounted how memories of previous ill health worked as a motivator in terms of adherence. P2, who had previously been hospitalised, says:

In my case why I remember is like if I stop taking it I am always in the hospital. I am always, I will just go down.

P2 now recognises that not adhering to her medication has serious consequences for her. Her phrase 'just go down' gives a sense of the rapid decline that can ensue if she is not vigilant. Similarly, P8 says:

Two years ago I stopped taking my medication. I was tired, I was pissed off so I just leave it and I travel for a week. But when I came back I collapsed. I was in

hospital for 2 months, but from that I have been taking my medication on time. If I am going somewhere I will take it with me.

Again, we can see how serious consequences of previous non-adherence lead to improved adherence in the present.

P1 talks in a similar but more generic way:

Before the starting it was difficult but when I start taking it I feel better, I say I'm not going to joke with this because I need my life so I take it.

P1 is expressing her realization that when she doesn't take the tablets she feels unwell and this spurs her on to adherence.

P10 describes how gaining knowledge about her condition worked as an aid for her adherence:

I went to college to have, um, an advanced diploma in HIV and STD studies. So after I get more knowledge about it I decided to come back to my medication.

This extract demonstrates the practical value of gaining knowledge. As she learnt about the condition and how the medications work, P10 made her own choice to take ART again.

P8 has her own motivational spur:

You know it's gonna, only go away if you are taking your medication. You become like a normal person.

P8 is attempting to gain some value from the pejorative stigmatized image of HIV. The desire to rid the shame and become 'normal' again becomes motivation for adhering to medication.

#### *Relational Motivators*

Some of the women reported family to be an important motivator for adherence:

I have to take this thing to be here for my family, even when I was married I have to be there for my husband and my children. That is something you have to be looking at, if not then what are you living for? (P2)

My doctor said to me no... it's only, you are going to be on tablets for the rest of your life (big sigh). I found it very, very difficult to accept it, but initially I said I have to because of the sake of the baby. (P5)

P5's love for her unborn baby worked as a powerful motivator to help her accept both her condition and its treatment and to try to adhere.

Members of the family can also encourage adherence:



Sometimes she [friend] and my daughter are so fussy now, every minute they call me to make sure you are take it. (P2)

P6 appreciates the positive feedback she receives from her family in response to an improvement in her appearance as a result of taking the medication:

So I do take them then gradually, gradually, everybody was smiling at me again, even my smallest, ‘Ah mummy, you are back. You are not like a skeleton again’.

P6’s daughter’s use of the word skeleton here is interesting, because without ART, P6 is depicted as someone who is close to death. The medications bring her back from this fate, something that is reflected back to her via her relationship with her daughter.

P1 also asserts the value of people seeing her looking better if she takes the medication. When she adheres to her medication, she looks healthy, something that is reflected back to her via her relationships with others. In this way, this feedback from her relationships works as a motivator to adhere:

If you don’t take your medication people will know that you are sick but with taking the medication it’s good and I am taking it and feeling good about myself. Nobody knows my secret. When I am taking it, people don’t know. I am good looking but they don’t know what’s inside.

P1 sees medication as a way of guarding against an association with the sick role, something she clearly wishes to avoid. The medication allows P1 to be good looking and hence to feel good about herself. Of course her account has an edge. While the medication makes her look better and therefore brings her close to others, it also creates a gap as she is left alone ‘inside’ with the shameful secret of having HIV.

#### *A Sense of Collaborative Agency Over the Medication*

Several of the women expressed that they shared with their doctors a sense of joint agency over their medication experience. P1 said:

Any medication that does not fit me and I ask them to, they will change it.

Her use of the words ‘fit me’ here emphasise the importance of the medications suiting P1, rather than her having to fit around them. She is working in conjunction with her healthcare team, whom she feels very confident will switch the medicines if she asks them to. Further to this, P10 says:

So I give to him, this is what I want. So we are going to look for medication that goes like. If there is none, we have to check again (both laugh)! We have to adopt something, sort of thing! So I was quite happy we find what I needed.

There is a strong sense of partnership between P10 and doctor, emphasized by the repeated use of ‘we’. Together, they are able find the right medication for her. Again, there is a strong sense that the medications are having to fit in with P10’s life, rather than her having to submit to their unyielding nature. P10 clearly knows what she wants here, and this ability to define her needs and, in collaboration with the health-care team, retain her agency leads to a more positive relationship with the medication.

Relatedly, P6 says:

I like to be active. I don’t like to be sick. Likewise I don’t want to be poorly or sick so I like taking my medication the way they have prescribed.

P6 has faith in the doctors to help her achieve her desired state of vitality. She understands that the doctors’ instructions around the tablets, as well as the tablets themselves, are important in terms of adherence and effective treatment. Hence we can see here how a feeling of collaboration with the doctors allows some of the women to gain an enhanced sense of agency and to feel more positive about their treatment regimen.

## **Discussion**

### **Negative Experiences of Antiretroviral Medications**

Nine of the 10 women talked about negative experiences around taking ART. A novel finding of this work is the degree of difficulty reported in taking the medicines, with physical features representing a barrier to taking ART. One paper [28] and one review [16] mention that the size and taste of tablets can be a barrier to adherence, but this is not explored in any great depth.

Sankar et al. [17] make the point that, “Stigma is a kind of self-awareness of an undesired status” (p. 215). The big, bright, unignorable appearance of ART tablets alerts some of the women in the current study to their internalised stigma every time they face taking them, which becomes a barrier to adherence. This feature of the tablets themselves is worthy of further exploration, perhaps via a qualitative study asking participants directly about their feelings around the physical features of the tablets, since a deeper understanding of the reactions elicited by the appearance of the tablets might illuminate possibilities for making them easier to swallow.

Our findings also show that for some participants, there was a disconnect between their expectations about ART's effects and their experience of health. Participants felt that they were adhering, but their blood results or symptoms were not responding in the ways they expected. For P4, this seemed connected to a sense of being entirely passive within the treatment; it was something that happened to her, rather than something in which she actively engaged—a finding reflected in the experiences of Sankar et al.'s group of 'somewhat adherent' participants [17].

Earlier research suggested that some people of black African heritage living with HIV in London felt that ART wouldn't work for them because it had been tested on white people [29]. There was also some suspicion amongst those living with HIV at around the same time as to whether ART was harmful rather than beneficial (see e.g. 17, 28). Our findings suggest that this narrative has moved on. While there is no longer a suggestion that ART in general is harmful or doesn't work, some people living with HIV may feel that ART doesn't work for them personally. This sense of disconnect may come from a lack of understanding of how ART works and how to adhere to treatment correctly. There is plenty of literature to support the notion that, like our participants, many people taking ART believe themselves to be adherent when in fact they are not taking their tablets in the correct manner (see e.g. 16, 27, 30, 31). Indeed, some findings show that worse HIV symptoms correlate with lower adherence [32], suggesting that those with the most need have the least knowledge. It seems that despite the high rate of education offered to people living with HIV about ART, more work is needed in this area.

Many of the women in the current study described their ART regimen as a feeling of being trapped in a monotonous life sentence. This could lead to feelings of depression, and to deliberately 'forgetting' in order to escape the prison of adherence. Feelings of hopelessness [27] and depression [16] connected to adherence to ART have been noted elsewhere in the literature but our work points to the extent of the tedium or relentlessness. Previous findings have described examples of deliberate forgetting (see e.g. 15, 33) of medications. However, these instances are usually connected to issues around stigma, such as not wanting to be seen taking drugs, rather than a feeling of monotony associated with the regimen. In this way, our novel findings are again suggestive of themes to consider when modifying interventions to improve adherence.

Participants in this study also found that social context, in the form of work or family life, could have a negative impact on their adherence levels; if participants didn't want to disclose their HIV status to work colleagues or family members, then taking ART near them became challenging. This is a finding that is consonant with existing literature. Flowers et al. [12] demonstrate how the wider social

context of being a person of black African heritage living with HIV in London can impact on adherence in terms of concerns about deportation, separation from loved ones, problems in accessing healthcare and so on. Just as it was for P9 in the current study, living in shared housing presented a problem for some of the women in another qualitative study [11]. The demands of childcare have been named as a barrier to adherence in various studies [16, 17, 34], whilst family commitments are cited elsewhere [31]. We can therefore see that social context can make adherence challenging. This problem deepens, since a lack of disclosure to loved ones has been shown to lead to social isolation and depression, which can create further barriers to adherence [13, 15, 16]. It would therefore seem that disclosure to understanding friends and family should be encouraged, so that social context can be utilised as a support, rather than a threat.

### Temporal Improvement in the Experience of Medications

Several of the women describe an improvement in their relationship with ART as time passes. Tablets became normalised, and participants found treatment combinations over time which they believed suited them better. Remien et al. [28] have described how adherence to ART is a dynamic process that changes over time, which clearly reflects the experiences of these participants.

Although previous work has suggested that attitudes towards ART change, it is unclear how they change over time. One review [16] suggests that confidence in the effectiveness of medications can improve as the medication is shown to work through good blood test results, feedback from others, and discussions with people who are taking the same combinations [16].

Sankar et al. [17] report that higher adherence correlates with worsening symptoms, suggesting a possible improvement in adherence over time. Findings elsewhere contradict this, suggesting that adherence in fact worsens as time goes on [5] and as symptoms increase [32]. These mixed findings highlight the benefits of idiographic, qualitative research such as in both the current paper and other successful IPA studies (see e.g. 20), since the story is unlikely to be the same for all people attempting to adhere to ART. Gonzalez et al. [32] highlight the need for more longitudinal research to explore this dynamic process of adherence to ART, a recommendation which the findings in the current paper support.

### Spurs to Adherence

Various factors were found to facilitate adherence for the women in the current study. As has previously been stated,

one paper [32] has shown that increased HIV symptoms correlate with a lower level of adherence, a finding which seems to contradict the suggestions of the women in the current study that previous highly symptomatic periods of time make adherence easier. However, perhaps what our study shows is how people living with HIV may react to highly symptomatic periods once they have survived them, rather than how adherent they are whilst those periods are taking place. The findings of Sankar et al. [17] seem more in line with ours, where participants who had developed AIDS were more likely to be adherent than those who were less symptomatic. Several other studies [28, 34] have found that a desire for good health is a strong motivator for adherence; it seems logical to guess that such a desire might follow a period of extreme ill health. Just as P10 utilised her increased knowledge of HIV as a motivator, it has also been found elsewhere that greater knowledge results in better adherence [17, 30].

Our in-depth, qualitative findings include the novel finding that conceptual motivators for adherence, such as using ART to feel closer to normality, or retaining a sense of autonomy over the regimen, can help with adherence. This demonstrates further the importance of idiographic work in this field, which can highlight hard to access motivators for adherence, and stresses the importance for healthcare teams of taking each person who struggles with adherence on an individual level and listening to what may be pertinent for them.

Participants also talked about relational facilitators to adherence; family, and especially children, were great motivators for several of the women. The impact of children on adherence crops up frequently within the existing literature. However, this is a complex area, as sometimes children can be motivators, and as described above, their presence can be a barrier to adherence. This pattern is somewhat mirrored in the current findings, in which we can see that social relationships can be both motivational and problematic depending on the circumstances. For example, living with others can work as a barrier, whilst caring for children can work as a motivator.

One review of the literature [16] agrees that children can be strong motivators for adherence, and that they can also help their parents to remember their medications, as we saw P2's daughter doing. Findings elsewhere [11, 28, 30] back up this positive picture. Doyal and Anderson have shown that it is not just mothers for whom children work as a spur to adherence; their qualitative study looking at heterosexual African men living with HIV in London shows that fathers are also aided in their adherence efforts by their children [13].

For some of the participants in Sankar et al.'s study, children worked as a barrier to adherence [17]. These African-American women lived in fear of their HIV status

being disclosed. In particular, they worried that their status being discovered would lead to bullying and stigmatisation for their children. Therefore, if the women were in situations whereby being adherent (such as collecting medications from a chemist or taking ART in a public place) might put their children at risk from associated stigma, they would be non-adherent.

Interestingly, excellent adherers in another study [27] rarely mentioned other people as motivators, but instead were motivated from within, citing a desire to stay physically healthy as a major reason for taking ART correctly. In contrast, those who felt that others, such as children, relied on them to adhere were more likely to fall into the sub-optimal adherence group. However, it should be noted that the excellent adherers within this study were open about their HIV status and likely to have strong social support, so perhaps there is an important difference to be teased out between a feeling of support and a feeling of dependence for some people living with HIV.

Finally, our findings suggest that a sense of collaborating with healthcare teams over ART leads to a heightened sense of agency and greater adherence to ART—which is consistent with existing literature [16, 17, 28, 30]. Our work highlights how a sense of collaborative involvement with the medical team can also enhance the patient's faith in the efficacy of the regimen. We would therefore recommend that clinicians try to involve their patients in decisions around ART as much as possible in order to encourage a sense of active engagement within care.

## Reflections and Limitations

Although we believe that this paper is an important contribution to the literature around adherence for people of black African heritage living with HIV, it does have some limitations. Firstly, identifying non-adherent participants was challenging. Adherence can be hard to quantify, since patients may find it hard to speak openly with doctors—and indeed researchers—about their adherence habits, or may not have the same understanding of adherence as clinicians do [27, 35]. Consequently, we identified those we believed to be non-adherent by looking at blood results and reviewing patient notes, but it is conceivable that we didn't find all the non-adherent participants we could have done. Indeed, the most non-adherent patients—and therefore the most vulnerable—will be lost to follow up and therefore impossible to recruit via hospitals. This is an ongoing challenge for any researchers tackling the issue of non-adherence [36].

In addition, as mentioned earlier, it might have been useful to speak to those who did adhere well to their medication in order to uncover information about facilitators for adherence. However, this would have compromised

IPA's principle of homogeneity [19], so wouldn't have been appropriate for this study. Future researchers may wish to speak to this patient group.

We explained earlier in the paper our rationale for a homogeneous sample of black West African women. This enabled us to examine the personal experience this specific group in some depth. It would be valuable to follow this study up with further work with other purposively selected samples, for example black West African men, sub-Saharan women, sub-Saharan men.

We consider this paper to offer a detailed insight into patients' experience of HIV medication, and believe it is the use of IPA that has enabled this. Of course, any single study and any one methodology can only offer a partial contribution to the bigger picture. The growing receptivity to a wider repertoire of methodologies within the social and health sciences means that we will increasingly be able to explore topics through a range of different lenses, and the triangulation of those different perspectives will afford a more comprehensive and complete portrait of the phenomenon under investigation.

## Conclusion

In this paper we have presented in-depth, idiographic findings from an interpretative phenomenological analysis of the experience of medication in a purposively selected group of West African women of black heritage living with HIV in London, UK. We have provided detailed evidence of their negative experience of adhering to the aversive regimen of the medication, which could leave the women feeling trapped. Our findings have also demonstrated how for some, treatment had improved over time. Further, we have pointed to factors which can act as spurs to adherence. We consider the paper to make a contribution in its own terms but we hope it may also act as a catalyst to further detailed research on the experience of other groups of people living with HIV, or other people having difficulties adhering to potential stigmatising medication regimes.

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