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## **The framing and fashioning of therapeutic citizenship among PLWH on ART in Uganda**

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## Abstract

**Background:** Health care providers can have a big influence on how people living with HIV (PLWH) understand, cope with and self-manage their condition. In this paper we analyse the interactions of PLWH with government and non-government organisations (NGO) providing antiretroviral treatment (ART) in Uganda. We examine how these providers helped PLWH to reconceptualise or 're-frame' their understanding of HIV and enhance capacity to self-manage the condition.

**Methods:** Between 2011-12, 38 PLWH (20 women, 18 men) were purposively selected from three contrasting anti-retroviral (ART) delivery sites in Wakiso District (Entebbe government hospital, referral health centres, and an NGO, The AIDS Support Organisation (TASO)). Two in-depth interviews were held with each participant.

**Results:** Government providers and TASO played an important role in supporting and shaping participants' HIV self-management processes. Re-framing processes began, in most cases, with health workers providing *information* to enable PLWH to construct more optimistic illness perceptions about the controllability, consequences and timeline of HIV, and re-appraise their situation in a positive light. Framing processes provided PLWH with useful *concepts and language* for emotional and cognitive coping, including disease normalisation, resistance thinking (against stigma) and a sense of belonging to a responsible community of PLWH. Given the low social status of many of the participants, particularly poor women, framing institutions were vital to build self-confidence and positive self-management options. Advice for *practical self-management* tasks, to promote one's own health and take responsibility for the health of others, was also absorbed, although it could not always be put into practice due to poverty or gender relations (influencing negotiations over safer sex practices). Notably, 37 out of 38 participants had become proud adherents to ART. The frameworks provided by TASO and government services had given participants a structure to live with HIV and regain control. ART providers are spaces for the development of a form of therapeutic citizenship, involving social interactions within the institutions and a shared sense of identity, responsibility and belonging to an HIV community, both enacted and imagined.

**Conclusions:** Positive framing institutions which build knowledge, use empowering language and offer a shared sense of purpose and motivation for self-management are important for many PLWH in resource-limited settings and the success of ART programmes

## Introduction

### Rationale and objectives

HIV diagnosis can cause profound disruption to people's lives and identity. The ability to come to terms with the newly acquired condition is likely to be shaped by the individual's disposition, and the support they seek and receive. This support can come from family, friends and, depending on the context, a range of government and non-government organisations (NGOs). In this paper we analyse the role of an NGO and government providers in the lives of people living with HIV (PLWH) in Uganda, and how people's interactions with these providers influenced their self-management of HIV. These organisations and their interventions can have a big influence on how PLWH understand and cope with the condition, helping to 'reconceptualise' or 'reframe' interpretations of the illness and how to self-manage (Abel et al. 2004; Watkins-Hayes et al. 2012).

The role of these 'framing institutions' is important for antiretroviral (ART) programmes because they rely on patients becoming active and effective self-managers. Although early fears of low adherence across resource-constrained settings have not been realised, and good adherence rates often reported, the reliability of adherence measures remains contested (Jaffar et al. 2008). Moreover, as the time period which many PLWH have been on ART extends into several years, on-going support from health providers to promote self-management and adherence is important (Beard et al. 2009; Mbonye et al. 2013a).

Nguyen et al. (2007) convincingly argued that achievements of high adherence in earlier ART projects in parts of Africa have several explanations, such as potentially non-adherent patients being excluded or early programmes receiving exceptional resource levels. Another explanation gives credit to the PLWH themselves, their good adherence explained by the concept of therapeutic citizenship. PLWH's personal experiences of HIV, and collective processes of support and empowerment, fashioned activists who saw themselves as the bearers of rights (to treatment) and responsibilities (including adherence) (Nguyen et al. 2007). More recent analysis has also shown the motivation for effective self-management and adherence to be the product of social and collective processes (Ware et al. 2009).

As more people in resource-limited settings access ART through conventional and less well-resourced models of ART delivery, the process of 'framing' and 'fashioning' knowledgeable and active patients, who can self-manage HIV effectively, has become critical for the success of this global project (Schneider and Coetzee 2003). It is likely that the majority of PLWH will not become activist therapeutic citizens, as described by Nguyen et al. (2007), but PLWH still need to develop a sense of purpose and motivation to sustain engagement with the health system and continue to self-manage.

In resource-limited settings, knowledge about PLWH's self-management processes on ART is limited, and tends to focus on adherence and health outcomes, rather than on other social and psychological self-management processes. Studies are beginning to explore these processes (Martin et al. 2013; Mbonye et al. 2013b; Russell and Seeley 2010; Wouters 2012), but only a few studies have examined in detail how the self-management frameworks and

messages discussed with patients are absorbed and affect aspects of their self-management (Allen et al. 2009).

In this paper the narratives of PLWH in Uganda on ART are analysed to examine the role and effects of health care providers on their journey to becoming effective self-managers and 'adherent' patients. The analysis is informed by two concepts: framing institutions and agents, and how these influenced self-management processes (Watkins-Hayes et al. 2012); and the concept of therapeutic citizenship (Nguyen et al. 2007), which encapsulates how framing processes 'fashioned' a sense of collective identity, and responsibility for health, among a group of PLWH. Implications for ART programmes are discussed.

## **Framing agents and the formation of therapeutic citizens**

### *Framing institutions and framing agents*

Framing institutions "...generate language, adaptive skills and practical knowledge that shape how individuals interpret a new life condition..." (Watkins-Hayes et al. 2012: 2030). These institutions might 'name and frame' HIV in ways that cause detrimental effects for people. For example a negative conceptualisation of oneself might be reinforced if implicit messages are given about 'blame' or 'needing to keep it secret'. Framing agents can also enable people to reconceptualise their situation more positively, cope effectively, and "ultimately see it as a platform for growth" (Watkins-Hayes et al. 2012: 2030). Several inter-related elements of the framing process can be distinguished:

- Provision of *information* about HIV, and how it can be treated, to help the patient acquire knowledge, and reconstruct their perceptions of the condition, for example that HIV is treatable and there is hope for the future.
- Supporting PLWH to use and develop *language* and *conceptual frameworks* which help them adapt emotionally and cognitively. When individuals can discuss traumatic experiences in a language that helps them 'cognitively reorganise' their situation, rather than ruminating on it, this can help people make more sense of their situation, see ways forward, which reduces negative emotions and improves coping with HIV (Abel et al. 2004; Chesney et al. 1996).
- Advice and instructions about *practical health-related self-management tasks*, such as monitoring the condition, diet or sexual behaviour.

The above framing processes will influence PLWH's illness perceptions and pathways to effective self-management. "Illness perceptions", part of a larger theory regarding the appraisal of health and choice of coping mechanisms (Leventhal et al. 1992), cover beliefs about what the illness is, how it is caused, its timeline (chronic or acute), how it may be controlled, and its consequences. Information which helps PLWH develop positive perceptions of their condition, such as a belief that the illness can be controlled and that with treatment its consequences can be limited, are likely to build hope and motivate self-management for example (Reynolds et al. 2009).

The effects of framing processes on people's self-management of chronic illness can be analysed using categories of self-management process distilled from the literature. Self-management is a complex, dynamic and interactive process, involving practical tasks, and psychological and social adjustments (Kralik et al. 2004; Russell and Seeley 2010; Schulman-Green et al. 2012; Sharpe and Curran 2006; Strauss 1990; Swendeman et al. 2009). Schulman-Green et al. (2012) distinguish three broad processes: a person's work at managing illness needs (learning, recognising symptoms, taking treatment, adopting healthier behaviours); activating resources (for example from social networks and also the health system); and the more complex tasks of 'living with the condition'. This latter group of self-management processes includes the emotional and cognitive work of 'adjusting' to the condition (coming to terms with a new condition, making sense of it), and adjusting to a new sense of self (managing identity, dealing with stigma) (Schulman-Green et al. 2012). These adjustment processes can be broadly defined as the incorporation of an illness and treatment into one's life and identity (Russell and Seeley 2010), and more specifically in psychological terms as the "...the process to maintain a positive view of the self and the world in the face of health a problem" (Sharpe and Curran 2006: 1161).

### *HIV citizenship / therapeutic citizens*

The concepts of therapeutic citizenship and local moral world (Kleinman 1992) informed our analysis of the effects of framing processes on people's adjustment to living with HIV on ART. The concept of therapeutic citizenship arose from analysis of the experiences of PLWH who had "enacted a way to move forward with their lives" (Nguyen et al. 2007: S32), using their biological status to claim resources and treatment from a network of support groups and organisations. As ART became available but remained scarce, PLWH sought to re-fashion themselves, individually and collectively, as therapeutic citizens, belonging to a global community, who became activists and members of social movements that made claims for the rights to treatment and social justice, especially in settings where state provision had been limited (Kielmann and Cataldo 2010; Nguyen et al. 2007).

Therapeutic citizenship describes processes of identity formation and action based on experiences of illness and treatment which are socially and historically specific, for example influenced by the nature of the state and service provision. A well-cited example of therapeutic citizenship formation is in South Africa, where HIV activism and the rise of the Treatment Action Campaign was forged in the context of political transition, an activist legacy from the anti-apartheid movement, and a state which was slow to expand access to ART (Fassin and Schneider 2003). In this paper we apply the concept of therapeutic citizenship to an analysis of the 'framing and fashioning' of people's identities, their sense of collective belonging and motivation, which can affect self-management on ART.

The political and treatment context in Uganda at the time of our research was different to that analysed in South Africa. Access to treatment had increased through the expansion of conventional ART delivery at a range of NGO and government providers, and traditions of political activism or protest are limited. So in Uganda it is unlikely that therapeutic citizenship will manifest as political or social activism in the way Nguyen describes. Instead, because ART is now widely available, framing institutions might be focused on the fashioning of therapeutic citizens who can be 'expert' and 'active' patients, who can self-

manage effectively and adhere to ART (Kielmann and Cataldo 2010; Schneider and Coetzee 2003; Swendeman *et al.* 2009). Depending on the institutional context, this could lead to the production of disempowered, 'compliant' HIV patients (Mattes 2011), or to the formation of knowledgeable and active therapeutic citizens who have shared experiences, identities and sense of belonging to a wider group of PLWH.

The form of therapeutic citizenship described above can be conceptualised as a "local moral world" (Kleinmann 1992), which refers to a body of concepts, language, beliefs, morals and practices that are shared by others. Local moral worlds are constructed through practices and interactions in particular contexts, and are likely to coalesce around organisations with which people engage. For example one could describe the local moral world of worshippers at a particular church, and here we describe the local moral worlds of PLWH who are on ART and attend TASO or government health care providers. Their local moral worlds as they relate to living with HIV have been framed and fashioned by these organisations, and constitute their 'therapeutic citizenship', a set of shared beliefs, responsibilities, moralities and practices, cohering around a network of HIV organisations in the local setting.

## **Methods**

### **Research design and study site**

In 2011-12 qualitative and quantitative data were collected for a study which looked at the coping, adjustment and self-management processes of PLWH on ART in Wakiso District, Central Uganda, and which also measured several outcomes among PLWH and a control sample such as quality of life and depression. In this paper we present the qualitative findings on the role of health workers in participants coping and self-management processes.

Three types of ART delivery site in the district were selected to recruit participants for the qualitative study: the HIV clinic at the government hospital in Entebbe; three government health centres that have referral links to Entebbe hospital; and the Entebbe branch of a well-established non-governmental organisation, The AIDS Support Organisation (TASO).

Wakiso District, which encircles the capital city Kampala, was selected as the research site because of the presence of established government and non-government treatment providers, and because the district has urban, peri-urban and rural characteristics. Many people in rural areas near the town still practice cultivation as their main form of livelihood, but there are also people engaged in fishing, various forms of trade, as well as formal employment.

Ethical approval for the study was obtained from the UVRI Science and Ethics Committee and the University of East Anglia, UK. Overall approval was granted by the Uganda National Council for Science and Technology. Pseudonyms are used in this paper to maintain confidentiality.

## **Sample**

To be eligible participants must have been on ART for more than one year. A list of eligible patients was compiled for each facility, and a systematic random sample taken using intervals to generate twice the number of cases required. These lists were then stratified by age and gender, and 42 participants were purposively sampled from the gender and age categories to ensure gender balance, a mix of ages, and a range of patient experiences and ART regimens. Four could not be interviewed successfully or more than once and were excluded from final analysis.

The sample is unlikely to be typical of all PLWH in this setting, and the results must be interpreted in this light. The participants had gone for a test and started treatment, and they were open enough about their status to be willing to participate in the research.

## **Data collection measures**

Participants were interviewed three times. The first two interviews were unstructured life and illness history interviews. Due to the wide-ranging and sensitive nature of the questions, these data were collected over two interviews. The two interviews were not taped, because experience in this setting indicated people are more open when not being recorded, especially in the first few interviews, but notes were taken and detailed life and illness history narratives were written up in English by the interviewers.

A third interview was semi-structured, and this was taped, transcribed and translated into English. The question guide was informed by issues raised in the life history interviews as well as the research objectives and related HIV self-management frameworks. These interviews explored participants' approaches to self-management, changes in their lives and wellbeing since becoming HIV positive and starting ART, and what factors helped or hindered their self-management. The use of several visits to meet participants allowed a degree of trust and rapport to develop, which in many cases led to rich discussions of participants' experiences.

## **Analysis**

Qualitative data were organised and initially analysed using QSR Software NVIVO 9 to support data management. To check the rigour of analysis, two researchers independently did the initial coding and checked results. Themes (nodes) and sub-themes were identified based on the narrative content, the research questions and the conceptual frameworks informing the research, in particular sociological frameworks for researching illness self-management. Thematic interpretations of the data were discussed and agreed by the team at a two-week analytical workshop held in Entebbe, Uganda in 2012. Themes were tested by checking counter examples and exceptions. The specific themes presented in this paper were analysed and refined further by the lead author(s). Quotes used in the paper are either the words of the participants or the interviewer's words used in the write up of the first interview. Pseudonyms are used with quotes to protect the anonymity of participants. Frequently repeated expressions used by participants across the interviews are not quoted but cited using italics.

## Results

### Participant characteristics

Table 1 summarises the socio-demographic characteristics of the 38 participants (18 male and 20 female). Thirteen were from the government hospital, 11 from the three referral health centres, and 14 from TASO Entebbe.

**Table 1: Sample for the qualitative study (n=38)**

Age/ sex	M	F	Total
0-17	0	0	0 (0%)
18-25	0	2	2 (5%)
26-40	10	10	20 (53%)
41-60	7	7	14 (37%)
61+	1	1	2 (5%)
<b>Total</b>	<b>18</b>	<b>20</b>	<b>38 (100%)</b>

More than half of the participants had some primary education and the majority were married or in a relationship. Their main economic activities were subsistence farming, fishing, construction work and petty trading.

### The influence of framing agents on illness perceptions

The majority of participants (31/38) were experiencing illnesses, some very serious, before finding the courage to go for an HIV test, with disruptions to their personal, economic and social lives. Some had lost their partner or a child to the disease. Their recollections of how they felt when they faced the health worker and received their test results revealed very negative illness perceptions. Common phrases included: *my life is over, you know you are going to die, who will care for the children, I will be rejected* (italicised phrases capture commonly expressed feelings across the narratives). Participants described their feelings of fear and loss of hope, and some worried so intensely that they felt they would die of worry before HIV.

At TASO, first encounters with staff were usually with trained counsellors, whereas at government facilities the participants first met nurses. TASO provides a more holistic approach to HIV care compared to government providers, with the latter mainly providing ART and accompanying ART orientation classes before a patient starts taking the drugs (held once per week for a month). Unlike the government health facilities, each of the TASO patients was assigned to a specific counsellor who was responsible for their wellbeing. However the information received by participants appeared to be similar across the two groups.

All 38 participants enthusiastically recalled how health workers changed their understanding of HIV. They learned how one gets infected, how it multiplies and attacks the immune

system, and that treatment was available which could control the disease and keep its consequences to a minimum. They were therefore helped to (re)frame HIV as a controllable not a terminal disease, with a future orientation extended from months to years, but on the condition that they adhered to the treatment and followed advice about promoting health.

New knowledge and illness perceptions improved psychological well-being. The threat of HIV could be reappraised, and from a situation of worry and despair, participants drew strength and hope for the future:

“My heart became strong because of the things that we were told by the health workers during counselling” (Judith, Female (F), age 27).

“They told me that you can live for many years on ART, and that if you eat well and stop worrying you can survive for a long time... that helped and encouraged me so much” (Paloma, F, 31).

“...I do not spend time thinking about how I am sick, no, no, no! That I am going to die. That was in the beginning when I used to get many thoughts....Now I have moved away from that stage and counselling helped me to overcome that” (Tom, male (M), 44).

For several participants, the initial side effects after starting ART were serious and caused fear and doubt about what they had been told. They feared that the stories they had heard about ART were being realised (*they kill you, they have a skull and cross bones on them*). The health workers' role at this time to encourage and assure them this was normal was especially important.

“When I called my counsellor and told him how the drugs were affecting me after about two or three days, I felt like I had no life and many things were happening to me like bad dreams, my private parts swollen...and I felt like life was coming to an end. My counsellor told me to go to TASO...When I reached the counsellor he encouraged me by telling me that the drug was very strong but I had to use it. He told me to drink a lot, eat well until the body gets used to the drug. He told me that the beginning is always hard but I will adjust...”(Peter, M, 38).

One explanation for participants' receptiveness to the health worker information was their great need for help and any words that would give them hope. Health workers gave them both. Over the days and weeks following diagnosis, they received only heartening information about ART and the manageability of the disease.

Two recurring experiential themes in the narratives also explain PLWH's rapid reappraisal of their condition. The first was people's recovery of health on ART: they felt for themselves that HIV was treatable and controllable. The second experience, frequently and powerfully told in the narratives, was the importance of 'seeing others' with HIV who looked well, and identifying with these others' positive experiences (Mazanderani et al. 2012). This identification was relatively easy because these others also had HIV (they are like me) and their health embodied what they desired to be. It was motivational because it reaffirmed

the knowledge they had acquired from health workers about recovering, and also helped them see they were not alone (see section 3.2):

“When he heard there were drugs that would help him continue to work if he followed what the doctors told him to do, his hope was restored and he also remembered his friends who were very sick and when they joined TASO, their life was restored and they became healthy again” (Benson, M, 34).

### **New concepts and language for coping**

Health workers supported individuals to develop psychological coping and self-management skills. One of the first things participants were told was *not to worry, because this will make you sick*. This was a simple message, but appears to have been absorbed as a process to aspire to:

“He told me that I had to be strong and not worry. That when you worry a lot, you die soon” (Bridge, M, 42).

“They taught me that if I worried too much I would lose weight and get problems so I cast my worries aside...We were told that when you are sick that should not stop you from being happy so I try to be happy all the time” (Joy, F, 27).

With the help of health workers, 37 out of 38 participants learned to accept their condition. In fact listening to the advice of the health workers and taking the treatment was said to be a key feature of acceptance:

Accepting her status did not come immediately, but when the health workers told her to stop worrying, she said to herself, something done cannot be undone, so she decided to accept the truth in order to get better and truly she got better and no longer worries because she knows that the situation is irreversible” (Ruth, F, 58).

Health workers provided concepts which supported psychological coping, ways of thinking about HIV and one’s position in the epidemic. Several themes in the narratives revealed that counselling had allowed participants to develop a language that ‘normalised’ HIV. First, HIV was reconceptualised as a normal disease, *like many other diseases*.

“Things have changed (HIV is more accepted)...now it is as if it is like any other disease, like you see sickle cell, pressure, ulcers or cancer” (Tom, M, 44).

For some, the remarkable recovery of health on ART meant HIV was even seen as less serious than other illnesses.

“The person without HIV can get malaria and he dies, leaving me behind with HIV” (Mathew, M, 51).

A related theme was evident in commonly used expressions, derived from counselling, about HIV being just one of many causes of death. An example of such an expression across

the narratives was *you can die from many other diseases and many other things; death comes to us all, so how is HIV any different?*

Second, HIV was also framed as a normal disease through reference to its prevalence in the community, and how many people were affected by it. Health workers had told them from the start *you are not alone, look around you*. All the participants drew on this language, using the phrases *I am not the only one, I share this problem with many others*:

“We are very many on drugs in this area...we are many and they admire us...” (Grace, F, 32).

“It is difficult to find a family that has not been affected by HIV in this generation” (Suzan, F, 43).

“...It’s everyone’s problem and you can hardly find a family without HIV infections and deaths” (Dorcas, F, 42).

Third, framing processes were experiential as well as through counselling, as was the case with illness perception changes. PLWH soon learned they were not alone because of the crowds they saw when they went to TASO or the government clinic. They gained strength from seeing this community of PLWH:

“We are at a point when we assume that everyone is HIV positive until they have been tested and told otherwise” (Anne, F, 29).

For stigmatising illnesses like HIV, framing agents have the potential to offer an alternative language for thought and speech, especially for marginalised groups, which can assist coping and resist dominant stigmatising discourses (Watkins-Hayes et al. 2012). The reconceptualisation of HIV as a normal disease helped participants reappraise their identity as a ‘normal’ person.

Health workers also encouraged resistance thinking by making comparisons with others in the community. The vast majority of participants used a similar language of comparison between themselves and *the many others who had not gone for a test and were ignorant of their status*. They could view themselves, individually and as a group, as knowledgeable and responsible, they had taken action to get tested, to gain control of the situation, and were not harming others:

“They (the health workers) told us that we were better than those who had not bothered to know their status, that we were better than those that were laughing at us. They laugh at you, saying that the motorcycle has come to your home, yet they are also sick but do not take the responsibility to go and get tested so they don’t know their status. That is what made me brave” (Judith, F, 27).

“Ever since I have known my status and got ART I have been very happy...At times I sit back and smile alone and then say there is someone who is HIV positive but he lacks knowledge...yet the support is available and the drugs are free” (Linda, F, 29).

## The fashioning of responsible patients

### *A framework for managing health and living with HIV*

Participants described how health workers provided a package of advice and instructions about how to sustain their physical health:

“She said that they were told many things...The counsellor would teach them about the dos and don’ts while on ART... the first thing they were taught was to adhere to the drugs... She added that balanced diet, acceptance, drug effects like hallucinations and skin darkening were taught to them, abstinence for those who could, condom use, testing children for HIV, and making a will” (Dorcas, F, 42).

Participants were also told about the negative health consequences of not following the ‘rules’, especially drug adherence. They described a type of ‘contract’ between themselves and the health workers, which provided a useful ‘framework’ for living with HIV:

“They give you the drugs, you follow the instructions, and stop worrying” (Judith, F, 27).

“It (the counselling) is very useful because after counselling I get to know how I am supposed to move on with my life. I become strong at heart and know that I have to live in this way. (Jacob, M, 32).

“I knew that I was finished and was just waiting for the day I would die. But sticking to the words of the *Basawo* (health workers) has helped me... and that is why I look really fine now.” (Jerry, M, 45).

The same instructions about self-management were described by women and men who used TASO and government providers (Box 1). These are similar to those reported elsewhere from Uganda (Allen et al., 2011). Some reflect both a public health and a moral discourse about sexual activity. Instructions were given to participants during initial individual counselling sessions, subsequent ART orientation group sessions, and then on-going group sessions on clinic days. The key elements relevant to the framing of therapeutic citizenship are examined in more detail below. We focus on whether participants had accepted and integrated the framing messages into their concepts and language, whether they had affected ways of thinking about health self-management, and whether they should strive to abide by the rules, even if it was not always possible.

### **Box 1: Practical rules for self-management**

#### **Adherence to medication**

Set the times each day to take the pills

You may get side effects

Take the pills with food

Do not share the pills

If you vomit straight after taking the pill, take another

If travelling, pack the pills in your bag before anything else

#### **Health promotion behaviour: diet, hygiene and other drugs**

Eat a nutritious diet

Boil water to drink; drink a lot of water

Personal hygiene such as hand washing

Use a mosquito net

Stop drinking alcohol

Stop smoking cigarettes

#### **Self-monitoring and managing the body**

Report side effects

React quickly to illness, seek treatment

Do exercise, but do not over work: know the limits and reduce workload

Get CD4 tests done

#### **Preventing transmission, responsibility for others**

Use condoms

Disclose status to partner

*Messages targeted particularly at men:* do not be promiscuous; be faithful to your partner; give up on multiple partners

*Messages targeted particularly at women:* abstain (if you can); reduce sexual activity; avoid pregnancies; *'Giving birth weakens health'*

If you want a new partner, find a partner who is also infected

#### *The responsibilities of adherence and eating well*

Adherence messages had been understood by nearly all the participants, across gender and socio-economic status. An acceptance of the medicalization of their lives was evident: taking the drugs was ingrained into their minds:

“I take my drugs without a reminder – I am programmed to take them...” (Naome, F, 26).

“To me now, ARVs are like eating food. I have to eat breakfast, lunch and supper so that is how I am. I take my drugs like food and that is how it is” (Tom, M, 44).

Participants took great pride in their adherence, saying it was one of their greatest achievements. They used metaphors for the drugs, indicating they warmly embraced the regimen: *drugs are my food; I respect the drugs, they are like my mother and father*:

“These drugs are like food for me, can you forget to eat food?” (Suzan, F, 43).

“I cannot forget, I never forget. It is like eating food: drugs are food, so how can you forget food?” (Matthew, M, 51).

One man was not adhering to treatment, possibly due to mental illness and lack of money for the accompanying food he said he needed to take with the drugs. Another (Angelo) said he did not take an evening tablet four times a month because he went out drinking with friends and was worried about mixing the treatment with alcohol. Only in serious situations (relating to bereavement and migration) were two female participants forced to stop taking the drugs for a prolonged period.

Messages about eating a good diet, clean water and hygiene had also been absorbed into the language of self-management. These were relatively easy messages to accept and ones which all participants strived to do within the constraints of their budgets:

He tries to eat very well as recommended by the doctors, and to drink about three litres of water (*he was sipping from a one and a half litre bottle of water as we conversed*). He also said that he was advised to take raw onions because they act as immune boosters and he makes sure that he takes this at least four times a week (Benson, M, 34).

Poverty meant many of the participants only ate one main meal a day, and 4 out of 20 women (20%) and 5 out of 18 men (28%) really struggled on a daily or weekly basis to get enough food, so they could follow what they understood to be food-related rules: taking the drugs with food (a rule for older classes of drug, which might still be framing behaviour for those on newer regimens) and eating a nutritious diet. And although a third of the women could meet the ‘good diet’ requirements, the majority struggled on some occasions:

“She tries as much as possible to follow whatever she was taught, but it is hard to always follow the balanced diet as money is scarce (Ruth, F, 58).

“Poverty means we cannot always follow the recommended diet” (Bridget, F, 33).

The prominent narrative of *I take the drugs but cannot always eat the recommended food* strengthens the argument that participants had absorbed the values and responsibilities of adherence, or at least were speaking in the language of that local moral world in the context of the interview. They were determined to adhere despite food shortages:

“Even though I do not have something to eat because of the scarcity of money, I swallow the drugs because I know my life depends on them.” (Jacob, M, 32).

“..he said that if you do not have enough food to take along with the drugs, you are in trouble. Even if he does not have the food, he would rather take the drugs in pain

because they are more valuable to his life than the food. He told me that he and the wife are sometimes forced to take the drugs without the food because there is no money to buy even posho or beans..." (Paul, M, 39).

### *'Responsible' alcohol use*

Strong advice to stop drinking and smoking was given to men and women, although interviews suggested this advice was targeted more towards men. Men's narratives were more preoccupied with issues around stopping alcohol consumption. The majority of men said they had stopped drinking because it can make you forget to take the drugs and health workers said it would hinder their efficacy:

He used to drink alcohol, but when he tested positive he stopped because he was advised by the health workers that alcohol is stronger than the drugs (ART). He was told that when he drinks alcohol and takes the drugs, the liver first works on the alcohol and by the time the drug reaches the liver, the liver is spoilt and cannot work effectively" (Benson, M, 34).

All the men (and women) had accepted the need to stop drinking, and some men had completely stopped, but several of the men's interviews indicated that 'stopping' alcohol meant a substantial reduction in the frequency of drinking and a cessation of binge drinking:

"Every Wednesday and Sunday, I go to thank God for helping me stop drinking alcohol. I realized that alcohol would make me forget taking drugs and it also contains acids which might not go well with the drugs I am taking. I used to drink all types of alcohol from beers to local brew. I sometimes feel like taking *malwa* (local brew made of millet), and if I get *omulamba* (made from sorghum) I drink it because it is light and very delicious." (Davis, M, 43).

Several men drank because it had become integral to their lives, pleasure and their social life. Angelo said that the reason he went for a drink four times a month was to sustain his friendships and social life:

"It is hard for someone to stop eating the kind of food (i.e. beer) he grew up eating"...He thinks that he cannot leave alcohol because when he sees a friend drinking, he also feels like drinking although he does not take it every day (Angelo, M, 47).

Participants' self-management responses were indicative of a desire to change behaviour and follow the instructions. Not surprisingly this could be a hard behaviour change to put into practice, notably for the men but also for some of the women, and often the language of 'trying' to change rather achieving it was used.

"I eat a good diet; I try to avoid drinking alcohol" (Gloria, F, 29).

### *Preventing transmission: responsibility for the health of others*

Sexual behaviour messages, and the constraints that people face or aspirations they need to negotiate when trying to change these behaviours, are well documented in Uganda (Allen et al. 2011; Martin et al. 2013; Mbonye et al. 2013a; Seeley and Russell 2010). Participants understood the advice they had received about sexual behaviour as an important, if not central, part of their adjustment to living with HIV, and as a serious responsibility to protect their own health and the health of others.

Sexual behaviour messages were implicitly normative or moral, because being ‘responsible’ (using condoms, not having multiple partners for example), and thinking of others’ health, is clearly what one *should* be and do in this situation. But these moral messages mapped easily on to the biomedical logic that health workers wanted to impart as well: to avoid infecting others, it makes sense to reduce sexual partners and sexual acts, and to use condoms.

Sexual behaviour change messages were also gendered, in that their content appeared to be targeted differently towards men and women, and in general required different types and degrees of behaviour change for men and women. Although appearing gender neutral, messages targeted behaviours more usually identified with men: promiscuity; multiple partners; and greater agency over the use of condoms. They targeted the normatively ‘less moral’ or medically ‘more risky’ behaviours of men.

Narratives showed that sexual behaviour messages had been understood and absorbed, and that participants did their best, in their particular circumstances, to take that advice on board when they made decisions. But of course these decisions were not always fully in the hands of the individual, and constrained by gender relations, economic necessities, stage in the life course, a desire for children, and so forth.

Half the women said they were now practising abstinence. This decision for some was made following widowhood, and was reinforced by messages from the clinics. It was a decision also made easier because of stage in the life course (e.g. they had had children already). Some women also emphasised the positive decision to *give up on men* and avoid the stress and trouble that men cause, as well as to protect their physical health:

“I stayed away from men because we were told by counsellors that if you have frequent sex you die quickly” (Suzan, F, 43) .

Others were practising abstinence, even though they were younger, for similar reasons. Although they did not have a man to bring in money, it made for an easier and healthier life:

“...ever since she got to know about her HIV status, she has never got married again and she believes that this has also helped her... during orientation, they were told that those who abstained lived longer and that is what she is following” (Mercy, F, 35).

Two of the younger women were single but aspired to have a child if they could meet the right partner (Linda, Gloria). It was noticeable that their status appeared to have empowered them to take their time about finding the right partner.

Women in partnerships were negotiating the rules to fit their circumstances. Some were with the partners they had before diagnosis and ARVs, and six were with new partners whom they had met after diagnosis (2 of these had not disclosed their status to their partner). In general their agency around disease self-management decisions relating to sex was constrained due to poverty and economic dependency, the strong if not absolute expectation that they would have children, and their subordinate position in a patriarchal culture. For example, these women were using condoms but did so inconsistently or had stopped using them because it is difficult to sustain their use in long term relationships. Two of the women had had a child since starting on ART and one woman was pregnant at the time of research.

Men also aware of the changes to sexual behaviour expected of them, and from their overall narratives, changes in their life, their priorities and wellbeing, changes in sexual behaviour appeared to have been put into practice by all the men, to differing degrees. None talked about abstinence. Most men said with some conviction that they were faithful to their one partner, and most stated that they used condoms with their partner:

He used to be a party person, enjoying his life.... He used to go to bars... But when he was taught by the *Basawo* (health workers) that his health would be affected by this lifestyle, he changed for the better... "I gave up on promiscuity and alcohol because they could affect my drugs. I also left partying because I could easily die early. Sometimes, the other person might have a worse virus than yours and they give it to you; I gave up on all that" (Jacob, M, 32).

"I also found out that my wife was not infected and decided to stick to her... I started sticking to condoms because I did not want to infect my wife, as we had been taught" (Jacob, 18).

"I have sex with my wife but not on a regular basis. We are told that frequent sex can make you weak. They also told us to use condoms during the sexual encounters to prevent reinfections and unwanted pregnancies" (Jerry, M, 45).

Men's responses overall can be summarised as 'abiding by most of the rules, most of the time', and choosing to interpret them in ways which enabled them to sustain existing relationships and desires. For example one man, Peter, had stopped 'partying and seeking women', but continued to be with two wives, using condoms with both partners. Some men did continue to have sexual partners outside marriage, although they 'no longer went with so many women'. For example Mark, who had had children with three women and now lived with only one wife, did not use condoms with his wife, but said he did so when he had sex with other women.

Some of the men did not use condoms with their (also infected) partner because one or both partners wanted to have a child (Bridge, Dominican), and one man admitted he simply did not want to:

He is currently practicing safe sex, but thinks he will stop using condoms because his girlfriend has started demanding a child (Isaac, M, 38).

“The main reason (for using condoms) is not to re-infect my partner. I also use them for family planning. But most times, you realise that you are not enjoying, and sometimes I say that condoms were not meant for us and that is why I do not use them” (Paul, M, 39).

### **The institutional setting and collective fashioning of therapeutic citizens**

Among this group of PLWH, why had framing messages been so readily absorbed, and framing processes fashioned such effective self-managers of the condition? Individual psychological predispositions, or support from family and friends for example, are likely to be some of the factors. But here we focus on the importance of the care setting and the participants’ social interactions with and within that setting.

#### *Institutional caring and trust*

Participants described how well they were cared for, treated and respected at TASO. Among those who used the government hospital or health centres, the majority were also positive about nearly all of the health workers. Good inter-personal quality of care and the respect shown in these relationships generated trust in the information and self-management advice provided, and helped sustain patient engagement with the health system and self-management:

When I went to TASO, I felt like I was with my friends (Naome, F, 26).

When I came to the clinic they showed me love (Judith, F, 27).

The health workers at the hospital clinic were very warm and welcoming, which gave her courage to remain there and keep going back. (Ruth, F, 58).

“What has helped me most is the counselling that I have been getting from the *Basawo* (health workers)... They give us encouraging words that make us strong..., it brings hope to the heart ...” (Paul, M, 39).

He came to realize that the doctor at the health centre was the person who would help him live longer. This is because he is the one who took him through counselling and told him about the effect of the drugs like dizziness, nausea and loss of appetite, and how to deal with them. Besides, the doctor is a very caring person. When he meets him, he asks him about everything and also advises him on how to go about a few challenges especially to do with health (Davis, M, 43).

The institutional context of care and support at TASO was a particularly powerful narrative, and illustrated the profound influence of TASO on people's lives and their desire to take responsibility for their health. At the government hospital, however, a few participants (male and female) did express dissatisfaction about the rudeness of one or two nurses.

### *The fashioning of group membership, and collective identity and responsibility*

Group counselling and information sessions brought people together to provide messages of advice and reminders about adhering to drugs. Participants spoke about TASO and government facilities as a space, and their regular appointments as a dedicated time, where they could have caring and productive interactions with staff and with others with HIV, to share stories and experiences. TASO or the HIV clinic were spaces where new friends, support networks and identities were forged. It was a place where individuals found encouragement and motivation to start or go on managing their illness effectively. Female participants talked more about the support and benefits of finding new friendship groups at service providers, friends that they had made because of their HIV status.

"...This is a great feature about meeting people at the clinic, and everyone has to wait for hours anyway.....we also give each other a call to check up on each other and things like that....we are encouraged because we are not alone; so many others are ill" (Bridget, F, 33).

"We sit and converse as a family" (Ruth, F, 58).

"The thing that has helped me is the fact that people comfort me when I go to the clinic and they give me great advice". (Joy, F, 27)

Coming together and sharing experiences helped create a sense of membership or relatedness, of belonging and solidarity:

"When we are gathered at the clinic, we benefit a lot. This situation unites us and we are the same. In fact, we call ourselves members; so when we meet, we simply greet each other with 'hello member'. It is as if we are in a club.... " (Tom, M, 44).

"There are people that we meet at the clinic and we don't talk to each other but we know each other, they live around here, I meet them and we greet one another. They might ask you for money and you help them knowing that you are a family..." (Jerry, M, 45).

The 'Them and Us' resistance thinking mentioned above reinforced the sense of collective identity or belonging. Overall the narratives demonstrated the formation of a local moral world at TASO or the clinic, a network of people who felt a sense of identity and citizenship in a wider community of PLWH. Among most of the participants, this collective identity also reinforced motivation to sustain effective self-management.

"When we went to the seminars we learned, and all of us were in the seminar. I became firm like a hero who has joined a war, because this is like war, you cannot

retreat. When I got to know I was infected... I said to myself be strong so that I see to it that the government takes care of me and I get medication. I became strong and now I do my work (Davis, M, 43).

Being a 'member of the club' also imbued a sense of obligation or responsibility to act as a role model for others in the community, and to support others in the collective with their self-management:

"When we meet and talk, a person might say he still drinks some alcohol and you take the opportunity to tell them that the health workers say alcohol is bad, you should leave it if you still need your life or good health, and to continue with your plans, so first stop taking alcohol and see how your life will be... There are people who have just started on ARVs but we have been on medication for about four years, so if there is a new person we have to guide him or her on what to do. You see that?" (Tom, M, 44)

"That woman was at the clinic and she cried so much...I asked her what the matter was and she told me to leave her alone and that she did not want to talk. I told her to tell me what the problem was so that I could help her. She told me that she did not know that her husband was infected, that he simply brought her for testing and she was told that she has HIV. I then told her that since she was here (TASO) she was going to be in good health... I told her that once you get to TASO and they give you drugs, you follow the instructions, stop worrying then all the things that were making you cry will go away... After thinking through what I had told her she thanked me and stopped crying. We then started talking and watching TV and I told her that all those people that you see are sick even though they are looking good. I told her that she was lucky to know her status and start on treatment immediately. You will be healthy, able to have children, educate them and live for another twenty years...The woman became so happy..." (Judith, F, 27).

The health workers had asked the participants to support newly arriving patients: one of the roles and responsibilities of a therapeutic citizen was to counsel others.

## **Discussion**

### **The importance of framing institutions and agents for PLWH in Uganda**

Our findings show that government and NGO HIV care providers played an important role in the lives of PLWH in Uganda, offering them information, concepts, language and skills that enabled them to build self-management pathways. Health worker intervention and influence appeared to focus on the self-management category of 'focusing on health and illness needs' (Swendeman et al. 2009; Schulman-Green et al. 2012). However, their influence extended into a wide range of other psychological and social self-management domains.

The sample for this study is unlikely to be typical of all PLWH in this setting. They had gone for a test and started treatment, they were adhering to ART, and although the majority were cautious and selective who they disclosed to, they were open enough about their status to be willing to participate in the research. Another possible limitation is the lack of

observation of many self-management behaviours. However the main purpose of this paper is to examine whether participants had accepted and integrated the framing messages into their concepts and language about self-management, and their sense of belonging as a form of therapeutic citizenship. Our methods of multiple interviews, the building of trust and rapport, and observation of the home and family environment make us confident that the narratives did reflect participants' self-management aims and behaviours.

Positive patient-provider relationships can play a role in improving self-management and health outcomes (Johnson et al. 2006). Participants were, overall, positive about the quality of care they received at TASO and government providers, and findings show that good health worker-patient relationships were vital for building trust and patient receptiveness to health worker framing messages.

Framing institutions played an important role in the lives of the participants in this study. Reframing processes began, in most cases, with health workers providing *information* to enable PLWH to construct more optimistic conceptualisation of HIV, and re-appraise their situation now and for the future in a positive light. This early framing played a large role in early acceptance processes and rebuilding hope and strength to move forward. The framing agents played a crucial role in helping the participants see that they could cope, and gave them tools for coping (Leventhal et al., 1992). Framing processes also provided PLWH with useful *concepts and language* for emotional and cognitive coping, including disease normalisation and resistance thinking, which helped the reduction of self-stigmatisation. Similar processes of normalisation following ART and counselling have been found in the region (Roura et al. 2009b).

The effectiveness of counselling and cognitive reconceptualisation interventions to improve psychological wellbeing and HIV self-management in industrial settings has been demonstrated (Abel et al. 2004). Given the scale and burden of HIV in Sub-Saharan Africa, there is a continuing need to expand the low cost interventions which encourage PLWH to talk, learn and develop new ways of conceptualising the disease, to help psychological adjustment, reduce stigmatisation and promote self-management.

The advice and instructions for *practical self-management* tasks, to promote one's own health and take responsibility for the health of others, was also absorbed, although could not always be put into practice. Notably, 37 out of 38 participants had become proud adherents to ART. But looking at self-management more broadly, the frameworks provided by TASO and government services had given participants a helpful structure to adjust and live their lives, to regain control over the disease and their life. This partly explains why it was so eagerly taken up by this particular group of patients. 'Following the rules' made them feel good, gave them a sense of achievement. It showed one had accepted, was taking responsibility, and moving forward. The doctor-patient relationship was hierarchical, but remained a productive partnership: when participants said 'I abide by the rules', the narratives indicated this meant 'I accept my status, I can do something about this, and am taking ownership of it'. This contrasts with another study in the region, which concluded that an ART programme was creating medicalised and disempowered patients (Mattes 2011). HIV self-management is for life, however, so whether such motivation over the long term can be sustained is now a key issue.

## **The formation of therapeutic citizens**

Framing processes fashioned effective self-managers of HIV, 'responsible patients', through one to one interactions, and shared experiences. Participants' personal engagement with ART and self-management was socially fashioned. Our findings show that TASO and government providers were spaces for the development of a form of therapeutic citizenship, founded on biological experience (HIV positive), claims to resources (ART) (but in Uganda, not framed as 'rights' among PLWH), and a set of responsibilities.

The main traits of this form of therapeutic citizenship, identified from the narratives, we characterise below:

- Motivation to learn and acquire new knowledge
- Acquisition of new concepts and languages about HIV, and resistance thinking
- Acceptance of medicalization of life and adherence to treatment
- Become expert and active self-managers of their condition
- Take ownership and responsibility for own condition
- A sense of responsibility for the health and well-being of others
- Raising awareness through small acts and speech, everyday forms of resistance against dominant stigmatising discourses
- Forming new identity and a collective sense of belonging to a wider community of PLWH.

The concept of therapeutic citizenship must be contextualised and historically located to have meaning and applicability. Among the 38 people in our study, none could be described as activists as conceptualised by Nguyen et al. (2007). In the Ugandan context, there has not been a history of active civil society movements or politicised HIV activism as seen in settings like South Africa (Robins 2006). The main NGO working on HIV, TASO, developed as a support and care organisation.

Now that ART is being delivered to over half the population needing it in Uganda, therapeutic citizenship refers more to a local moral world, an HIV community, characterised by a shared experience, sense of purpose, a desire to take ownership of one's health and a range of responsibilities. Participants played a role in self-fashioning their own commitment to self-management. The findings also show that participants obtained advice, support and encouragement from various actors, not just health care providers, particularly support from family members. But their commitment was in particular socially fashioned as members of TASO or the clinic, as attendees at collective events and social interactions at TASO or government facilities, and through their informal friendship networks of PLWH. They also felt a belonging to an imagined HIV community, one that extended beyond the range of social interactions and networks, to other PLWH in Entebbe and beyond.

As Nguyen et al. (2007) argue, the fashioning of effective self-managers and adherent patients must be understood within the social landscape of HIV interventions and the framing processes that operate there. This approach:

“...contrasts with approaches that examine adherence as the behavioural outcome of individual-level determinants” (Nguyen et al. 2007).

The remarkable similarity of the narratives, about their journey from illness to recovery, what they had learned, or what had changed in their lives, to some extent reflects the narrative as a device that people use to transform illness from an individual to a collective experience (Hydén 1997). But it is also testimony to the shared experiences and local moral worlds of the participants in this setting, shaped in the same social context, by similar experiences and in a similar institutional environment: they underwent common framing processes and acquired the same concepts and language about recovery, change and self-management.

The harsh economic and social circumstances faced by many participants in this setting mediated their self-management strategies and the fashioning of their therapeutic citizenship. Income poverty meant, for example, people had to work harder and eat less nutritious food than they had been advised. Gender relations meant women could not always negotiate safe sex, and deeply held norms about having children meant younger men and women sometimes wished to have children and so had to negotiate with advice about preventing transmission. But what was so revealing from the narratives was that in the face of these difficulties or constraints, the PLWH remained determined to work to make a success of their self-management, to adhere to the drugs. For them the main challenge was not HIV, but the hard struggle of poverty.

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