



Finding meaning: wellbeing among  
people living with HIV taking  
antiretroviral therapy in Uganda

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## DEV Working Paper 50

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## **Finding meaning: wellbeing among people living with HIV taking antiretroviral therapy in Uganda**

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## Abstract

**Background:** Long term self-management of HIV in resource-limited settings is becoming an important priority for health providers and patients. The wellbeing of people living with HIV (PLWH) is important to promote and support continued adherence to antiretroviral therapy (ART). This paper analyses dimensions of wellbeing among a group of PLWH in Uganda who have been on ART for at least one year.

**Methods:** In 2011-12, a qualitative study of PLWH's self-management of HIV was conducted in Wakiso District, Uganda. 38 PLWH (20 women, 18 men) were purposefully selected from a government hospital, three referral health centres, and the non-governmental organisation, The AIDS Support Organisation (TASO). Two in-depth interviews were held with each participant.

**Results:** The main challenge and stressor for participants' wellbeing was poverty, not HIV, and in fact for the majority, effective self-management meant HIV appeared to be no longer a factor undermining wellbeing. Narratives revealed differing degrees of resilience in the face of material hardship, and higher levels of wellbeing in a variety of other life domains. Access to good quality HIV treatment and counselling services and positive interactions with health workers were important: counselling enhanced participants' cognitive and emotional responses to their condition, giving them hope and motivation to move forward. Recovery of health and bodily appearance contributed to self-esteem, social confidence and reduced levels of self-stigmatisation. Psychological adjustment mechanisms that enhanced wellbeing were evident: comparisons of health before and after treatment added an additional level of appreciation of their current health and appearance, and social comparisons with those who had not gone for a test made participants feel knowledgeable, responsible and better citizens than 'others'. The ability to work again provided basic needs and also gave many a sense of purpose, achievement, and kept people busy and 'reduced negative thoughts'. Living with HIV also appeared to have enhanced people's opportunities for social contact and new social relationships, and collective social experiences at the clinic created a sense of membership and belonging which enhanced wellbeing.

**Conclusions:** Social and psychological processes are vital to wellbeing and mitigated the negative wellbeing effects of poverty and ill-health. The gains derived from investment in ART programmes for the wellbeing of participants in this study offer lessons for how forms of chronic care can be improved for other conditions.

## Introduction

The expansion of antiretroviral therapy (ART) in resource-limited settings has improved the health status of millions of people living with HIV (PLWH). In Uganda for example PLWH on ART have the same life expectancy as the general population (Mills et al. 2011). As sustained self-management of HIV over the long term becomes an important priority for health providers and patients, HIV care and research is beginning to focus on PLWHs' quality of life (QOL) or wellbeing in addition to clinical outcomes. In this paper we take QOL and wellbeing as synonymous concepts, referring to material, subjective and relational domains of life that make up what people have, what people can do and what people think or feel (McGregor 2006). PLWHs' wellbeing on ART is important for the sustained success of ART programmes: diminished wellbeing can result in failures to adhere to treatment, whereas a satisfactory and meaningful life can help motivate people to go on self-managing the condition, including treatment adherence (Abel et al. 2004; Beard et al. 2009).

Several studies in Uganda show improved QOL among PLWH after starting ART (Alibhai et al. 2010; Bajuninwe et al. 2009; Mutabizi-Mwesigire et al. 2014; Stangl et al. 2009). Similar findings are reported from ART programmes in South Africa and India (Kohli et al. 2005; Wouters et al. 2009). Comparing QOL outcomes between PLWH on ART and not on ART, a systematic review of studies from developing countries found that people on ART had significantly better physical functioning, mental health and emotional wellbeing (Beard et al. 2009).

More surprisingly, a few studies in sub-Saharan Africa, including Uganda, are finding higher QOL among PLWH on ART compared to their HIV-negative counterparts (Negin et al. 2013; Nyirenda et al. 2012; Scholten et al. 2011). These counter-intuitive findings are explained by PLWH's better access to quality health care (and counselling) than the HIV negative sample (Nyirenda et al. 2012), and greater social contact created by regular visits to the clinic (Kuteesa et al. 2012; Wright et al. 2012). These studies raise questions about the mechanisms which contribute to enhanced wellbeing among PLWH on ART in resource-limited settings, and how they manage challenges which still prevail such as poverty and food shortages (McGrath et al. 2014; Mutabizi-Mwesigire et al. 2014). In addition to the more tangible benefits such as access to care and social contact, what other processes are operating to enhance wellbeing? Might PLWH be making psychological 'adjustments' to their condition, so that even though material circumstances are difficult, they sustain a higher level of subjective wellbeing than other groups with similar circumstances? Might they have developed a 'resilience': the development of coping mechanisms and cognitive and emotional adjustments which help adaptation and return to normal functioning following a shock such as serious illness (Lazarus and Folkman 1984; Richardson 2002).

This paper presents qualitative findings from a study in Entebbe, Uganda, on PLWH's self-management of HIV and the objective and subjective factors, including psychological adjustments, affecting their wellbeing. It applies sociological perspectives on chronic illness self-management, and also concepts from health psychology to understand psychological adjustments to illness, and how people find meaning and benefit when living with HIV. The combination of these approaches allows analysis of the material environment in which people live, social (inter-personal) relationships, and psychological (intra-personal) factors

influencing wellbeing. The qualitative findings complement quantitative findings on wellbeing collected for the same study, which found higher QOL reported by PLWH compared to a community control sample (Martin et al. 2014).

## **Conceptual framework**

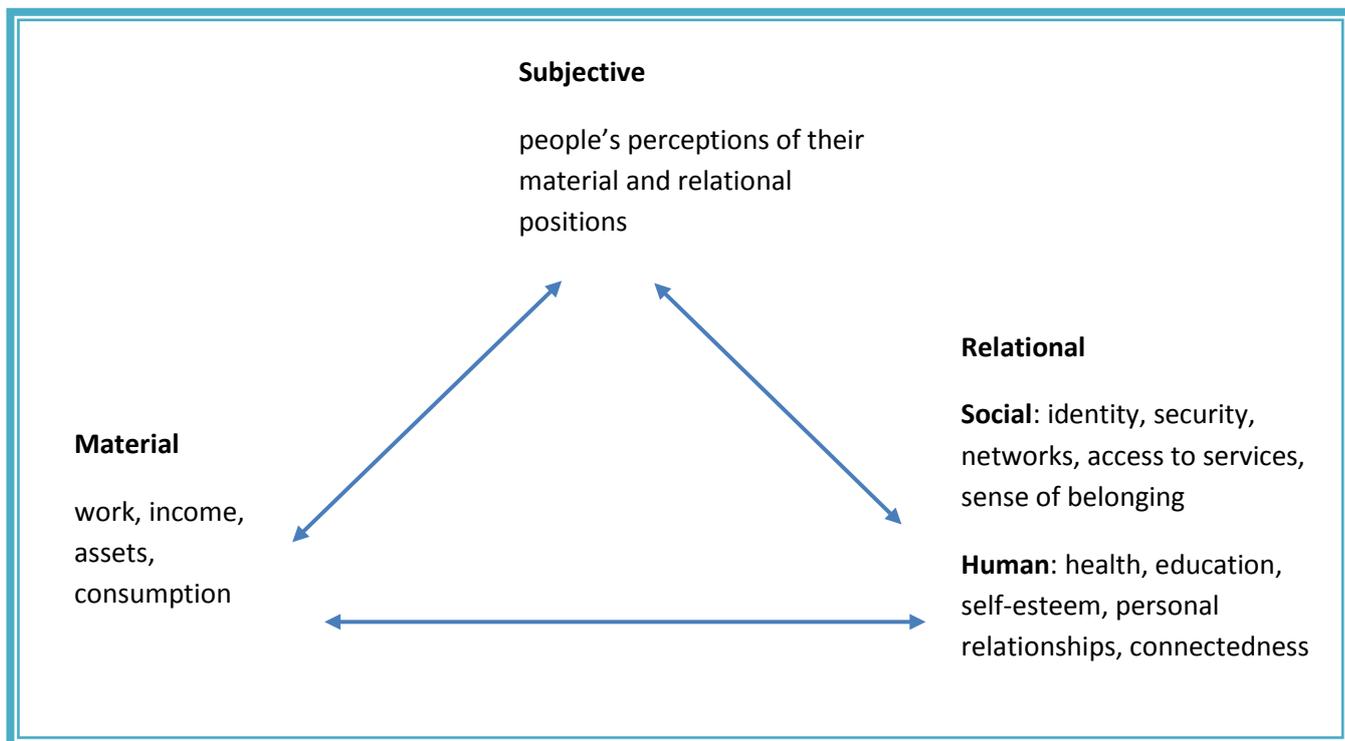
### **Self-management and wellbeing**

A person's self-management of chronic illness is a complex, dynamic and interactive process, which includes processes of adaptation and adjustment (Kralik et al. 2004; Russell and Seeley 2010; Sharpe and Curran 2006; Strauss 1990; Swendeman et al. 2009). This 'adjustment' to living with a long term condition can broadly be defined as the incorporation of an illness and treatment into one's life and identity, 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). Self-management involves practical, social and psychological processes, which Schulman-Green et al. (2012) categorise as: a person's work at managing illness needs (such as adherence to treatment), activating resources, and the more complex tasks of 'living with the condition'. This latter set of self-management tasks 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). Self-management processes are ultimately part of a person's work to maintain a satisfactory quality of life (Barlow et al. 2002).

Wellbeing is a complex, multi-dimensional construct incorporating various domains (for example material standard of living, health, social relationships, self-esteem). It refers to external, 'objective' aspects of life (externally observable or verifiable) and 'subjective' aspects: how people perceive and experience different domains of life, their levels of satisfaction, their aspirations in life and whether goals or expectations have been met (Ruta et al. 2007; White 2009). Wellbeing therefore includes conventional dimensions of material wealth or deprivation, such as income or nutrition, but also focuses attention on "how individuals feel about their health or economic status" (White, 2009: 3).

In this paper we draw on the wellbeing framework developed by the ESRC research centre on Wellbeing in Developing Countries (WeD) at the University of Bath, UK (MgGregor 2007; White 2009), and health psychology concepts which examine the role of psychological adjustment for quality of life (Ruta et al., 2007). White (2009) describes the WeD framework using a diagram which integrates material, subjective and relational dimensions (Figure 1). The relational is sub-divided into social and human dimensions, each of which includes the more conventional aspects of life such as social networks, access to services, education or health, but their grounding in the relational also requires analysis of social divisions and inequalities which influence these dimensions of wellbeing. Each of the material, human and social dimensions of wellbeing can be assessed objectively and subjectively.

**Figure 1: Dimensions of wellbeing**



Objective material conditions include work, income, assets and consumption. Objective health and social conditions include, for example, physical functioning, access to health services or social networks. A person's 'objective' conditions of life, however, do not necessarily predict how that person subjectively assesses their wellbeing. This subjective assessment of different domains of life focuses the concept of wellbeing on a person's perspectives, values and aspirations, "...in particular their response to the central question 'is my life going well, according to the standards that I choose to use'" (Camfield 2009, citing Diener 1984). The gap between what a person aspires to do or be in life, and what they can actually achieve, is central to wellbeing (Ruta et al. 2007). The aspirations and standards against which an individual assesses their wellbeing can change over time, as psychological adjustments are made to new situations (Ruta et al. 2007).

### **Psychological adjustment mechanisms**

When people experience serious illness or disability, psychological adjustments may enhance subjective assessments of wellbeing. In this paper we refer to the concepts of response shift, contrast effects, social comparison and sustaining variables.

Response shift theory, for example, refers to a change in a person's standards, values or concepts about what constitutes a good life when faced with serious illness, referring to three inter-related mechanisms (Sharpe and Curran 2006; Sprangers and Schwarz 2009). First, the internal standard by which wellbeing is subjectively assessed may be recalibrated, whereby a situation previously judged as average may now be judged as good. Second,

reprioritisation can occur, whereby the relative importance of life domains may change, for example giving more value to health or to family relationships than to work. Third, wellbeing may be more radically reconceptualised, so that domains may be added or removed from a person's subjective assessments of wellbeing. For example, a person with limitations in mobility may find a new purpose in life, finding new meaning in creativity and abandoning physical activity.

The linked concepts of 'contrast effect' and 'social comparison' may be linked to response shift. Contrast effects between a current state of health and a previous one can lead to a recalibration of standards. For example a person who would have judged a state of physical functioning as 'poor' *before* they fell seriously ill may afterwards judge this state as 'good' (Tversky and Simonson 1993). Contrast effects may also be due to social comparisons (Stigglebout and de Vogel-Voogt 2008). In the face of threat, uncertainty increases the need for people to engage in social comparisons (Arigo et al 2012) which may result in response shift (Barclay-Goddard et al., 2009). Recalibration occurs for example when a comparison to those doing less well (downward social comparison) redefines one's perception of "poor" wellbeing, enhancing one's own wellbeing (Gibbons 1999; Sprangers and Schwarz 2009). Alternatively, comparisons with those who are effectively self-managing a similar condition and look well can create hope and motivation which enhances wellbeing (Schwarz and Strack 2003).

Sustaining variables are aspects of a person's social or personal life that act as 'buffers against hardship' which sustain subjective wellbeing above that of others with comparable objective material circumstances. They contribute to an emotional resilience against external shocks such as a decline in health or wealth (Ruta et al. 2007). To illustrate, one category of sustaining variable frequently cited in the literature is having valued social relationships. A second type is having a moral framework or code to live by, which helps people to experience life as meaningful, for example through spiritual beliefs and practices (Ruta et al. 2007; Sharpe and Curran 2006; Sprangers and Schwarz 1999; Trevino et al., 2010). Core personality traits, such as extroversion, optimism and an internal 'locus of control', characterised as a person's ability to view an event such as an illness diagnosis as a challenge that can be managed and overcome, can also sustain subjective QOL above that of others with similar objective circumstances.

## **Methods**

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

In 2011-12 qualitative data were collected for a study which looked at the coping, self-management processes and wellbeing of PLWH on ART in Wakiso District, Central Uganda. The study also measured quality of life and depression outcomes among a wider sample of PLWH (n=260) and a control sample. In this paper we present the qualitative findings on PLWH's wellbeing on ART.

Three types of ART delivery site in the district were selected to recruit participants for the qualitative study: the HIV clinic at a government hospital; three government health centres

that have referral links to that hospital; and a 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 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 and various forms of trade, as well as formal employment in teaching, health care, and cleaning services.

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. Four could not be interviewed twice and were excluded from final analysis.

## **Data collection measures**

Participants were interviewed twice by a team of experienced Ugandan researchers based at the MRC, Entebbe. The first interview was an unstructured life and illness history. Due to the wide-ranging and sensitive nature of the questions, these data were collected over one to three visits, depending on how long the participant could spend with the researcher on each visit. The interview(s) 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 second 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, and changes in their lives and wellbeing since becoming HIV positive and starting ART, for example with respect to work and daily activities, relationships, spiritual life, and social activities. The effects of these processes were examined in terms of how people felt about their activities and achievements (or disappointments). The use of more than one visit 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 ensure analytical rigour, one researcher independently did an initial coding of the interviews and this coding was checked by a second team member who analysed a sample of interviews. 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. Frequently used expressions used by participants across the interviews are not quoted but set out using italics.

## Results

### Participant characteristics and material wellbeing

Table 1 summarises the demographic characteristics of the 38 participants. Thirteen were from the hospital, 11 from the three referral health centres, and 14 from TASO.

**Table 1: Participant demographic characteristics (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>

Table 2 briefly summarises participants' socio-economic situation, derived from the qualitative interviews and observations in or around their homes. These 'objective' aspects of material well-being had a substantial influence on the wellbeing of participants in this setting. They also shed light on the importance of social and psychological domains of wellbeing: despite the challenges of poverty, the majority derived benefit and resilience from these other dimensions.

**Table 2: Participant socio-economic characteristics**

Gender / relationship	Material wealth status	Name (age)	Livelihood/work	Assessment of food security *
Single women	Financially independent, adequate income	Happy (46)	Self-employed as entrepreneurs, e.g. invested in businesses such as poultry, bar, shop, houses to rent	Good / adequate diet
		Grace (32)		
		Linda (29)		
		Hannah (46)		
	Dependent on family	Gloria (29)	No work, relies on parents	Adequate diet, although sometimes not enough nutritious food
		Ruth (58)	Lives with grown up children; does some gardening and pigs	
	Getting by	Naome (26)	Municipal council cleaner	Adequate diet, although sometimes relies on family support
		Joy (27)	Food Vendor	
	Income poor	Ann (29)	No work, relies on support and temporary odd jobs	One meal per day
		Nana (46)	Subsistence farmer though keeps a little for sale.	
Suzan (43)		Rock breaking, grass weaving, cultivation		
Extremely poor	Mercy (35)	Small vegetable and charcoal stall	Daily struggle to get food	
	Jackie (61)	Municipal council cleaner		
Women with a partner	Adequate income	Dorcas (42)	Teacher, cultivation (subsistence and for sale)	Good / adequate diet
		Paloma (31)	Bar worker / actress	
	Income poor	Sarah (38)	House wife	One meal per day
		Ritah (39)	Small scale subsistence farmer	
		Julie (37)	Farmer	
		Judith (27)	No steady job but makes table clothes for sale	
	Extremely poor	Bridget (33)	Hair stylist	Daily struggle to get food
Single Men	Adequate income	Aaron (40)	Teacher, cultivation	Good / adequate diet
		Tom (44)	NGO worker	
	Income poor	Davis (43)	Caretaker on land	One meal per day
		Vincent (74)	No work	
	Extremely poor	Simon (30)	No work	Food shortage. Sometimes days without a meal.
Men with a partner	Adequate income (although money worries still expressed)	Benson (34)	Transporter: takes people and cargo from island to mainland.	Good / adequate diet
		Jerry (45)	Policeman	
		Dominian (38)	Mason / builder	
		Peter (38)	Quarry merchant	
		Matthew (51)	Security guard	
		Mark (31)	Fishing business	
		Jacob (32)	Fisherman	
		Derrick (38)	Cultivation/quarry worker	
	Income poor	Paul (39)	Construction work	One meal per day
		Fred (47)	Load carrier	
		Bridge (42)	Boda boda (motorbike taxi)	
		Isaac (38)	Brick laying	
		Extremely poor	Angelo (47)	

\* Food security categories (good/adequate diet, one meal per day, daily struggle, food shortage) were developed by the researchers based on their observations and the interviews.

Nearly half of the participants were income poor (8/18 men; 10/20 women), and with differing frequency struggled to meet basic food needs. Those who were able to cultivate around their homes were usually able to eat one meal a day, but a small minority in extreme income poverty faced a daily struggle for enough food (Table 2). Several participants said that inadequate food intake made taking the drugs more difficult.

For all the participants with school-age children, school fees imposed a large burden on constrained budgets. All struggled to pay fees, perhaps with the exception of one or two participants with formal employment. Among the poorest school fees were unaffordable, causing sacrifices to other essential consumption or the forced withdrawal of children from school.

In contrast about half of the participants, men and women, had an adequate material standard of living through their professional salaries or successful investments in businesses such as fishing, housing for rent and poultry farming. They had often had the advantage of access to capital from family members.

The main subjective perspective on material wellbeing in the narratives could be distilled as *our main challenge is poverty*. Participants' worries about income poverty, rather than HIV, were the main stressor in their lives and a cause for *too many thoughts* (an expression used to describe stress, low mood or depression). For the poorer men and women in the sample, HIV had largely been 'forgotten' and it was the stress of poverty which threatened overall wellbeing. Because the majority of participants were self-managing their condition effectively, poverty and food insecurity were the main criteria which distinguished how well they were 'coping' with life on ART:

Suzan said that even though her health has improved she is still faced with financial constraints and challenges. Her children need food and money for school fees..."I worry so much about not having money and I talk a lot about that issue with the counsellors...I have failed to pay school fees for my children and I do not have any one to help me so they are now at home... When they are sent away from school I get so angry and I feel that my heart is not settled, so when I get money I pay it to the school then my heart settles (Suzan, female (F), age 43).

"What worries me so much is the (financial) situation we are in as you see. I have a big family...but...I sometimes worry and ask is this child going to be chased away from school, what are we going to eat, and this gives you sleepless nights... But if it was not for that, my heart would have been settled and I have everything, I would be okay..." (Peter, male (M), 38).

"For me the only problem that I have is money... all that I think about is money" (Joy, F, 27).

For poorer women the necessity of having to work hard to survive had costs and benefits. For example among those who were single, there was a sense of freedom and their work generated a sense of achievement in providing for their children, but this came with having to work very hard and a daily struggle to survive economically.

Men with lower incomes tended to express the economic struggle in terms of their failure as a man to fulfil their economic obligations to support the family. The better off men who had spare money to invest still complained about the challenge of income poverty, especially paying school fees. They imagined that if they had more money, all their worries would be solved:

“...when we go (to the clinic), sometimes we talk and say that people who have money and are HIV positive, are okay. Ask me why? (Why sir?). First of all, they do not worry about anything because they are able to do anything. When he needs something to eat, he gets it. When he wants to do something, he does it. The problem is lack of money...The life of someone who has money is different. He is always okay because he is able to get whatever he wants...Now for my case, I want to drink milk every day but I cannot afford it because there is no money...I can take milk once per week but for a rich man, he can drink milk every day anytime, which I cannot afford” (Tom, M, 44).

Despite the worries of poverty, most participants’ narratives also showed differing degrees of resilience in the face of material hardship.

“I learnt to do away with what I cannot afford to get. I only have to give myself peace, though at times human nature overrides because challenges never end” (Sarah, F, 38).

The majority had a determination to keep going, to keep taking the drugs, even when food was lacking, which indicated their commitment to self-management (which includes adherence to drugs), and continuing value for life and hope for the future. This appeared to sustain wellbeing above what might be expected given their material economic and health circumstances.

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. But in most cases, he sacrifices his share for the rest of the family and he believes that God will provide for the family the next day (Paul, M, 39).

The rest of the paper analyses the key relational (social, human) and subjective (or psychological) processes which affected the wellbeing of this group of PLWH.

### **Access to and benefits of HIV services**

In Uganda, HIV service infrastructure has received substantial investment since 2004, supported by external funding. Treatment and counselling are available from government and non-government providers, which is often not the case for other conditions. Participants had access to these specialised treatment and counselling services, at TASO and at government providers. They praised the fact that they could get life-saving ART free at

the point of delivery, the drug consistently referred to as *the most important thing that has helped me to cope*, and *the drug that makes the difference*.

Participants' experiences of HIV services were in general very positive, for the majority varying from strong satisfaction to exuberance about the way the health workers had cared for them, shown them respect, given them the courage to go on, and saved their lives. This was particularly the case for TASO patients:

"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...if they had not encouraged me I would be dead.... (Judith, F, 27).

At the government hospital most (but not all) participants were satisfied with inter-personal quality of care, which was important for sustaining patient engagement:

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

One participant compared the quality of health worker care at the HIV clinic compared to the 'usual services':

"The way our *Basawo* (health workers) treat us, it is not the same as those who administer treatment for malaria or fevers. They treat us like people...they counsel us and they take care of us. They (health workers who give other treatment) are really difficult people...they even slap you" (Jerry, M, 45).

Advice and counselling had very positive effects for people's cognitive and emotional responses to the disease. It helped participants reconceptualise HIV as a controllable not a terminal condition, which reduced levels of uncertainty and anxiety, gave hope for the future, and brought motivation and strength to carry on, benefiting psychological wellbeing.

"My heart became strong because of the things that we were told by the health workers" (Judith, F, 27).

"What has helped me most is the counselling that I have been getting from the doctors... it brings hope to the heart" (Paul, M, 39).

The benefits of counselling extended beyond HIV and ART topics, to other area of, and difficulties in, life:

"Counselling is good, it could be about anything - husbands, medication, food, money.... just to talk to someone" (Bridget, F, 33).

## **Recovery of health and reduced self-stigmatisation**

The recovery of health on ART, and prevention of further illnesses, was of fundamental importance to participants' wellbeing. They reported renewed strength and energy, and ability to pursue work and to do other 'normal' domestic and social activities. They emphasised not just how well they felt, but how well and normal they *looked*. Looking normal was a persistent and powerfully expressed theme across the men and women's narratives. In a social and moral context of continued stigmatisation, dealing with stigma is an important self-management task for PLWH if they are to come to terms with a new sense of self and identity and achieve a satisfactory quality of life. Looking normal had significant benefits for self-esteem, identity in the community and social confidence. They could 'pass as normal', pursue life 'like a normal person', and participate in social and economic activities:

"I count myself amongst the uninfected ones because people no longer look at me in disgust...People no longer say 'I will not eat with him'...I will not be taken the way I was in the past" (Jacob, M, 32).

Processes of reduced self-stigmatisation were evident in most of the narratives, arising because of the recovery of health and a normal appearance, returning to normal activities, and effective support and care from health workers, who played an important role in helping participants come to terms with their condition and develop a language that reconceptualised and 'normalised' HIV. They began to reconceptualise HIV as a treatable and manageable disease, *just like many other diseases*, rather than a death sentence. HIV was also reinterpreted as just one of many causes of death: *you can die from many other things; death comes to us all, so how is HIV any different?* HIV was also reconceptualised as a normal disease through reference to its prevalence in the community. Health workers had told them from the start *you are not alone, just look around you*. All the participants drew on this language:

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

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

For this particular group of PLWH, recovery of health, looking normal and reduced self-stigmatisation were key aspects of enhanced psychological and social well-being.

### **Psychological adjustments: contrast effects and social comparisons**

Thirty-one of the 38 participants (82%) had been suffering from serious and frequent opportunistic infections before ART, and some had been close to death. After starting ART, all 31 participants had recovered their health. Dramatic health improvement on ART caused strong contrast effects and potential 'response shifts'. They made stark comparisons of their health *before and after treatment*, which appeared to add an additional level of appreciation of their current health and bodily appearance. They no longer took their health for granted, and allocated greater value to it:

“What has encouraged me most is that ever since I began taking ARVs, I feel that I am cured...It is now about three years and I do not fall sick...I have not had a cough again. I used to cough a lot... I do not have any itching or pain....the drugs... really give me strength...” (Mark, M, 31).

Participants had recalibrated their standards of health, giving more value than they would have done before to ‘feeling normal’, and it appeared that they had also given greater priority to their health over and above the value given to other domains of life. The fact that they could wake up feeling strong and ready for a day’s work held immense value and benefit. Physical recovery also generated a sense of pride and achievement in their hard work and adherence:

“In the past there was so much fear (about HIV)... (But now) I drink my beer and I tell the people around that I am HIV infected, and I am proud...I show off because I look good” (Mark).

Satisfaction was enhanced further because their recovery proved wrong those in the community who had spoken negatively about them because ‘they had HIV and were already dead’:

“When people see him now, they exclaim that he has a powerful engine. This is because he is strong and can now work and do anything. These are the same people who were saying that he was going to die” (Peter, M, 38).

She was looking very good and everyone who had heard that she was about to die marvelled when they saw her a year after (Sarah, F, 38).

Similar contrast effects were evident with respect to how participants looked before and after treatment:

“It’s unfortunate that I don’t have any photos near here, but in those days when I had just tested, I would fear to sit in a congregation or I would feel small whenever I would meet with other people. But nowadays I no longer care because I don’t carry any sign of HIV. I don’t care being looked at. But in the past I used to be suspicious whenever someone looked at me because I had lost weight and used to cough ... I would think they are saying I am infected” (Ruth, F, 58).

Psychological wellbeing was also strengthened through self-enhancement social comparison effects. Participants derived benefit from making social comparisons with ‘the many others’ who gossiped but who had not gone for an HIV test and were ignorant of their status. They viewed themselves as knowledgeable and responsible, compared to these others, because they had taken action to get tested, gained control of the situation, and were not harming others. ‘Them and us’ comparisons also helped foster a sense of *collective belonging* to a group of responsible patients, which enhanced wellbeing:

“They (the health workers) told us that we were better than those who had not bothered to come and know their status that we are better than those who were

laughing at us. They laugh at you, saying that the (TASO) 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).

A second form of social comparison which diminished stigma and enhanced psychological wellbeing was with those of higher social status who also had HIV and attended the clinic. This convinced several poor participants that HIV is not just for those who are of lower status and somehow 'to blame':

"What made me strong was the fact that when I went to TASO I found there so many sick people including those that drove powerful cars. Knowing that even rich people went to TASO gave me a lot of strength" (Julie, F, 37).

### **Working hard**

The ability to work again and to begin new productive ventures was an important aspect of objective and subjective wellbeing. Work was of immediate material importance because, to differing degrees, it enabled participants to meet the basic needs of food, shelter and education for children.

"...Being at work... it has sustained me because I do not get financial worries. I think that would have disturbed me being there without any source of income, but now that I have a job, it has helped me a lot to live a life today" (Matthew, M, 51).

For poorer male and female participants the material benefits of work were especially important, notably for the group of single women with children who were struggling to make ends meet:

She said that work has really helped her because it is the family's source of income and without it, she does not know whether they would survive. ... It is farming that has kept her going ever since her husband died because she did not yearn for men for support any more. It's from farming that they get what they need to eat and also to educate her children. Since food is available, it helps her deal with worries (Nana, F, 46).

Work was important for subjective wellbeing in its own right, not just a means to commodities. Participants talked about how much they valued the ability to fulfil their roles and responsibilities as a woman or a man, such as digging in the garden, doing productive work to provide for their family and preparing food. Among the men, there was great satisfaction in feeling strong again, and to be able to do hard physical work such as fishing, building or carrying.

Work was also a means of cognitive coping for men and women: keeping busy and 'reducing negative thoughts':

"Work keeps me busy... I do it with a purpose that it may sustain me and keep me healthy. It also keeps me peaceful" (Ruth, F, 58).

“To be there without thinking a lot and not getting worried is because of my work of digging, looking after animals. I have goats, pigs and hens. So all my thoughts are on this work... I do not take time to be worried that I am sick. I do not have that in my heart” (Angelo, M, 47).

Work helps him clear the mind and focus on the future. He does not think about death as others do but just works with the time he has left on earth. *“Work reduces many thoughts, most times it is these thoughts that kill people...I don’t have self-pity that I am going to die now; I work to be okay in the future...if you are doing something, then you don’t have such thoughts”* (Derrick, M, 38).

For some, work was particularly significant for wellbeing because it was their quest for personal growth. This was particularly noticeable among some of the single and relatively better off women, who had managed to obtain capital and were working hard at new enterprises. These ‘projects’ generated a sense of achievement and independence:

She feels proud of her chickens and she takes care of them whole heartedly and that’s why she doesn’t fall sick... when she is talking about it (her business), she is happy... While taking care of the chicks, she told me that even when she finishes feeding them, she sits there. “I love my chicks and during this stage, I cannot sit in my house or sleep for long hours. I make sure I look after them well and this makes me very busy and the day can go unnoticed... Working for myself has helped me so much during this period of “sickness” and I don’t worry about anything. I want to tell you that I am not even aware of the illness” (Linda, F, 29).

Grace said that she is proud of her poultry business because she now has over two thousand layers and she gets good money from the eggs. The poultry business was set up six years ago with the help of her family... She said that her work, prayer and her child have given her the strength to cope with her illness. I told her to explain that further and she told me that she did not go to school but at least she has a successful business and is proud to pour her energy into it (Grace, F, 32).

### **Social relationships and enhanced social contact**

Good social relationships and a sense of connection are an important source of wellbeing in their own right, and can also act as buffers which sustain subjective wellbeing following other stressors, such as the onset of illness or job loss (Ruta et al., 2007). A variety of relationship types played a significant role in people’s self-management processes and wellbeing, in terms of the motivation and support they provided, or stresses they caused. Children were an important source of happiness and motivation to stay well and work hard, to support them now and leave land or a house for them in the future. Meeting and talking with friends provided relaxation and a sense of normalcy about life. Intimate relationships with long standing or new partners had more mixed effects, for example a few of the women in relationships said their partners were the main source of stress in their lives. Here we focus on two types of social relationship which substantially increased wellbeing.

### *Affirmation of love and support*

At the time of diagnosis the majority disclosed to at least one close family member, to get support and remove the worry and burden of their secret. To the surprise of most participants, they received strong support and encouragement. Support from family at a time of great need had been essential for participants at the time of diagnosis and continued to enhance wellbeing:

“My uncle has taken care of me. Even though he has a family of his own, he has never forsaken me. I feel very good, I have peace of mind because I know that he is there (smiling)” (Paloma, F, 31).

“Mother at first cried and said that God you have decided to take all of my children with HIV but later on she told me to be strong. My older sister who is HIV positive was around so she comforted me and counselled me and that helped me so much” (Gloria, F 29).

The fact that many participants’ close family showed that they cared, and that they gave material and emotional support, gave those participants great encouragement to seek treatment and to fight on to get better. Narratives included words to the effect of *I am here because of that person and their support*. Because people cared, they wanted to get better, to look forward:

“Having people around you is enough to recover” (Ruth, F, 58).

For many, HIV had created a situation in which close family had proved to them that they were loved and valued. Unexpectedly, HIV was also a trigger for some people to start rebuilding more positive relationships, especially with their children, their parents and their siblings.

### *Close-knit HIV-related support networks*

Living with HIV on ART created opportunities for social contact. Participants spoke about TASO and government facilities as a place and a dedicated time (their appointment days) where they could have caring interactions with staff and also meet others with HIV and share stories and experiences. HIV services were a space where new friendships and support networks were built, where the need to adhere to drugs and change life could be discussed and sustained. Female participants talked more about the support and benefits of finding new friendship groups at service providers.

“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).

These collective social experiences created a sense of membership, a collective identity, which generated a sense of belonging, solidarity, in-group confidence, and so enhanced wellbeing:

“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....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).

“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).

Successful self-management, adjustment and wellbeing among this group can therefore be understood as a set of individual and collective processes in this particular social and institutional context.

### **Psychological mechanisms: The search for meaning and benefits**

#### *Appreciating life*

Participants sought meaning and found new benefits not just from their renewed health, but from a second chance at life as a whole. For many this was a chance to reappraise and do things differently. However, a contrasting narrative was the caveat that numerous uncertainties about the future remained: their health could deteriorate, the medicine might stop working, or access to the medicine might end. A second chance at life, coupled with uncertainty about the future, caused participants to recalibrate the value they gave to each new day. Life would not be taken for granted:

“Whenever I sleep, I say thank you God for the new day that I am still alive; let me go and see what to do” (Peter, M, 38).

A closely related theme was the appreciation participants found in their daily activities and achievements related to work, relationships and spiritual activities. Great personal satisfaction was derived not just from doing things, but new ways of being: such as being more independent again, working hard to put the house, garden and life back in order, and ultimately regaining control over one’s life.

#### *New priorities and a new purpose*

Participants were also rearranging their priorities about what was important in life. They had developed new plans and some felt a new purpose in their lives. Often this new purpose was practical, involving plans and hard work, as illustrated by the pride and

personal growth felt by the women who had invested in poultry businesses (see Working Hard above). A new purpose to work hard and be responsible was more commonly expressed in terms of ensuring they would leave something for their children:

This illness has taught me to think about the future because previously whenever I would get 10,000 I would use it to drink, knowing that I would make more money the following day. But now, when I get some money, I only use a little so that I can plan for the future. So on the other hand, this illness has helped me. The other time, I used to spend everything aimlessly and I was always quarrelling with my wives because I would come home late in the night... (Peter, M, 38).

"...I am not saying that I am going to die soon, but I have to plan and also work hard. I actually know that life is short and I have to utilize this chance" (Dorcas, F, 42).

The illness and the treatment had, for some like Peter quoted above, been a catalyst to learn and live a better life:

"After getting better, I felt I had become new and also got new plans" (Mercy, F, 35).

A new purpose was also expressed in spiritual terms. In a context where there is a widespread belief in God and where evangelical forms of Christianity are widely practised, some people's narratives about sickness and recovery closely resembled the religious narrative of sin, punishment and redemption. Their sickness and physical recovery was closely associated with becoming born again spiritually. God and ART together had helped some to see what is important in life, given a new spiritual purpose or code by which to live, and this gave people resilience in the face of poverty, sustaining well-being:

"God loves me so much and he knows that I don't have anyone who can support me apart from Him. That is why he has protected me from getting bedridden, keeping me strong and able to take myself to the hospital...every day before going to bed, I must thank him for the gift of life" (Hannah, F, 46).

Some participants had become 'experts and advisers' in their community to whom neighbours and relatives went for advice about HIV, and they encouraged others to get tested. For the majority this role as an advisor and supporter was not an open one, but undertaken in certain situations when they could see somebody was scared or sick and needed help. The desire to help others 'in the same situation' derived from compassion but also from a sense of responsibility to help, as a member of the collective patient group or therapeutic 'community': this responsibility to others was part of being a 'therapeutic citizen' (Russell et al. 2014).

## **Discussion**

Our findings add to a growing body of research showing enhanced quality of life among PLWH after beginning ART in resource-limited settings (Beard et al. 2009; Mutabazi-Mwesigire et al. 2014; Russell & Seeley, 2010). Although we have no before and after comparisons, or comparisons with HIV negative people from similar backgrounds, the

findings also suggest that subjective wellbeing had been restored to what might be called a 'normal level' in this setting. They also begin to reveal possible reasons why our study found higher quality of life measures among PLWH on ART compared to a community control sample (Martin et al. 2014).

Thirty seven out of 38 participants were adhering to ART and self-managing HIV effectively. Referring to the chronic illness self-management framework of Schulman-Green et al. (2009), they were doing the tasks and adjustments likely to generate positive wellbeing outcomes. They were managing illness needs (such as adherence, attending appointments, adapting behaviours); mobilising health care resources and social, spiritual and material support; and engaging in important social, emotional and meaning-based processes which were enabling them to normalise their situation, adjust their sense of self and deal with stigma. Self-management self-efficacy, "...feelings of mastery and control over health outcomes" (Swendeman et al. 2009: 1327), was evident. Improved health meant that the challenge of poverty had become the main stressor in many of the participants' lives.

Two caveats to this overall conclusion require note. First, not all PLWH in this setting can self-manage effectively on ART or achieve levels of wellbeing evidenced here. Many people cannot adhere to the drugs because of food shortages, as one case in our sample illustrated. Our sample is unlikely to be typical of all PLWH in this setting. They had gone for a test, started treatment, were adhering to ART, and although the majority were cautious about to whom they disclosed, they were open enough about their status to be willing to participate in the research. Second, most of the participants had been on treatment for 2-3 years and were still experiencing the additional enhancement to wellbeing derived from psychological benefit finding, such as 'before and after treatment' contrast effects. But over time expectations are likely to rise again which can lower levels of satisfaction if these are not met.

"As years on treatment accumulate, researchers will need to track the transition from the buoyancy of treatment optimism to the doldrums of treatment fatigue when the promises of ART are checked by the reality of life with an infectious, sexually transmitted, chronic disease" (Beard et al. 2009:1354).

As the participants got used to being well on ART, the struggles of poverty returned to temper wellbeing for poorer men and women. In fact it was the different levels of economic struggle among the participants which most differentiated their levels of overall wellbeing, a situation found in other studies (Wright et al. 2012; Mutabazi-Mwesigire et al. 2014). Economic challenges, and the fact that HIV is a contagious condition and remains stigmatised, mean that it remains a particularly difficult chronic condition to manage (Mbonye et al. 2013; McGrath et al. 2014).

The dimensions of wellbeing identified in this study match well with existing QOL or wellbeing frameworks. They map closely onto the four domains of the WHOQUAL-BREF (Skevington et al., 2004), emphasising satisfaction with physical health and functioning, psychological health (e.g. feel that life is meaningful; acceptance of bodily appearance), social relationships (e.g. satisfaction with personal relationships, support from friends), and

the environment (e.g. (dis)satisfaction with income; satisfaction with access to health services).

The wellbeing framework described earlier in the paper (Figure 1) is useful for further consideration of the wellbeing themes found in our study. Our results showed material and relational dimensions of wellbeing, in terms of 'objective' conditions and how these were perceived or experienced 'subjectively'.

Material dimensions of wellbeing were prominent in participant narratives. The challenges of poverty caused stress for the poorer participants. But resilience in the face of harsh material conditions was also evident and stemmed from the psychological and social processes discussed in this paper, many of which acted as 'buffers' to sustain wellbeing beyond what would be expected given material and health circumstances. Key sustaining variables identified match those discussed by Ruta et al. (2007) and included:

- Higher value and greater priority given to health and 'peace of mind' above other material aspects of life
- Greater appreciation of life and a sense of new purpose to life
- A stronger or more clearly defined moral framework and code for behaviour, associated with self-management of HIV and also linked to faith, which when achieved brought a great sense of fulfilment
- Social relationships and a new feeling of collective identity as part of a community of PLWH
- A strengthened faith in God, which provided substantial emotional or spiritual wellbeing.

Personality traits such as 'hardiness' or locus of control were also evident in the majority of participants' narratives, but these potentially important factors underlying the group's adjustment and wellbeing were not explored or measured in this study.

In the social-relational dimension, participants' access to specialised HIV treatment and counselling services free at the point of delivery, and caring, respectful and productive interactions with health care workers, had a considerable positive effect for objective and subjective wellbeing. The higher quality of care provided by HIV services compared to other health services in parts of Sub-Saharan Africa have reported elsewhere (Ooms et al. 2008). Increased social contact at clinics among a 'community' of PLWH enhanced support and a sense of belonging, and was another factor enhancing wellbeing. Greater social contact at health facilities triggered by HIV has elsewhere been shown to increase quality of life among PLWH on ART (compared to HIV negative counterparts) in South Africa (Nyirenda et al. 2012), and in Uganda research has identified the positive impact of greater social support on QOL amongst people on ART (Bajunirwe et al. 2009).

The findings reveal the importance of relational processes for wellbeing. PLWH felt they had become part of a 'community' of PLWH, a group who looked after each other and who no longer faced difficulty alone. Participants spoke of their shared membership of an organisation like TASO or the hospital clinic, and their shared experiences of HIV and the demands of ART. This shaping of group identity and relatedness among PLWH on ART has

been identified in several other studies looking at the benefits brought to self-management by these collective experiences (Nguyen et al. 2007; Ware 2009; Whyte 2012).

In the human-relational dimension, improved health and appearance were a key factor underpinning wellbeing, and subjective aspects of this dimension were reduced self-stigmatisation, greater self-esteem and social confidence. For stigmatising illnesses like HIV, 'framing agents' such as health workers have the potential to offer an alternative language for thought and speech which can assist coping and resist dominant stigmatising discourses (Watkins-Hayes et al. 2012). The health workers in this study helped participants to deal with and resist stigma. Similar processes of reduced internalised stigma have been reported in other studies in the region (Russell and Seeley 2010; Roura et al. 2009). However anticipated stigma and fear to disclose remains a deep-seated problem (Roura et al., 2009, Mbonye et al. 2013) which causes on-going stress (Mutabazi-Mwesigire 2014).

There was evidence of psychological adjustment processes leading to enhanced wellbeing. Although a pre-post design is required to fully explore response shift, participants made clear 'before and after' contrast effects which were linked to response shift recalibrations. The response shift elements of reprioritisation and reconceptualization were also present. The generation of new plans, for example, represented a reconceptualization of QOL and post-traumatic growth in terms of personal growth and self-development, or a re-evaluation of life and its meaning (Hefferon et al., 2009). Participants also actively made social comparisons to enhance subjective wellbeing. These psychological mechanisms match closely the 'making meaning' or 'benefit finding' self-management processes identified by Sharpe and Curran (2006) and Schulman-Green et al. (2009).

The wellbeing gains for participants derived from investment in ART programmes offer lessons on how systems of chronic care can be improved for other conditions. Affordable and good quality care services can make a big difference to people's wellbeing (Negin et al. 2013). The factors underlying wellbeing also highlight low cost changes to health worker practices which can enhance wellbeing, for example treating people with respect, encouraging a collective sense of identity and responsibility around treatment, and advice and support which enhance self-esteem and give people the language and concepts to reframe their sense of self and challenge stigma (Watkins-Hayes et al. 2012).

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