AIDS PATIENT CARE and STDs
Volume 27, Number 12, 2013
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DOI: 10.1089/apc.2013.0254

Tasks and Strategies of Self-Management of Living with Antiretroviral Therapy in Uganda

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Abstract

There is increasing interest in promoting and supporting self-management of HIV and antiretroviral treatment (ART), including in resource-limited settings. Although the impact of HIV and ART on people in Uganda has been explored, little attention has been paid to how people self-manage. This qualitative study collected data from 20 participants on ART in Wakiso district, Uganda, using in-depth interviews, life histories, and observations to explore the tasks and strategies of living with ART. The identified strategies were compared to two existing self-management frameworks. Results highlighted a range of tasks including obtaining, taking, and adhering to ART medication, monitoring their condition, living with stigma and managing disclosure, maintaining general health, and adjusting to new roles. Participants described a range of strategies or behaviors to manage, which they actively created and used, tailored to their needs and environment. Comparison with existing frameworks revealed many similarities, with some local differences in enactment, and greater emphasis in our sample on obtaining the medication. Interventions to support people with self-management in Uganda, and possibly other resource-limited settings, require careful adaptation to local settings. The degree to which each of these strategies may improve health and quality of life requires further investigation.

Introduction

With the advent of antiretroviral treatment (ART), HIV now can be managed medically. To support people living with HIV (PLWH), the World Health Organization proposes decentralizing care, simplification of treatment and clinical monitoring, sharing the tasks of managing illness, and self-management by PLWH.[1,2] Models to extend HIV care in resource-limited settings may include interventions to support self-management as part of that care.[3] However, we currently do not have good evidence in these settings about what people are doing to manage their illness, how well this is working, or what support to provide. Recent articles continue to point out the need for a greater understanding of the experience of living with HIV, particularly in resource-limited settings.[4]

Several studies in sub-Saharan Africa have explored issues around adherence to medication. Long waiting times at clinics, costs of care, and level of provider knowledge about HIV have been shown to influence patient satisfaction,[5] providing different challenges around accessing ART. Factors affecting discontinuation have been found to include long waiting times, lack of provision of transport to clinics, poor communication between patient and healthcare provider, preferential use of traditional medicines, experience of many side effects, fear of discrimination, and lack of belief in HIV diagnosis or the utility of ART.[6–9] As participants discontinue ART, it is not clear how others who remained adherent managed the challenges faced. One study explored strategies used by people in four sub-Saharan African nations to manage HIV symptoms.[10] Participants described strategies of taking medication, use of traditional treatment, self-comforting, changing diet and taking exercise, seeking help, spiritual care, remaining active, and using cognitive coping strategies. This study, however, does not make reference to ART: being conducted in 2005 it is likely that ART was not widely available. At an individual, psychological level, perceived coping self-efficacy predicted adherence to ART in a study in Kenya.[11] One strategy, therefore, that can support taking ART is belief in one's ability to cope. There may be other cognitive as well as behavioral strategies.

Studies in Uganda have explored some challenges of ART,[12] examined the impact of ART adherence on life activities,[13] investigated the impact of ART on social relationships and how these are managed,[14] and explored the rebuilding of livelihoods.[15] The impact of HIV on working life in Uganda is

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largely negative, with ART allowing people to re-engage in work, but typically in a more informal or less-well reimbursed setting.[16] This reveals the economic impact of HIV and ART, at least in the short term; however, it is not clear what approach people use to manage this. The transformative impact of ART has been highlighted, showing how ART allows people to manage their illness, to return to sexual relationships, to work, and to create a "normal" life, albeit often a changed version of what was normal.[17] Taken together, these studies provide an understanding of some of the challenges faced, including side effects, stigma, social isolation, and uncertainty regarding a way of gaining resources. These studies also provide some ideas of how people manage at an individual level; however, this is largely limited to addressing issues around medication adherence, which is one element of self-management. There is some consideration in the literature of how HIV and ART can have an impact at the social level regarding relationships and livelihoods. This provides some insight into how people manage their social relationships, particularly managing new sexual partnerships while on treatment.[18] However, the strategies people use in resource-limited settings to complete the tasks of living with ART, have not been covered in depth.[19]

This article aims to describe self-management tasks experienced and strategies used by people living with ART in central Uganda. This extends beyond medication adherence. Self-management is a much researched concept in the global north; therefore, a secondary aim of this article is to explore to what extent existing frameworks are relevant to people in Uganda. Documenting the challenges and their management provides evidence of the everyday experience of living with ART. This understanding can then inform intervention development and policy.

An overview of self-management of HIV

Self-management refers to a person's ability to manage symptoms, treatment, and consequences of living with a chronic condition, with the goal of achieving/maintaining a satisfactory quality of life.[20] Self-management is active participation in treatment.[21] It comprises an individual's knowledge, behaviors, and cognitions; however, it crucially also relies on interaction with others and the availability of resources.[22] Behaviors include taking medication, ensuring access to food and water to take medication, attending medical appointments, managing changes to sense of self, changing activities, and challenges of stigma and disclosure.[12,21,23] A complex set of behaviors is required, which varies by condition and context.

Attempts have been made to delineate different elements of self-management. Two frameworks are discussed here, selected because one relates to processes in self-management generally and the second focuses on elements of interventions and support for HIV. First, Schulman-Green et al.[24] completed a qualitative meta-synthesis of self-management across conditions. Self-management processes were grouped into three broad categories of focusing on illness needs (completing health tasks, changing behaviors to minimize disease impact, and sustaining health promotion activities), activating resources (navigating the healthcare system, benefiting from psychological resources, and obtaining social support), and living with a chronic illness (including making sense of and adjusting to illness, integrating illness into daily life, and reevaluating life). Some of these activities involved interaction with the healthcare system, managing relationships with healthcare professionals, and exercising choice of providers.

Second, relating specifically to HIV self-management, Swendeman et al.[25] reviewed the content of self-management interventions for HIV and compared these with the content from interventions for other conditions. They created a framework of intervention elements across the three broad areas of physical health, psychological health, and social relationships. Elements included health promotion behaviors, prevention of transmission, self-efficacy and empowerment, reduction of negative emotional states, collaborative relationships with healthcare professionals, and positive social and family relationships.

There are some obvious commonalities across the two frameworks. Both, like other reviews of self-management interventions, use literature predominately from Europe, North America, and Australia, reflecting the locations where this approach has been adopted. With the notable exceptions of research in China and Cambodia, the HIV self-management framework is currently not able to consider HIV self-management in developing nations, with no research from sub-Saharan Africa included. The majority of the self-management literature focuses on the individual in the context of healthcare systems with multiple health professionals.[26] It is not clear to what degree self-management differs in resource-limited settings with fewer healthcare practitioners, and a culture that may be less individualistic. A comparison of data about self-management strategies from a sub-Saharan African context with existing frameworks is conducted in this article.

Methods

The study was undertaken in Wakiso District, central Uganda. This study drew on patients accessing ART from a hospital and other lower level health centers within Wakiso. Many participants lived in rural areas around the town of Entebbe. The population is mixed, because people from many different tribes have settled near Entebbe. Although there is a strong Roman Catholic presence in the district, many other Christian denominations as well as Muslim groups are also represented. 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 people who are formally employed in teaching, healthcare, and cleaning services.

Forty potential participants (20 men, 20 women) living with HIV, were randomly selected from the hospital patient list. All eligible hospital patients had previously been candidates for inclusion in an ART trial. In the course of that study, information on income and living arrangements was collected. This information was used to aid the purposive sample selection for this study. Twenty participants (10 men and 10 women) were purposely chosen from this longer list to represent different wealth groups, ages, and living arrangements for people who had been accessing ART for > 1 year. After random selection from a list of patient numbers supplied by the hospital, participants were contacted either by telephone or at the time of their next clinic visit. Informed consent was obtained from all participants. Ethical approval was provided

by the Science and Ethics committee of Uganda Virus Research Institute (UVRI) in Uganda and the Uganda National Council for Science and Technology.

Participants were followed up once every month for a period of 8 months. Each participant received a bar of laundry soap as a token of appreciation after each interview. Two experienced interviewers used a combination of qualitative methods, including in-depth interviews, life history calendars, and observation to gain insights into the participants' background, work, relationships, experiences with HIV and ART, and future plans and to obtain an in-depth understanding of how PLWH manage ART over a long period of time. Interviews were conducted in Luganda, and rough notes were made (including noting verbatim quotes) in the field and later written up immediately after the interviews into full transcripts translated into English. This approach was used to build rapport with interview subjects and allow reflection on the content of earlier interviews. Tape recorders were not used, to facilitate informal discussion between interviewer and participant.

Data were managed using NVivo version 9. Thematic analysis was undertaken.[27] All data were read, reread, and coded for meaning and content by three of the authors (Martin, Kiwanuka, and Kawuma). Findings were compared. Themes were created by grouping of similar codes. Similar to grounded theory approaches, themes emerged from the data, without prior specification of a framework and with no attempts at formal hypothesis testing.[28] Once created, similarities and differences were explored within the data for each theme. The themes were derived without reference to the existing frameworks, and comparison with the frameworks occurred when thematic analysis was complete.

Results

The participants were between 26 and 58 years of age (mean 42). Fourteen participants were from the Baganda tribe. More than 50% had primary level education, and there was no marked difference between men and women. Nine were married and out of these, six were men. Two married men were in polygamous relationships. Five participants were single (all women), three were widowed participants (two men), and two (both men) were divorced. Six participants were operating small businesses such as hardware shops or restaurants, or were selling second hand clothes. Four were small-scale farmers, four were builders, and two were unemployed. All participants had at least one child. Sixteen were receiving their ART treatment from the hospital whereas four accessed their drugs from peripheral health centers.

In relation to follow-up, 12 participants (mainly women) completed eight interviews, whereas only three men completed the eight interviews; four (males) were interviewed on seven visits, one (male) for six visits, two (one male and one female) for five visits, whereas another one (male) was seen for only four visits. In addition, one male participant was lost to follow up after his fifth visit, because of imprisonment.

Themes emerging from the data indicated a range of tasks and strategies involved in living with HIV and living with ART. Managing ART itself entailed obtaining, managing, taking, adhering to instructions for, and benefiting from ART. An additional task relating to HIV was condition monitoring. Stigma and disclosure were further issues of living with HIV. Finally, tasks of life more generally were evidenced, with strategies used to maintain health and adjust to new life roles. Table 1 provides an overview of the tasks and strategies revealed.

Obtaining medication

Issues around obtaining medication took up a significant amount of the discussion time. Whereas the benefits of ART were acknowledged, there were practical challenges around accessing this vital medication.

Before ART initiation, all participants were taken through health counseling sessions, including instructions about ART, health behavior, and work. Many patients appreciated being able to access free drugs, and the messages from health workers gave them hope about being able to lead normal lives again. Obtaining medication was supported by the belief that ART was seen as utterly vital: "like fuel in a car, when it runs out, then the car has to stop and cannot move" (Remmy [please note that pseudonyms are used throughout], 30 years old). Many participants made it clear that they would persist with adherence because they felt benefits from the medication and wanted to be healthy.

Although receiving a 2 month supply of drugs was discussed as preferable, some received 1 month's supply at a time, because of a poor adherence record, increased monitoring because of recent initiation or regimen change, poor health status, or lack of stock of medications at the health facilities. A cycle was observed: poor adherence and experience of (self) stigma led to people avoiding the clinic until they were extremely unwell, increasing the stress and frustration of the clinic staff, leading to unpleasant subjective experiences at the clinic for patients, which encouraged them to avoid the clinic, and so on.

Limited supplies, leading to more frequent visits, were a concern for many. Transport fees and long waiting times (several hours), leading to loss of income or resource-providing work, were discussed. Other stressors were files getting lost, unpleasant experiences with clinic staff, and irritation caused by waiting. People had to adapt because of the crucial need to obtain drugs to improve health.

Several people described obtaining medication for themselves and their spouses, which meant that there were transport costs for only one person and loss of only one person's income. Making friends with staff in order to be seen more quickly or so that staff could pick up drugs for them was another strategy. Transfer to clinics closer to home was desired by some. Arriving at the clinic early was described "as reducing waiting time." Other strategies were also used:

> "*it is sheer confusion*" [at the clinic] and because of that, every time she goes there she feigns sickness such that she appears too sick and is the first to be sent to see the doctor who prescribes their drugs (Suzan, 40 years old).

Experience and management of taking multiple tablets

All participants were taking more than one tablet a day, with many taking four antiretroviral drugs and other medications such as co-trimoxazole (used to manage opportunistic infections). When the number of tablets to be taken was altered, some participants felt worried and sought information. Suzan asked "but won't we die due to taking too many drugs?" Concern about potential toxicity from taking many medications was seen in several interviews. One 40-year-old male participant linked this concern directly to his low adherence, as

Table 1. Summary of Strategies Used to Self-Manage By Study Participants

Task	*Strategies evidenced by some participants*
Obtaining medication	Attempt to obtain 2 month supply Manage clinic visit; e.g., go early, collect for someone else
Taking multiple tablets	Focus on health benefits of medication Use water and food to help take tablets Plan in advance so as to have water and food available Try to stay healthy so as not to have to take other medication also Understand the regimen and changes to it Obtain information
Side effects	Learn from counseling so as to understand side effects Use food and water when taking tablets Be patient and endure Use co-trimoxazole Remember that taking the medication is required for staying healthy
Maintaining adherence	Plan in advance if traveling Plan in advance so as to have food and water Consider the drug normal and beneficial Involve family members and friends to remind you to take drugs Self-monitor adherence using, e.g., mobile phones Keep to a routine Know the time so as to be able to take drug at the right time of the day using, e.g., a radio Understand how to use the medication and what to do if a dose is missed Make social comparisons with those who are very ill if not taking their medication
Impact on life	Focus on improvement to health rather than difficulties; e.g., ART does not cure Focus on activities can now do e.g. work and provide for children
Condition monitoring	Have CD4 count tests, including gaining resources to enable this Know CD4 result, as this gives peace of mind Obtain information
Living with stigma	Avoid gossip Remember that with medication, people look healthy Remember how many people are affected by HIV Try to accept HIV status Conceal status Seek acceptance, support, and others who are also HIV positive
Disclosure	Make a choice about whom disclose to Turn disclosure into educating others to promote prevention/adherence Use nondisclosure to protect self (e.g., from stigma) and others (e.g., from fear and worry)
Maintaining general health	Obtain information Keep to a healthy diet, exercise, and drink enough water Avoid stress Maintain a positive outlook Change sexual behaviors; e.g., stopping, sero-matching, condom use
Adjusting to new roles	Continue with "normal" life; e.g., have children Continue/change/start work Join groups for support so as to share resources and support Become an advocate and community educator Focus on the future

he had believed "all drugs are good but if taken in huge amounts, they tend to become poisonous to the body."

Whereas Betty, age 33, described the need to take medication as simply "tiresome," others talked of the stress of taking drugs every day, complaining of the need to remember to travel with them and adapt in order to adhere:

> He said that he has to pray and also fast but because of the drugs, he cannot fast because he needs to take the drugs with food (Interviewer's notes on Iqbal, 39 years old).

Other illnesses requiring medication increased the stress of taking ART. This was because "you may end up taking about a dozen tablets a day" (Tyson, 37 years old). This increased the importance of maintaining health to avoid having to take additional tablets. Taking several tablets and ensuring that food or water was available for this could be particularly challenging if one was away from home (Happy,43 years old) and it was easy to forget (Tyson).

Medication regimens were changed because of drug availability or difficulties with side effects. For some, this was the only time when their treatment was commented upon: "The only time I got problems with the drugs was when I was changed to another type" (Tyson). Some reported receiving information and education regarding regimen changes, which

was useful. "They told us that the system of getting one tablet had phased out and it was supposed to be two per day" (Kawooya, 47 years old). Such changes felt frequent, confusing, and of concern to some. However, others experienced no concerns or difficulties with changes: "I want life so I will take the drugs" (Teopista, 58 years old).

The act of taking the medication was discussed by most participants. Linked to side effects, several participants named the importance of taking the tablets with water, and, if possible, having something to eat. Access to food and water was not always possible, and for some presented a challenge in itself. Others developed strategies to cope: keeping food with tablets, growing food specifically for medication, having a container of drinking water and always carrying water.

> She then shows me three large flasks on top of her cupboard and says she normally keeps tea and porridge in them so when it is time for taking her drugs, she makes sure that she has eaten something before swallowing the drugs (Interviewer's notes on Stella, 37 years old).

Experiencing and managing side effects

Participants named a range of side effects that they had experienced during their early months on ART, including loss of appetite, physical weakness, headache, burning sensations in the stomach, nausea, vomiting, diarrhea, joint pain, numbness in the extremities, changes to skin color and thickness, and boils. Whereas not every participant experienced side effects, many had other health conditions, such as tuberculosis or malaria, or were also taking co-trimoxazole. Therefore, it was difficult to attribute causes to "side effect" symptoms.

Despite difficulties, no participants stated they had stopped taking ART because of the side effects, as ART was seen as giving health. Counselors had told people what to expect, and the likelihood that side effects would subside over time. Because of this, Tyson "didn't panic" when side effects occurred.

Experiences with co-trimoxazole were mixed. Some reported that co-trimoxazole helped with the side effects. Others would have liked to take co-trimoxazole, as it was perceived to be useful, but were concerned about the sheer number of tablets to be taken. Some reported stopping co-trimoxazole without notifying physicians. This was associated with different beliefs about medications. ART medications were believed to be essential for health, whereas co-trimoxazole was seen as helpful but not essential.

Strategies were used to manage side effects, such as taking ART tablets with food and water, as advised by health workers. Seeking medical treatment for side effects was not always possible, because of the cost, in terms of both clinic fees and time away from employment. Side effects were managed with patience and time; they can naturally subside as one gets used to the drug or can simply be endured.

Maintaining adherence

ART demands good adherence, and many participants reported managing this. Missed doses of ART were the result of forgetfulness, hiding medication from others because of nondisclosure, being asleep, busyness, other health conditions, not having food or water, being away from home, or stressful events.

> At least once a week she forgets to take her drugs […] sometimes she has too many things she is worried of and therefore fears to take the drugs in such a condition that they could harm her. She also adds at times she has not eaten food and cannot take drugs on an empty stomach and yet other times she remembers to take her drugs when the time is past (Interviewer's notes on Nanziri, 26 years old).

Attitude to and understanding of ART were also important. One participant had volunteered as a health advisor, and discussed the support people needed to adhere:

> In the past days, we lost one of our patients but his wife brought us five tins of drugs which he had not been taking all along. You know people lose hope since the drugs don't act right away and they give up on it (Javira, 47 years old).

Whereas worries that drugs may cause harm reduced adherence, believing that drugs were important, understanding how to use them, and the impacts of missing doses supported adherence:

> Once you miss taking the drugs at a given time, you should wait and take at the next dosage time because if you resist and still take, the drugs may interfere with the next dosage you are to take hence making an over dose… when you miss for about 1 or 2 months, your CD4 level may deteriorate hence making it difficult to revive the blood cells once you get bed ridden (Philly, 40 years old).

A range of strategies were used to support adherence, including planning to have food and water and for travel. Children, siblings, spouses, other family, neighbors and friends were called upon to give support:

> All my children know that I take these drugs and even some times they remind me when I am asleep in the evening that "father, won't you take your medicine" and I take (Javira).

Self-monitoring of adherence was described, using mobile phones and radios to track when medication was taken, and setting alarms to prompt adherence. Routine was useful – many reported having a set time of day to take medication, choosing a convenient time. Mafabi (age 41 years) commented that "the drugs [are] a part of his life or as food eaten every day."

A shift from difficulties with adherence to taking medication regularly was evidenced in some participant's stories. Initially, in early interviews, one participant described very poor adherence and feeling uninterested in taking medication. In subsequent interviews, she described using multiple strategies to maintain adherence, including using the radio to know the time, keeping the drugs in the same place, planning in advance and taking drugs with her when she travelled, and gaining support from her children, who reminded her to take the tablets every day (Namusisi, 50 years old).

Social comparisons were used to maintain adherence. For one woman:

> There is no way she can miss taking her drugs because one day while at [clinic], she saw three men who were very sick and the health worker told them that the reason they were very sick was because they had stopped taking their ARV's (Interviewer's notes on Betty).

Impact of ART on life

ART "changed life for the better" (Nanziri) for many. For participants, life could have hope and a future once again, for example:

> He even wanted to commit suicide since he had no hope left in his life… He told me that all this he got rid of after he had tested

> and attended the counselling sessions […] and also given hope that the drugs were soon to be introduced. It's this that gave him hope and a new meaning of life (Interviewer's notes on Javira).

However, several participants referred to ART as a "burden," One participant described his frustration that ART does not cure:

> let the doctors get us some drug that can treat this disease instead of the ones that we keep on taking that don't cure (Kawooya).

It was very common among the sample for people at that time to only get an HIV test after periods of serious illness. As such, ART had given strength back, prevented repeated episodes of severe illness, and reduced frequency and intensity of opportunistic infections. Participants focused on these improvements. Several people described how they had been bedridden prior to taking an HIV test, and that ART then allowed them to reclaim life. Charles (age 47 years), who had two wives, talked of once more being able to care for two families after a long period of illness.

Condition monitoring

Participants discussed CD4 counts, which were seen as important. For some, this facilitated access to drugs, as a good adherer with a good CD4 count could obtain 2 months' supply. CD4 levels provided a goal for treatment for some and reassurance for others. CD4 tests were costly to participants; however this barrier was overcome by several, because of the perceived importance of knowing their count. CD4 tests then provided "peace of mind" (Joseph, 34 years old). One participant described his actions to get the money for the test:

> The last time he had come to [clinic] to test for CD4, they told him that the whole test would cost him 50,000/=which he didn't have then and he told them that he would come back with the money after selling off his goat (Interviewer's notes on Kawooya).

People demonstrated they were actively engaged in monitoring and understanding their condition, to better self-manage. A few described seeking information to understand what might affect their CD4 counts, sometimes in order to take action to improve their health.

> Via internet he has discovered that CD4 is very confusing because it can't stay stable for long. He said that he discovered that one can test CD4 in the morning when it's high but test again later when it has reduced may be when you have been stressed or worried of something (Interviewer's notes on Happy).

Living with stigma

Initially when they had tested HIV positive, some participants could not mix freely with their families or communities. At this stage, feelings of shame, self-blame, and worthlessness led to depression, self-imposed withdrawal, and even suicidal feelings.

> He said that when he first tested and was told that he was infected, he did not want to mix with people any more […] and that's why he even refused to go in for the drugs at the first time. He added that whenever he thought of the way he would appear after getting sick and slimming, he would feel like running away from his home because he didn't want his children to know about his status (Interviewer's notes on Happy).

Some said they no longer experienced stigma, partly as with medication people "look healthy" (Iqbal and Innocent, 40 years old) or because HIV is common (Teopista). Others experienced stigma resulting in verbal and physical abuse. For example, one person was treated badly by family for having darkening skin, seen as a sign of being on ART (Remmy).

People developed strategies to manage stigma. Nanziri, a 26-year-old with a new baby, described how she lied that she did not have enough breast milk to explain why she was not breastfeeding, using concealment to avoid HIV-related stigma. This woman had already experienced stigma and discrimination at work because of her status, and had been accused of being bewitched by a female elder in the community. In addition, she managed her medication by stating that she had a stomach condition; however, this subterfuge, and her other stressors, reduced her adherence.

Self-stigma was experienced by most of the participants, judging from the actions of those who tried to conceal the fact that they were HIV positive. Others spoke about acceptance of their HIV status and social acceptance, achieved through seeking places where people were supportive, particularly others who were also HIV positive. Counseling from The AIDS Support Organisation (a nongovernmental organization) was mentioned by several people as being useful in talking about stigma, and as a safe place where stigma could be reported.

Managing disclosure and family

Disclosure of their HIV status was selective. Among the people more freely disclosed to were spouses, relatives, friends, and some members of the community who later became their drug companions (a person chosen to help remind them to take their medication). When it came to disclosing to children, participants had mixed ideas. Some believed that disclosing to the children would help get psychosocial support from them. However, others felt that disclosing would worry them and destabilize their future. Resty (40 years old) had disclosed to her children. Her daughter, who was in senior school, sometimes went to the clinic to pick up Resty's monthly drugs in case Resty was not able to go. Whereas for Philly "the only thing that stopped him from telling them was getting scared and thinking their future was doomed since they were getting all the necessary support from their parents."

Where they believed it would dispel fears, parents did tell their children. One participant described how she explained to her son that she had HIV, but was taking her medication and, therefore, reassured him that she was staying well, unlike her sister, who died. The disclosure was prompted because "her son kept wondering why she has to go to the clinic every month yet she didn't look sick" (Stella). On his part, Javira said that by disclosing his status and the fact that he was on ART to his older children, he was able to use it as a way of counseling them to live safely and avoid contracting HIV.

ART could increase the need to disclose, as clinic visits and medication in the home needed to be explained. Being seen waiting outside the HIV clinic for drugs meant others could draw their own conclusion.

Where possible, disclosure did not occur where relationships were difficult, or to those seen as "gossips." Disclosure can be risky, leading sometimes to support and sometimes to

accusations of witchcraft or adultery. A downside of disclosure was fear that this would deter potential partners. A common strategy was to elect to disclose HIV status only to people very significant in the participants' lives who needed to know about their status.

Managing to stay healthy

Participants described a range of other self-management behaviors. Several people attempted to maintain general health by ensuring they ate a balanced, nutritious diet, taking exercise and ensuring that they had water to drink.

> He told me that when he was still in the health education sessions before he started ART drugs, the doctors recommended fruits like papaws, passion fruit juice and many others which he takes and thus keeping up his body well (Interview's notes on Tyson).

Counseling gave an opportunity to obtain information and make sense of how HIV can be asymptomatic, vital information for one participant who could not understand how she had HIV, as she "had no related symptoms and wasn't thin" (Nanziri). Counseling covered the negative impact of worry and stress on health. This message appears to have been successful, as many participants talked of trying to stay calm, not dwelling on the negatives, and avoiding worry, as stress was seen as causing poor health.

Ill health owing to other conditions did occur, representing another set of stressors and requiring resources. For example, one participant experienced ongoing issues with boils, which may have been related to the ART and was interfering with her ability to work, threatening her livelihood and creating stress (Stella). Sometimes other illnesses were managed using herbal medicines, although this strategy was not reported for management of HIV itself.

Several participants described having sex less often than they used to because of advice from counselors. Generally, condom use was inconsistent, as were monogamy and/or abstinence. One woman described specifically avoiding sex, as she worried about how to negotiate condom use with a new partner. Although this appears to be a healthy choice in terms of HIV transmission, it belies the participant's adjustment and represents a potential impact on quality of life. She also stated of her partner "if he tests positive, then she will agree to marry him but if he is negative, then that will mark the end of their relationship" (Remmy).

Adjustment and new roles

Participants engaged in everyday life, including work, caring for family, and having children. Most participants had previously stopped work because of ill health. However, with the introduction of ART, they recovered, and all of them wished to work. Changing work type allowed people to make adjustments to their life to protect their health since their HIV diagnosis. This was constraining for some: "you limit yourself due to your health" (Javira). Participants moved to work with less physical impact. For some, reconceptualization of wellness was evidenced: a shift from being free from disease to being able to work. For example, a taxi driver, Philly, said "the day I fail to drive is when I will know that I am going to die".

Others joined groups where they would network with other people and pool resources to support themselves and their families. Group membership was mainly for financial purposes, where money would be collected and shared to boost business and buy household items.

Some participants described taking on a role of promoting testing and tackling stigma. One participant described her work of teaching new patients about ART, the importance of seeking help, "positive living and most importantly taking their drugs consistently" (Teopista). Another described how she encouraged people to talk about their problems and discuss them in a group so that they could find a solution together and live "positively with HIV" (Resty).

Meeting others with HIV facilitated adjustment. Hope was gained when seeing others who were HIV positive but looked well. Friends, family, and people met at the HIV clinic could all provide social and emotional support. Some described focusing on the future, specifically the future of their children, involving plans to provide education, food, and housing. Future plans to find work, buy plots of land, and construct houses were also seen, although, one participant stated that she "lives one day at a time" (Angella, 33 years old). Another stated "I have nothing and therefore don't make plans for tomorrow although as a human being I have so many wishes" (Nanziri).

Comparing to previous self-management frameworks

Comparing the strategies to manage HIV outlined by our participants to existing HIV self-management frameworks reveals several areas of commonalities, in addition to highlighting some key differences. These are summarized in Table 2.

The elements seen in existing frameworks were identified in our data. Gaining an understanding of their condition and completing health behaviors cover several self-management strategies that were commonly described by our participants and are identified in the existing frameworks. There were some differences in the degree to which participants were able to make treatment choices, limiting the presence of strategies such as "Accessing appropriate treatments and services." For example, changes to drug regimens might hav been made on the grounds of availability rather than as an empowered choice made by patients. Additionally, whereas our participants did modify lifestyle, there were limitations in the control participants had over their socioeconomic environment, meaning that changes in activity were not possible because of demands to earn a living in circumstances of limited choice. Re-evaluation of life, growth, and satisfaction were achieved by many of the patients in our study, predominately through taking on advocacy roles and/or focusing on the new chances they had and providing for children. Monitoring through seeking CD4 testing was particularly important for several participants.

Notably largely absent from our data were discussions about the healthcare system overall, other than comments on waiting times. Although the system was a topic of discussion, the majority of patients were grateful that they were receiving care and did not pass comment on the nature of the care that they received. Furthermore, discussion of processing and sharing of emotions was seldom mentioned in these data. Participants talked of avoiding stress and thinking too much, rather than describing processing of emotions. Two key themes in our data were around the behaviors of actually obtaining medication, and practical strategies that supported

Table 2. Summary of Comparison of Current Findings to Existing Frameworks

Framework	*Strategies observed in our Uganda data*	*Strategies in the framework not observed in our data*
Schulman-Green et al., 2012[24]	Learning about condition and healthcare needs Becoming an expert Creating and maintaining relationships with healthcare providers Navigating the healthcare system Recognizing and managing body responses Completing health tasks Changing behaviors to minimize disease impact Sustaining health promotion activities Identifying and benefiting from psychological, spiritual, social, and community resources Adjusting to illness Adjusting to "new" self Modifying lifestyle to adapt to disease Seeking normalcy in life Re-evaluating life Personal growth Striving for personal satisfaction	Processing and sharing emotions
Swendeman et al., 2009[25]	Framework for understanding health and illness Health promoting behaviors Adherence to medication Self-monitoring of physical health Accessing appropriate treatments and services Cognitive skills of self-management Reduction of negative emotional states Identity Self-disclosure of disease status and coping with stigma Positive social and family relationships Social support Preventing transmission	Self-efficacy and empowerment Collaborative relationships with healthcare professionals
Strategies highlighted in our data but not seen in other frameworks		
Obtaining the medication Planning in advance so have food and water for medication		

taking the medication. These strategies are less pertinent in the existing frameworks.

Discussion

This research aimed to explore the tasks and strategies of living with HIV and ART in a sample of people in Uganda. Results showed that participants were faced with a range of self-management tasks, covering ART, HIV, and everyday life, but that they used a range of active, and sometimes creative, strategies to manage the challenges of living with HIV and taking ART. This is an important reminder of the active rather than the passive role of people living with HIV and people living in poverty, relevant to both healthcare and development interventions.[29,30]

Practical strategies, including accessing social support, seeking information, and creating new social roles were all seen. Some strategies were more psychological in their nature. Patience, endurance, living "one day at a time," and having a future orientation situated in hopes for children were evidenced. Viewing ART as necessary and having few concerns about its impact facilitated medication adherence, mirroring existing psychological theory.[31] Emotion-focused coping was also used to reinterpret HIV and everyday life by focusing on the short-term and on positive thoughts for the future.[32] Overall, however, there was a lack of discussion of emotions. This may reflect cultural differences in the manner and social acceptability of discussing psychological matters.

The results support the positive impact of counseling, which assists with adherence, managing stigma, and psychological health. Interventions have been designed to improve self-management for people living with ART, for example.[25,33] There are several similarities between strategies described by our participants and those in interventions; for example, self-management interventions often include practical strategies to improve medication adherence, education about stress management, support to manage stigma via disclosure, and ideas about improving social support networks.[25] Our findings suggest that the content of self-management interventions to people living with ART in Uganda may be usefully adapted. However, people are creating their own, idiosyncratic strategies which fit their context, and it is these that can be usefully identified, shared in interventions, and built upon.

Strategies identified relate generally to existing self-management theory; however, our findings suggest some differences in this resource-limited setting. Existing self-management frameworks include interaction with healthcare systems and providers. Our participants did not refer to this aspect of self-management in any detail. Whereas there were a

range of providers available to our sample, the actual power to make a choice may have been limited because of access and availability. Furthermore, providers share information to control how people access different medications. Together with the limited number of care providers, this resulted in limited real choice regarding where to obtain care. Although participants were attempting to build and use relationships with healthcare providers, the emphasis on this as collaborative was not evident. Participants were navigating the healthcare system, however, creatively finding ways to be seen at hospitals more rapidly and to meet their health needs. Some described expertise in these strategies and sharing information with others.

Another difference from the traditional framework was around the costs of obtaining medication in terms of actual fees and income lost, highlighting the relevance of poverty. Additionally, many participants emphasized the importance of ensuring that water and food were available. Whereas this is likely to be a strategy used globally, the salience of this in Uganda is stark, given the limited resources and potential instability of livelihoods for our participants. Obtaining and taking the medication may be more basic health needs, whereas creating supportive collaborative relationships with healthcare systems can be considered as more complex, with people being free to focus on these issues when basic demands are met.[34] As healthcare systems develop in Uganda, a shift may be seen to more complex needs, and a change in self-management strategies.

Tensions between positive impact and challenges were observed. Many positive elements of ART were mentioned: better health, hope, and social support. However, some found taking the ART tablets unpleasant. There was a tension here: participants became stressed because of the structures and tasks surrounding accessing medication; however, they reported being counseled to avoid stress, as this is associated with ill health.

The importance of context in understanding the impact of HIV and ART is emphasized. HIV and ART seem to increase the importance of several practical tasks of life. For example, obtaining medication required time away from work, amplifying everyday financial concerns. Taking drugs required food and water, emphasizing the need to obtain these resources. Managing stigma and disclosure meant extra work around social relationships. Conversely, ART decreased the impact of HIV on sexual relationships and being able to perform everyday work, as episodes of ill health were decreased. Research across African nations has found that those with more money experienced fewer HIV- related symptoms.[35,36] The general context of life is vital to understanding the impact of HIV and ART, and how it is managed. Such local understanding is needed to inform any intervention.

Limitations

The study has several limitations. Whereas the current research outlines some of the strategies used by participants, it is not clear which of these may be beneficial to outcomes such as quality of life. The study recruited participants from a healthcare system providing routine care in a peri-urban area. Others, who lived farther from care, may not have had such access to information and support. Although researchers were experienced and built rapport with participants over repeated interviews, the common issue of social desirability affecting the research data must be acknowledged. Interviews were not audio-recorded and although notes were made during and soon after completion of interviews, there is potential bias from interviewers in what was recorded and how translation was conducted.

Conclusions

Recommendations for intervention and policy arise from these data. Self-management interventions in Uganda and possibly other resource-limited settings will require careful adaptation of components to address the identified local issues and to build on information from locally successful strategies. Consideration of how healthcare systems and policy can promote and support self-management is required. Several components of self-management were similar to those supported in interventions, with some locally relevant differences. The findings can be used to inform the content of future self-management interventions.

Acknowledgments

We are grateful for funding for this research from the "Evidence for Action Research Programme Consortium," funded by the United Kingdom Government Department for International Development and Medical Research Council (MRC). We are grateful to Professor Heiner Grosskurth, former Director of the MRC/UVRI Uganda Research Unit and Professor David Ross, former Director of "Evidence for Action" for their support. We are grateful to the hospital and health center staff for facilitating this research, and to all the study participants for spending time with us and sharing their experience.

Author Disclosure Statement

No competing financial interests exist.

References

1. Gilks CF, Crawley S, Ekpini R, et al. The WHO public-health approach to antiretroviral treatment against HIV in resource-limited settings. Lancet 2006;368:505–510.
2. Grubb I, Perriëns J, Schwartländer B. A Public Health Approach to Anti-Retroviral Treatment: Overcoming Constraints. Geneva: World Health Organization, 2003.
3. Wools–Kaloustian K, Kimaiyo S. Extending HIV care in resource-limited settings. Curr HIV/AIDS Rep 2006;3:182–186.
4. Wekesa E, Coast E. Living with HIV postdiagnosis: A qualitative study of the experiences of Nairobi slum residents. BMJ Open 2013;3: pii: e002399.
5. Church K, Wringe A, Fakudze P, Kikuvi J, Simelane D, Mayhew SH. The relationship between service integration and client satisfaction: A mixed methods case study within HIV services in a high prevalence setting in Africa. AIDS Patient Care STDs 2012;26:662–673.
6. Dahab M, Kielmann K, Charalambous S, et al. Contrasting reasons for discontinuation of anti-retroviral therapy in workplace and public-sector HIV programs in South Africa. AIDS Patient Care STDs 2011;25:53–59.
7. Hardon AP, Akurut D, Comoro C, et al. Hunger, waiting time and transport costs: Time to confront challenges to ART adherence in Africa. AIDS Care 2007;19:658–665.
8. Murray LK, Semrau K, McCurley E, et al. Barriers to acceptance and adherence of antiretroviral therapy in urban

Zambian women: A qualitative study. AIDS care 2009;21: 78–86.
9. Musumari PM, Feldman MD, Techasrivichien T, Wouters E, Ono–Kihara M, Kihara M. "If I have nothing to eat, I get angry and push the pills bottle away from me": A qualitative study of patient determinants of adherence to antiretroviral therapy in the Democratic Republic of Congo. AIDS Care 2013;25:1271–1277.
10. Sukati NA, Mndebele SC, Makoa ETs, et al. HIV/AIDS Symptom Management in Southern Africa. J Pain Symptom Manage 2005;29:185–192.
11. Kamau TM, Olson VG, Zipp GP, Clark M. Coping self-efficacy as a predictor of adherence to antiretroviral therapy in men and women living with HIV in Kenya. AIDS Patient Care STDs 2011;25:557–561.
12. Nyanzi–Wakholi B, Medina Lara A, Munderi P, Gilks C, on behalf of the Dart Trial Team. The charms and challenges of antiretroviral therapy in Uganda: The DART experience. AIDS Care 2012;24:137–142.
13. Matovu SN, La cour K, Hemmingsson H. Narratives of Ugandan women adhering to HIV/AIDS medication. Occup Ther Int 2012;19:176–184.
14. Seeley J, Russell S. Social rebirth and social transformation? Rebuilding social lives after ART in rural Uganda. AIDS Care 2010;22(Suppl 1):44–50.
15. Russell S, Seeley J, Ezati E, Wamai N, Were W, Bunnell RE. Coming back from the dead: Living with HIV as a chronic condition in rural Africa. Health Policy Plan 2007; 22: 344–347.
16. Wagner G, Ryan G, Huynh A, Kityo C, Mugyenyi P. A qualitative analysis of the economic impact of HIV and antiretroviral therapy on individuals and households in Uganda. AIDS Patient Care STDs 2009;23:793–798.
17. Russell S, Seeley J. The transition to living with HIV as a chronic condition in rural Uganda: Working to create order and control when on antiretroviral therapy. Soc Sci Med 2010; 70:375–382.
18. Apondi R, Bunnell R, Ekwaru JP, et al. Sexual behavior and HIV transmission risk of Ugandan adults taking antiretroviral therapy: 3 year follow-up. AIDS 2011;25:1317–1327.
19. Copeland TJ. Poverty, nutrition and a cultural model of managing HIV/AIDS among women in Nairobi, Kenya. Ann Anthropol Pract 2011;35:81–97.
20. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: A review. Patient Educ Couns 2002;48:177–187.
21. Jones MC, MacGillivray S, Kroll T, Zohoor AR, Connaghan J. A thematic analysis of the conceptualisation of self-care, self-management and self-management support in the long-term conditions management literature. J Nurs Healthc Chronic Illn 2011;3:174–185.
22. Fry M, Bates G. The tasks of self-managing hepatitis C: The significance of disclosure. Psychol Health 2011;27: 460–474.
23. Martin F, Caramlau IO, Sutcliffe P, Martin S, Bayley J, Choudhry K. Self-management interventions for people living with HIV/AIDS. Cochrane Database Syst Rev 2010, Issue 10. Art. No.: CD008731. DOI: 10.1002/14651858.CD008731.
24. Schulman–Green D, Jaser S, Martin F, et al. Processes of self-management in chronic illness. J Nurs Scholarsh 2012;44: 136–144.
25. Swendeman D, Ingram BL, Rotheram–Borus MJ. Common elements in self-management of HIV and other chronic illnesses: an integrative framework. AIDS Care 2009;21:1321–1334.
26. van Olmen J, Schellevis F, Van Damme V, Kegels G, Rasschaert F. Management of chronic diseases in Sub-Saharan Africa: Cross-fertilisation between HIV/AIDS and diabetes care. J TropMed 2012: 349312.
27. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:77–101.
28. Drew P. Conversation Analysis. In: Smith JA, ed. Qualitative Psychology a Practical Guide to Research Methods. London: Sage, 2003:133–159.
29. Petersen I, Swartz L. Primary health care in the era of HIV/AIDS. Some implications for health systems reform. Soc Sci Med 2002;55:1005–1013.
30. Harman S, Brown W. In from the margins? The changing place of Africa in international relations. Int Aff 2013;89: 69–87.
31. Horne R, Cooper V, Gellaitry G, Date HL, Fisher M. Patients' perceptions of highly active antiretroviral therapy in relation to treatment uptake and adherence: The utility of the necessity-concerns framework. J Acquir Immune Defic Syndr 2007;45(3):334–341.
32. Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: A theoretically based approach. J Pers Soc Psychol 1989;56:267–283.
33. Gifford AL, Sengupta S. Self-management health education for chronic HIV infection. AIDS Care 1999;11:115–130.
34. Maslow A, Lowry R. Toward a Psychology of Being, 3rd ed. New York: Wiley & Sons, 1998.
35. Makoae LN, Greeff M, Phetlhu RD, et al. Coping with HIV-related stigma in five African countries. J Assoc Nurses AIDS Care 2008;19:137–146.
36. Peltzer K, Phaswana–Mafuya N. The symptom experience of people living with HIV and AIDS in the Eastern Cape, South Africa. BMC Health Serv Res 2008;8:271.

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