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# The role of children in their HIV-positive parents' management of antiretroviral therapy in Uganda

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**Adjustment to life on antiretroviral therapy (ART) and living with HIV as a long-term chronic condition, pose significant medical, social and economic challenges. We investigated children's role in supporting HIV-positive parents to self-manage life on ART. Between 2010 and 2012, we conducted a qualitative study using semi-structured interviews with 38 HIV-positive parents who had been on ART for over a year. They were randomly selected from people accessing ART from three delivery sites in Wakiso district, Uganda. Data were analysed thematically. Participants reported children between the ages of 1 and 47 years providing support. Children were a source of happiness, self-worth, encouragement, and comfort. Both younger and older children supported parents' adherence to treatment through reminding them to take the drugs and honour clinic appointments. Older children provided money to buy medication, food and shelter. Parents reported that the encouragement they received after they disclosed to their children enhanced their survival. After HIV disclosure to their children many of their fears about the future were allayed. Thinking about their children's future brought hope. However, looking after younger children while on ART could be burdensome since some parents could not work to their full capacity due to reduced physical health. Children are an important resource in their parents' adjustment to living with HIV while taking ART. There is a need for children to be supported by appropriate policy and other social and health development structures.**

**Keywords:** Africa, care, caregivers, chronic conditions, family

## Introduction

*"My children have been so supportive and I cannot have worries when I am with them."* Ritah was 39 years old when she said this. At the time of the interview she had known about her HIV-positive status for three years. She was struggling to care for her sick husband living with HIV and provide for their family, while receiving support from her mother, sister, and her own children. Throughout her narrative she also spoke about aspirations she had for the future because of her children.

People living with HIV (PLWH) who are taking antiretroviral therapy (ART) need to adhere to the drugs, meet healthcare providers, and make adjustments to their life in terms of managing the condition and their health, and coping with set-backs or challenges such as stigma (Schulman-Green et al., 2012). These processes are often referred to as disease self-management: "...the ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions" (Richard & Shea, 2011, p. 261). Self-management is perhaps ultimately about sustaining a sense of wellbeing, incorporating the illness and treatment into one's life and identity (Martin, Kiwanuka, Kawuma, Zalwango, & Seeley, 2013; Russell & Seeley, 2010), and in psychological terms "...to maintain a positive

view of the self and the world in the face of a health problem" (Sharpe & Curran, 2006, p. 1161). A person's active participation in self-management is central to its success (Jones, MacGillivray, Kroll, Zohoor, & Connaghan, 2011).

Self-management is a *relational* process which is not just about individuals, but motivated and supported through numerous relationships with healthcare providers, family members, friends and peers (Kralik, Koch, Price, & Howard, 2004; Russell et al., 2016; Whyte, 2014). Supportive relationships have been identified as an important component in the promotion of healthy behaviours (Bull, Eakin, Reeves, & Kimberly, 2006), and good self-managers have been found to have extensive support networks in some settings (Gielen, McDonnell, Wu, O'Campo, & Faden, 2001). Disclosure of HIV status is needed for these supportive relationships to be mobilised, and with disclosure these relationships facilitate daily adherence to drugs, daily activities, coping with difficulties and health-promoting behaviours (Peretti-Watel et al., 2006; Skogmar et al., 2006; Smith, Rossetto, & Peterson, 2008; Swendeman, Ingram, & Rotheram-Borus, 2009). Some relationships will generate intrinsic motivation to self-manage and stay well (Adato, Kadiyala, Roopnaraine, Biermayr-Jenzano, & Norman, 2005; Wright, Zalwango, Seeley, Mugisha, & Scholten, 2012); others can generate pressures of duty or obligation to "behave responsibly" which encourage adherence to treatment (Ware, Wyatt, & Tugenberg, 2006).

Self-management and adjustment processes come with medical, economic and social challenges, exacerbated by poverty and treatment insecurity (Rhodes, Bernays, & Terzić, 2009; Russell et al., 2007). Less supportive or negative relationships might undermine self-management, for example, when a person does not disclose their status to a family member or intimate partner for fear of rejection.

Supportive relationships which might enable better HIV self-management include those between adults and their children. The intergenerational resource transfers and caring roles between parents/carers and children can be interpreted using the concept of “intergenerational contract” (Collard, 2000; Kabeer, 2000). The transmission of resources may fulfil a form of exchange between generations. McGregor, Copestake, and Wood (2000, p. 447) refer to this as the intergenerational bargain which sets out the “uncodified rights and obligations between generations” which bind the parties in the transfer of goods and services. For instance, parents may offer educational opportunities to children with the expectation that their own security will be ensured when they become older and more dependent (Whyte, Alber, & Van der Geest, 2008). Writing about the global South, Evans (2015, p. 202) defines this contract or bargain as the expectation: “...that the most economically active ‘middle generation’ makes transfers to the young with the expectation that resources will be reciprocated to them in old age when they require care and support, while also fulfilling their obligations to support their elderly parents.”

The norms and obligations which apply to this “contract” influence the transmission (or lack of transmission) of private, or access to public, resources from carer to child or from a youth/adult to an older person, as well as emotional and physical care and support. Children are expected to contribute to household work and the support of other family members from an early age. The expectations are mediated by gender norms and the child’s age. An adult male child, for example, might be expected to support an elderly parent financially, a female adult child more through caring roles (Evans, 2010). Family background and structure, parental education and wealth, localised norms of entitlement and existing patterns of distribution of resources in the household and society, are important in determining resource transfers to children and from children to parents (Anderson, 2013; Collard, 2000; Quisumbing, 2007). These factors also affect the building of psychological support across generations, what Sadl and Hlebec (2010) refer to as “intergenerational solidarity”.

In this paper we examine how this intergenerational contract operated between parents living with HIV and their children (some of whom were adults up to the age of 47 years), in terms of the resources, support and encouragement that children provided to their parents which built their confidence and self-efficacy as self-managers.

### **Children**

Children caring for parents with a range of impairments in the UK provide emotional support as a significant aspect of their caring roles (Aldridge & Becker, 1993; Dearden & Becker, 2004). Research in Namibia, South Africa, Tanzania and Zimbabwe (Adato et al. 2005; Bauman et al., 2006; Evans & Becker, 2009; Evans & Thomas, 2009) has shown that many young people provide emotional support to

parents and other relatives living with HIV, including talking to and comforting them, giving hope and reassurance, offering advice, being a confidante, keeping them company and being there for them.

A long-standing view of children affected by HIV in sub-Saharan Africa has been that they are passive victims, in need of care, who impose burdens on foster families, often grandparents. A growing number of studies from the region, however, show that children in households affected by HIV act as carers for sick or elderly adults and for other children (Evans, 2014; Lane, Cluver, & Operario, 2015; Skovdal, 2010; Skovdal & Ogutu, 2009; Skovdal, Ogutu, Aoro, & Campbell, 2009). Much of this work has focused on children’s roles in *caring for the sick*, but tends to neglect their roles in *caring about* (Evans & Becker, 2009) and supporting healthy family members living with HIV now on ART and self-managing the condition. With the advent of ART, while the caring for role has not entirely disappeared, instead of providing nursing care, children have taken on roles of “medicine companions” (Foster et al., 2010), confidante (Edwards, Irving, Amutah, & Sydnor, 2012; Evans, 2014), and providing ongoing emotional support to adults for various coping and self-management processes (Skovdal & Ogutu, 2009).

Being a child is relational rather than being age-related, and the categories “child” and “parent” extend beyond close family members. Cousins and neighbours can be children and or parents (Radcliffe-Brown & Forde, 1950).

In this paper, we examine the influence of both younger and older children on adults’ self-management of HIV. We assess how, in most cases, children supported their parents’ emotional, cognitive and practical self-management processes and adjustment to life on ART. We also draw from the literature on child carers which recognises the agency of children and the role of children as supporters of adults, rather than the once common assumption that they were just in need of care (Evans, 2010, p. 1478).

### **Theoretical framework**

This paper is informed by two systematic reviews of self-management processes. One reviewed common elements of self-management interventions (Swendeman et al., 2009) and the other patient self-management processes (Schulman-Green et al., 2012). We have synthesised these into one framework for this paper, distinguishing three broad domains of self-management (Table 1).

Potentially, children can play a role in all three self-management domains: they can help adults with the work of managing illness needs (e.g., reminders to take treatment, adopting healthier behaviours); they are an important social relationship/resource; and perhaps most importantly but less visibly, they might motivate and assist with the more complex and often relational tasks of “living with the condition”. This latter group of self-management processes includes the emotional and cognitive work of dealing with stress or difficulties, adjusting to the condition, adjusting to a new sense of self and finding meaning and value in life (Russell & Seeley, 2010). Good social relationships and a sense of connection are important sources of wellbeing and can also enhance psychological

**Table 1:** Common elements or processes of chronic illness self-management (frequently-used terms are in *italics*)

Domain or process	Tasks and skills
Focusing on illness needs and managing physical health	Learning: a framework for understanding the condition and taking action to deal with it Taking ownership of health; self-monitoring; <i>adherence to medication</i> ; becoming an expert and developing confidence/self-efficacy; <i>goal setting and prioritising</i> Health promotion activities: modifying diet, smoking, alcohol use; preventing transmission
Resources available and mobilised	Health care: (building) collaborative relationships with healthcare providers to make treatment plans and decisions <i>Psychological: drawing strength from circumstances; cultivating courage and motivation; maintaining hope &amp; positive outlook; building cognitive skills and resilience (e.g., building courage, motivation, feelings of control)</i> <i>Social relationships: (seeking) support from family and friends; developing partners in disease management; building new friendships and peer support</i> Spiritual resources: drawing strength and support from a higher power; being part of a spiritual community
Living with a chronic illness (psychological and social domains)	Processing and sharing emotions: coping with stress and anxiety Adjusting to the condition: normalising the condition; <i>envisaging a future on ART</i> ; developing coping strategies (e.g., self-talk) Adjusting to a new self and social identity: dealing with stigma; disclosure strategies <i>Integrating the illness into daily life: normalising life; carrying out normal roles of work and parenting</i> Meaning-based coping: <i>appreciating life, finding meaning in relationships; developing a new purpose and priorities, seeing opportunities and benefits, being altruistic</i>

coping in times of stress which sustains subjective wellbeing, for example, after the onset of serious illness (Dezutter et al., 2013).

The tasks and skills in Table 1 (highlighted in *italics*) are the main areas where we might expect children or relationships with children to play a role in PLWH self-management, based on both existing evidence and broader knowledge about inter-generational relationships and the expected roles of children in the Ugandan context (Rutakumwa, Zalwango, Richards, & Seeley, 2015; Whyte & Whyte, 2004).

## Methods

### Research design

The qualitative data presented in this paper were collected in 2010–2012 as part of a study on PLWH coping and self-management processes on ART in Wakiso district, Uganda. The district is located 18.6 km from Kampala and has urban, peri-urban and rural characteristics. Participants were recruited from three types of ART delivery sites in the district: 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). Here we present the qualitative findings from interviews with 38 PLWH, focusing on their relationships with their children and how this affected their self-management while on ART.

To be eligible participants must have been on ART for more than 1 year and over 18 years old. Eligible patients were listed for each facility. The government facility lists contained approximately 250 eligible patients, and the TASO facility list 900 had eligible patients. To reduce the numbers from which we would purposefully sample for the qualitative study, a systematic random sample was first taken using intervals to generate twice the number of cases required, anticipating refusals or early dropouts.

These lists were then stratified by age and gender, and 42 participants were purposively sampled from gender and age categories to ensure a gender balance and a mix of ages. We were interested in how a variety of relationship types (“social resources”) could enable or hinder people’s HIV self-management. Having a child was not a specific part of the selection criteria to participate in the study. Four participants could not be interviewed successfully or more than once (they decided to drop out after the first interview) and were excluded from the final analysis.

Ethical approval for the study was obtained from the following ethical review boards: the Uganda Virus Research Institute Research Ethics Committee in Uganda, and the International Development Research Ethics Committee, University of East Anglia, in the United Kingdom. Overall permission to conduct the research was obtained from the Uganda National Council for Science and Technology. Written informed consent was obtained from all participants in the research. Pseudonyms are used in this paper to maintain confidentiality.

### Data collection measures

Two in-depth interviews were conducted with each participant by experienced interviewers of the same sex. The first interview was an unstructured life and illness history interview, conducted over one to three visits due to the wide-ranging nature of the questions. These interviews were not recorded because experience in this setting indicated people are more open when not being recorded, especially in the first few visits. Notes were taken and detailed narratives were written up in English by the interviewers.

The second interview was semi-structured, and this was recorded, 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 HIV self-management frameworks. These interviews explored participants’ approaches to self-management, and changes

in their lives, relationships and wellbeing since becoming HIV positive and starting ART. The use of several visits to meet participants allowed a degree of trust and rapport to develop, which in many cases led to rich discussions of participants' experiences.

### Analysis

Qualitative data were organised using QSR Software NVivo 9. Data were analysed using thematic content analysis. To ensure analytical rigour, two researchers independently coded and checked results. Thematic interpretations of the data were discussed in more detail by the team at a 2-week analytical workshop in Uganda. Themes were tested further by checking counter examples and exceptions. 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 across the interviews are not quoted but set in italic.

## Results

### Participant characteristics

The socio-demographic characteristics of the 38 participants are summarised in Table 2. Thirteen were recruited from the government hospital, 11 from the 3 referral health centres, and 14 from TASO Entebbe. Table 3 shows participants' marital status and whether the participants had their own biological children living with them and the HIV status of the children. None of the participants were living with non-biological children at the time of the research.

More than half of the participants had some primary education and most were married or in a relationship. They mainly engaged in subsistence farming, fishing, building and petty trade. Nearly half the participants were income poor (8/18 men; 10/20 women), defined in terms of the frequency with which they struggled to meet basic food needs. The others had an adequate material standard of living through their salaries or successful businesses such as fishing, housing for rent and poultry farming. Those who could cultivate around their homes were usually able to eat one meal a day, but a small minority were in extreme income poverty and faced a daily struggle for enough food. Several

**Table 2:** Characteristics of the participants

Age/sex	Male	Female	Total
18–25	0	2	2 (5%)
26–40	10	10	20 (53%)
41–60	7	7	14 (37%)
61+	1	1	2 (5%)
Total	18	20	38 (100%)

**Table 3:** Participants' marital status, and their children and HIV status

Sex	Single	In a relationship	Had children	Average number of children per participant	Total number of HIV+ children	Average age of children (years)	Children's age range (years)
Males	5	13	12	3	1	14	2–47
Females	11	9	18	4	3	10	1–16
Total	16	22	30	3.5	4		

participants said that inadequate food intake made taking the drugs more difficult.

Among the 20 women participants, 11 were single mothers and 9 were in a relationship. Of the 20 women, 18 had at least 1 biological child, and 2 women aged 29 and 38 and in a relationship, did not have biological children. These two women expressed signs of depression like loss of interest for work, feelings of low self-esteem and loss of hope for the future; this affected their wellbeing. Eight women of relatively older age (mean age 42 years) had 4 or more children and 10 (mean age 35 years) had 1 or 2 children. All female participants stayed with their biological children. The mean age of their children was 14 years, ranging between 2 and 47 years.

In contrast to the women, most men (13/18) were in a relationship, and only 5/18 men were single. Unlike women, only 8/18 men mentioned the number of children they had probably because of local beliefs that say that it is a taboo for a man to count his children. A total of 11 men stayed with some of their biological children, and only 5 gave information on their children's age. The average age of the male participants' children was 10 years. One of the men did not have a child and he had lost hope of having children because his wife was over 50 years old and so, according to him, she was too old and could not give birth.

The study focused on adults (both men and women) on long-term ART and explored their self-management strategies. For this paper, the analysis focused on the role of (biological) children in their parents' self-management of HIV.

Women discussed their children's HIV status more than their male counterparts. Of the reported total number of children, only four were reported to be HIV-positive (see Table 3) by their parents. Three participants, two women and one man, mentioned that they had HIV-positive children. The rest were either reported to be HIV-negative or the parents did not know the children's status.

Before starting ART, most participants (31/38) experienced mild to serious illnesses. Some had lost their partner or child to HIV. Their recollections of how they felt at the time when they received their test results revealed very negative perceptions about being HIV-positive and a total lack of hope for the future. Common expressions included: *"my life is over"*; *"you know you are going to die"*, *"who will care for the children"*, and *"I will be rejected"*. Some participants feared that their worries would kill them before their illness.

Earlier on in the study, nearly all the participants (37/38) said that they were managing their condition well after ART initiation and adhering to their treatment regimen. For most of the participants, bringing up their children well was a motivation for their own self-management.

Disclosure was another important aspect of participant self-management, facilitating emotional, psychosocial and economic support from children, other family members and friends. However, our findings revealed that parents generally did not know how or when to disclose their status to their children (19/38), and that less than half (15/38) had managed to disclose to their children deliberately during family outings and meetings. Other parents reported inadvertent or subtler and “unsaid” ways of partially disclosing their status to their children without actually saying it. For example, talking about their “illness” and openly taking tablets enabled a gradual and implicit understanding for the child as she or he grew up. Some of the anticipated benefits of disclosure included being able to seek support, relieve the emotional burden of the secret, and to educate their children about the dangers of HIV:

*The reason why I disclosed to my children was that I wanted us to live as one and also help them not to fall in the same trap* (Hannah, female, 46 years).

Ruth’s story of her illness, for example, starts with the great worry she had about her children: first she thought she would die and leave them and secondly, she did not know how to disclose her HIV status to them. Her children also worried about her health yet she was unwilling to discuss it with them at that time. This tormented her until she decided to disclose her status to them. The support she received from them afterwards is a major factor behind her positive living. Her children told her:

*Mum, it is good you have told us because we were so worried and in fact we had discussed about it since it was obvious but we all feared to ask you. Thank you mum for disclosing to us.*

Ruth said that this was a great relief to her at that time and that her children started taking very good care of her.

For many participants, it was poverty, rather than HIV, which caused them stress and had the potential to undermine their self-management or wellbeing. Poverty among men and women was a cause of *too many thoughts* (an expression used to describe stress or low mood). Despite the challenges of work and paying school fees, however, at the time of the study only one man was not adhering well to treatment, possibly because of mental illness.

The centrality of relatedness in participants’ self-management processes was a key feature of participants’ narratives, and supportive relationships with children were an important part of the participants’ self-management and wellbeing. Using the three domains of self-management (Table 1) — focusing on illness needs; resources available and mobilised; and living with chronic illness — we examined the supportive relationships participants had with their children and how these helped their self-management processes.

### **Managing illness needs and physical health**

Participants said that their children helped them manage their illness, particularly with respect to taking the drugs each day, reminders about clinic appointments, and discussions about treatment seeking options. For example, 2 of Aaron’s (aged 40 years) children (aged 12 and 16 years) knew about his status because he disclosed to them and their mother

had also told them about her status. He said that there was no problem telling them at that time because they were not old enough to know the full implications of the disease. As they grew up they came to understand the disease better and that is why they would remind him to take his drugs.

Ruth, however, said that she had many tasks to perform and needed a lot of resources to manage the illness and there was no way she could have managed her health without support from her children, particularly her eldest daughter. She was her drug supporter and always accompanied her to the health facility. Her children even bought her a cell phone with an alarm to remind her when it was time to take her drugs.

For most of the parents, it was the younger children who took on the role of reminding them about taking drugs:

*...even the youngest knows my HIV status and they [children] at times ask if I have taken my drugs* (Mercy, female, 35 years).

*...children remind her [to take] the drugs and since disclosure, they always remind them [parents] about clinic appointments. “... Right now they know that both of us have HIV and they at times remind us [to go for] the clinic visit”* (Ritah, female, 39 years; children aged between 6 and 18 years).

*My children have helped me very much to survive because they remind me to take my drugs, so disclosing my status helped me a lot not to do things secretly* (Suzan, female, 43 years).

Children would help their parents manage their illness. However, if the children themselves were HIV-positive then this would add additional illness management tasks as well as emotional stress. The logistical difficulties and transport costs associated with accessing treatment for HIV-positive children added to cost burdens. Dorcas, a 42-year-old woman, explained that they struggle to raise money for transport to the hospital since it is a bit expensive. Each spends not less than 20,000 shillings (US\$5.5) per visit.

Some parents who had not yet tested their children (whom they suspected were born during the infection) expressed fear of the unknown. When Ann (aged 28 years) was asked about testing her children (aged 4, 7, 10 and 11 years) for HIV she said:

*I am worried that when I get them tested I will be told that one of them is sick and in need of treatment.*

### **Mobilising resources**

Participants mobilised healthcare resources, social support, material and psychological/emotional resources as part of their self-management. Among the parents who had disclosed to their children, most reported that they had been able to obtain support.

#### *Healthcare resources*

Accessing health services and good relationships with health workers were an important resource in the participants’ successful self-management (Russell, Namukwya, Zalwango, & Seeley, 2016). Single men and women who had older working children reported receiving significant support from their children to access health services. Older children helped their parents to access and use medical care

and they also accompanied their parents to health service providers to get involved in discussions about treatment needs. This further enhanced the quality of parent–child relationships as parents became closer and conversed freely with their children on issues about HIV and health in general. Similarly, young children played a considerable role in providing healthcare for their parents as well as nursing roles within the home environment.

#### *Material resources*

Older women and men would get material support from their adult children. For example, they provided nutritious food, shelter, start-up capital for small-scale businesses and money to buy or access medical care. Ruth's children, for example, provided her with food, which she felt was essential for her to be able to take the drugs and for disease management more generally. They even bought different types of treatment, both biomedical and traditional. When she was diagnosed with HIV, local herbs for HIV were in high demand and expensive, but her children managed to pool resources to help her access these remedies. Similarly, Vincent (aged 74 years) stated that he received a great deal of material (food and clothing) and emotional support from his children.

#### *Emotional/psychological resources*

Children were an important source of emotional support for PLWH. The journey to accepting their new identity and integrating the illness into their daily life was stressful and demanding for all the participants and they could not have managed alone. Children played a crucial role in their parents' stress management as they adjusted to managing their regular treatment and daily chores, once their health was restored. The presence of children was an important psychological coping resource, for example, at the time of diagnosis and subsequent self-blame and guilt. Women explained that children had comforted them at the time they were tested for HIV and found that the result was HIV-positive.

Ruth's children, through their caring and support and just "being there", helped her to come to terms with her new situation. She praised her children because they had assisted her with daily activities, household chores and responsibilities. This practical support was closely bound up with a sense of emotional solidarity, togetherness and support. In this setting, especially in rural areas, it is expected that women perform domestic labour roles. In the cases where children (usually girls or women) played an active role in supporting their parents with these activities, for example, looking after young children, washing clothes or cooking, the practical support also enhanced emotional wellbeing.

Younger children were a particularly important source of psychological and emotional support for parents because their presence provided a sense of encouragement and inner strength. Women spoke about this emotional connection and strength they drew from their children:

*My children have been so supportive and I cannot have worries when I am with them* (Ritah, female, 39 years).

*I am proud of my children because they make me forget the past....* (Ruth, female, 39 years).

Only 1 male participant, Tom (male, aged 44 years), talked about how he felt about his children who were aged between the ages of 10 and 24 years, and continually smiled whenever he talked about them. He said that they were very disciplined, did not disturb him and worked very well together. This was the source of his happiness. His 24-year-old daughter, studying at the university, encouraged him to take the drugs and called him frequently to know how he was doing. He referred to his children as his greatest source of support and comfort.

Most men, in contrast, did not talk much about emotions or feelings when they discussed their children nor did they talk much about the disclosure of their HIV status to children. They also did not mention the social support they needed from their children or that their children gave them, perhaps reflecting the masculine ideal of being both resilient and a responsible father who should provide for and support his family (Siu, Seeley, & Wight, 2013).

A prominent narrative among the men, however, was about the motivation that their children gave them to take the drugs, stay healthy and so be able to work hard for their future. Building the family's material assets and providing for the family were important sources of self-esteem and happiness for these men.

Aaron (aged 40 years) said that the greatest dream he had was to help his children finish school. Like many of the men, he also said that he would like to "leave something behind for the children", notably a piece of land and building a house. Aaron was confident that he would achieve this because he was working hard. Another participant, Mark, also said that HIV was a "wake up call" to start investing for his children.

*I used to be deep in thought about the house. As I told you earlier, by the time I got better all I could think about was the state in which I was going to leave my children. This encouraged me to work so hard; I was able to build the house* (Mark, male, 31 years).

Relationships can provide emotional and cognitive support, but this emotional attachment can of course also be a source of stress about the wellbeing of loved ones. The loss of children to HIV had been a source of great trauma for some of the participants, or if the children themselves were living with HIV then this could add emotional stress:

*When 2 of my children, 13 and 18 years old (those who are HIV-positive;) get sick, I get depressed and remember the ones who passed away, thinking that death is around the corner. Since X is very weak, that alone makes me sad and in such situations, I start to think about my HIV status and the person who infected me* (Hannah, female, 46 years).

Among the sample of 38 participants none reported any differences between the support or encouragement that they received from children who were or were not living with HIV. In general, children gave their parents a reason to take their drugs to prolong life, to watch their children grow, support them in their education, build them a house and secure their future. However, participants such as Hannah, who had two HIV-positive children, reported experiencing negative

emotions whenever her children fell sick because this brought back memories of the two children who had died of HIV-related illnesses.

The quality of the parent–child relationship also influenced whether children became a source of emotional support, or of stress. Poor relationships with children could be a source of stress which undermined emotional wellbeing. Hannah's story about her children was, however, the only one which showed how children could cause stress and have negative effects for the parents' emotional wellbeing and self-management of HIV. Hannah was a widow, had 10 children of whom 4 had died of HIV during childhood. Among the 6 who were alive, 2 boys (aged 12 and 18 years) were HIV-positive. As a single mother, she had worked hard and started a shop, constructed a house, and started rearing chickens and cows. However, over time her relationships with her older children deteriorated. She had invested in their education, but her son who was at university spent one year without doing the exams even though Hannah had paid the tuition fees. The son in senior four (who is HIV-positive) had refused to register for the final examinations and left school leaving all his property at the school. Even the girl who had completed senior six, did not show Hannah the results. She said that her children had taken away her peace:

*I had devoted my life to my children but they have turned against me [beating her and not listening to her]...I think they will rejoice over my death.*

Hannah said that her children are a great disappointment to her and have contributed to her poorer HIV self-management. She thinks her children affected her CD4 count.

### **Living with a chronic illness**

Adjustment to "living with" a chronic condition is the third self-management domain within our framework, encompassing a range of complex and long-term processes (see Table 1): adjusting to the condition and to their new sense of self or identity; managing their identity as a PLWH and coping with stigma (internal, anticipated or enacted); adjusting daily work routines to their new situation; and finding meaning, and perhaps a new purpose to life, through their illness experiences (Schulman-Green et al., 2012). Participants' relationships with their children were, overall, important sources of wellbeing and motivation to work at and perform these self-management tasks. Grace, aged 32 years, observed:

*This child is my strength, every time I get a problem, I look at his photo I get the strength to work harder... he has given me the strength to cope with the illness.*

Beginning ART and the subsequent recovery of health had given most participants great hope and a chance to reappraise the value of health and life. Participants spoke about living and working hard for the future again, often reappraising their situation and aiming to do things differently.

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. Life could not be taken for granted, which meant they also developed a strong orientation towards the present, valuing each new day. This combination of both a new future and stronger present-day orientation was a source of great motivation for the participants, and participants'

children were central figures in their motivation to work hard for both the present (for example, to pay school fees) and the future (for example, to leave land for their children).

Several participants stated that they were carefully taking their drugs each day because they had children. A case in point is Imelda (aged 41 years). She said that when she realised she was HIV-positive, she ensured that she got treatment as soon as possible because of her children: She said: "*I made sure I took the drugs so that I could take care of my children because I was told that when you miss the drugs, you die soon.*"

As participants sought a new form of "normalcy" in life, those who had children said that parenting gave them a great sense of "*being able to do normal things*" again, and a sense of satisfaction, achievement and courage from doing these normal tasks and fulfilling their responsibilities as a mother or father. Women could perform their roles as mothers and carers again and also got back to the work of earning money to educate the children and provide other needs. Dorcas, (aged 42 years) commented that "*work is her everything*" since it sustains her in many ways; educating children, she had managed to buy a piece of land and construct a house taking good care of herself and the family. She said that she uses every chance she gets because she thinks this is a second chance to life and she should put in extra effort "*since life is short*".

For men, children were primary motivators to take the drugs, stay healthy and work hard. Having recovered their health, many of the men had re-assessed their priorities, and all the men referred to a prominent ideal of masculine identity: taking on the responsibility of providing for their children and partners:

*I accepted to be tested and also to begin taking the drugs so as to be okay in order to work for my children...What I see is I mostly do things I used not to do...like prepare for my children's future (Fred, male, 47 years).*

*What pushes me to work are the children...I just try my level best to provide for them. I now have seven children and they all depend on me; and so I have to find a way to cater for them as a man should (Mark, male, 31 years).*

Achievements such as paying their children's school fees, constructing a house or simply being able to raise their children gave them great encouragement, and the respect they felt back from their children gave them confidence as parents and a feeling of self-worth.

Relationships can lead to satisfaction when roles and responsibilities are fulfilled, but these responsibilities can also demotivate and make life stressful if it is a struggle to fulfil them. Some of the poorer men and women said that their children created financial stresses. School fees placed a large economic burden on household budgets, which was one of the main sources of stress for participants with school-aged children:

*I have failed to pay school fees for my children and I do not have anyone to help me so they are now seated at home (Suzan, female, 43 years).*

Some men felt that they were unable to fulfil their provider obligations for the children, which in turn caused guilt,



self-blame, lowered their esteem, or negatively affected their psychosocial well-being. Bridge (aged 42 years) lamented:

*I think about my family and children a lot. What hurts me most is to think the state in which I will leave them. By the time I got infected, I had nothing to show for my efforts... I feel there is something lacking like leaving them a house, whatever the size might be. That is what I would like to do in my life right now.*

## Discussion and conclusion

Fostering closer family ties and relationships is important to enable people's adjustment to living with HIV and self-management. Family relationships provide significant support and care for people living with HIV (Rochat, Mkwanazi, & Bland, 2013), and our study shows how the inter-generational contract was mobilised by both parents and their children to obtain or give material and emotional support to parents' self-management of HIV.

There is a growing acknowledgement of the role of family in HIV care and treatment (Wouters, Masquillier, & le Roux Booyesen, 2016; Wouters, Masquillier, Ponnet, & le Roux Booyesen, 2014). Our findings show that strong and positive social relationships help to alleviate stress for individuals or family groups. Where young children are involved in care giving, it influences their sense of commitment, maturity, responsibility and self-esteem (Bauman et al., 2006; Donald & Clacherty, 2005; Evans & Becker, 2009; Robson, Ansell, Huber, Gould, & van Blerk, 2006; Skovdal et al., 2009). Although evidence exists of the negative effects of caring for children's education, health, emotional wellbeing, social lives and transition to adulthood (Aldridge & Becker, 1993; Skovdal & Ogutu, 2009; Thomas et al., 2003), like all relationships, those with children can be positive or negative, encouraging or discouraging. We found, for example, that poor relationships with children were a considerable source of stress for some people living with HIV which undermined their emotional wellbeing, particularly among single mothers.

Time orientation has a fundamental bearing on a person's emotional and social life, affecting their identity, self-concept and moral responsibility and, their future orientation (Davies, 1997). For parents, children are often an important motivator for their future orientation as they work each day and invest for the future. This assumption, often taken for granted, is only made visible when a shock such as an HIV diagnosis threatens this future. In the era before ART, an HIV diagnosis was a "death sentence" which had profound implications for PLWH hope for the future and therefore their emotional wellbeing in the present. An HIV diagnosis was a disruption to a person's future-outlook and created an uncertain and "provisional existence" which causes psychological and social problems (Ezzy, 2000).

Seeing treatment prolonging people's lives and hearing the encouragement of health workers and others to take ART has begun to change this time orientation, reframing expectation towards the future again. Although the legacy of past fears of imminent death can persist and haunt and shape the present (Seeley, 2014, p. 114), findings show, as parents living with HIV grasp the possibility of living

into older age, their children become a greater priority and reason for hard work.

Men were more reticent about acknowledging their children's contribution to their self-management than women. While women applauded the emotional and psychosocial support they drew from their children, men were more likely to attribute their source of motivation to themselves, and their ability to actively perform their fatherly role of providing, a finding corroborated by other work which looks at the role of perceptions of masculine roles in shaping treatment behaviour (Siu et al., 2013). Unsurprisingly, men who were unable to support their children/families financially were emotionally stressed.

Evans and Thomas (2009) have highlighted the emotional and physical importance of reciprocal social relationships between those cared for and the children undertaking the caring roles, but they have also highlighted the enormous strain on those relationships that caring entails in settings where a lack of access to resources and the sense of isolation put a considerable strain on the family. There is a continuing need for social and health development agencies/structures to recognise and understand the roles children and young adults play as carers and valued supporters of parents (and grandparents) and their self-management of chronic conditions, such as HIV (Becker, 2007).

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