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Full Length Research Paper

Sustaining social support for lifelong HIV treatment: Practices of patients on antiretroviral therapy in Uganda

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Social support is recognized as a critical resource in promoting adherence to antiretroviral therapy (ART) in resource-poor settings. However, supporter burn-out and stigma may constrain access to social support in the long-term. Little is written about how ART clients overcome these barriers to continue accessing support for lifelong treatment. Therefore, this article examines practices that enable HIV patients in a resource-poor setting to overcome the constraints of stigma and burn-out to continue accessing treatment support. The article is based on data from an ethnographic study of 50 patients enrolled on ART at two treatment sites. Fifteen of these patients were followed-up for six months. The main methods of data collection included in-depth interviews and participant observation. Dependent patients overcame the constraints of stigma and burn-out through three main practices: regulating the frequency of requests for assistance, using secrecy and lies, and continuously reconstituting the treatment support group. The study concludes that stigma and burn-out are serious threats to sustaining social support and concomitant adherence to lifelong ART. Integration of mechanisms for empowering patients to manage burn-out and stigma in HIV service delivery may improve prospects for sustained ART adherence in resource-poor settings.

Key words: Antiretroviral therapy, burn-out, people living with HIV, social support, stigma, therapy management group.

ABBREVIATIONS

OIs: Opportunistic Infections; **TMG:** Therapy Management Group

INTRODUCTION

Support from close relations during the treatment and management of illness is considered a key resource in facilitating access to healthcare in contexts of scarcity (Leive and Xu, 2008). In the treatment and management of HIV, social support is recognized as a critical resource in promoting and sustaining adherence to antiretroviral therapy (ART) in resource-poor settings (Nachega et al., 2006; Kunutsor et al., 2011; O'Laughlin et al., 2012; Nanfuka et al., 2018). However, sustaining social support for lifelong HIV treatment in a context of scarcity may be threatened by the stigma people living with HIV (PLHIV) continue to experience (Gilbert and Walker, 2010; Laar et al., 2017) and the gradual burn-out of supportive relations.

While Uganda has expanded free access to antiretroviral medicines (ARVs), HIV treatment creates additional demands for resources that must be accessed throughout the lifetime of a patient. These include medicines for prophylaxis, management of opportunistic infections (OIs) and side effects, transport to and from the

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treatment centres for routine collection of medicines (refill) and clinical review and provision of required diets as needed for medicine in-take, among others. Whilst these resources are critical for the success of ART, they are usually not part of the free treatment package (Whyte and Siu, 2014). Moreover, even access to free HIV medicines is often curtailed by health system related constraints such as stock-outs (Muyinda and Mugisha, 2015). Therefore, PLHIV have to devise alternative means to access requisite resources despite being enrolled on free treatment programmes.

Previous studies show that several HIV patients in sub-Saharan Africa depend on both kin and non-kin relations for treatment support. A study of three sub-Saharan African countries, namely Nigeria, Uganda and Tanzania, found that PLHIV on ART mainly drew on the support of relatives, friends, neighbours and health workers to access food, medicines and other requisite resources to adhere to treatment (Ware et al., 2009). Similarly, an examination of the different roles played by treatment partners in Tanzania shows that financially constrained HIV patients primarily access treatment resources such as food, medication and transport to the health facility by borrowing money from family, friends and/or lending groups (O'Laughlin et al., 2012). In Uganda, Tuller et al. (2010) found that HIV patients usually relied on the help of relatives, friends and fellow patients to mobilize transport for routine visits to the treatment centres.

Whilst reliance on others for everyday survival and in events of adversities, like illness, is the norm in many resource-limited settings (O'Laughlin et al., 2012); dependent HIV patients are faced with the challenge of sustaining support for a long-term treatment. This is because the management of HIV, like other chronic illnesses, usually imposes extra strain on the resources of supportive relations (Ware et al., 2009). In a setting where supportive relations often have competing demands and may be struggling to meet their own daily needs (Seeley et al., 1993; Nombo and Niehof, 2008), continuous requests for assistance can eventually wear them down. Therefore, sustaining support for the management of lifelong ART in a resource-poor setting may necessitate dependent patients to employ specific strategies, or else risk suffering consequences of burn-out.

Besides, access to social support for treatment and care is commonly constrained by HIV-related stigma, which remains prevalent in Uganda and other sub-Saharan African countries (Gilbert and Walker, 2009; Roura et al., 2009; Stangl et al., 2013; Kellettand Gnauck, 2016; Laar et al., 2017). An ethnographic study in rural Zimbabwe found that HIV positive people were accorded little support and care from their families and communities due to fear, moral considerations and perceptions that they were personally responsible for their infection (Duffy, 2005). In South Africa, strong fears of being stigmatized and discriminated against discouraged several positive people from disclosing their HIV status to benefit from available family and state-provided support arrangements (Gilbert and Walker, 2010). In Uganda, a systematic survey of HIV-related stigma identified cases where PLHIV were denied support after disclosing their HIV status to significant others (NAFOPHANU, 2013). How do dependent PLHIV deal with the risk of support loss associated with disclosure?

Whereas continued access to support is acknowledged as necessary to attain optimal adherence to free ART in resource-poor settings (Nachega et al., 2006; Ware et al., 2009; Kunutsor et al., 2011), little has been written about how dependent PLHIV circumvent the obstacles of stigma and burn-out of their supportive relations. Previous studies have discussed mobilization without providing insight into how PLHIV sustain support for their long-term treatment (Tuller et al., 2010; O'Laughlin et al., 2012).

This article examines the practices of PLHIV on ART in managing stigma and burn-out of supportive relations to sustain social support for HIV treatment in the long-term. Janzen's (1978, 1987) notion of the therapy management group (TMG) is applied as an analytic tool to map-out the supportive relations of individual patients. We argue for the need to move beyond mobilization to understand how patients navigate constraints to maintain the flow of treatment support. Such an understanding will provide insights into their resilience strategies. This knowledge can be drawn on to build and improve the capacity of HIV patients in resource-constrained environments to maintain access to vital treatment support.

METHODS

Study Design

The article draws on data from a study that examined how PLHIV on medicine in Uganda mobilize resources for the day-to-day management of HIV. The study employed an ethnographic approach. The approach allows situating observed social and cultural phenomena in their specific historical and cultural contexts. It provides researchers the opportunity to observe and experience events, behaviours and interactions as they unfold (Murchison, 2010). Therefore, using the ethnographic approach we were able to capture and generate contextualised explanations of HIV patients' behaviours, practices, concerns and thoughts relevant to the topic of study.

Study population and sampling

The study included adult females and males aged 18 years and above enrolled on the ART programmes of Naggalama Hospital and Mukono Health Centre IV (HCIV). Both health facilities are located in Mukono, a peri-urban district close to Kampala City. Naggalama

Hospital is a private not for profit facility while Mukono HCIV is a public health facility.

The treatment centre was the entry point to all the participants. At the beginning of the study, 50 PLHIV on medicine (25 from each of the treatment centres) were purposively selected for the study. Drawing on the findings of Guest et al. (2006) we considered that the 50 participants were sufficient to provide insights into the diverse experiences of PLHIV on medicine. The selection was based on a mix of both demographic and treatment-related characteristics such as marital-status, gender, age, length of period on ART, distance from the health facility, occupation, disclosure status, number of people with HIV in the household and whether they were on ARVs or only prophylaxis and currently suffering from any illness such as an OI. The initial phase was followed by the identification of 15 (5 men and 10 women) out of the 50 respondents for extended follow-up. These were selected based on unique attributes such as advanced age, residence far from the treatment centre, discordance, ill health and dependence.

Data Collection

The first author conducted data collection. The main methods employed were in-depth and narrative interviews and participant observation. The 50 respondents were initially involved in in-depth interviews at the health facility, which lasted approximately one and a half hours. These provided broad insights into the patients' treatment needs and experiences with accessing support. The questions asked included the forms of support they often required, sources of support and their reliability, challenges in accessing support and how they were managed.

The patients selected for follow-up were visited on a monthly basis for six months, from September 2015 to March 2016. Nevertheless, we kept in touch beyond this period. The visits lasted approximately six hours. In the homes, the patients, and where possible their significant others, were engaged in narrative interviews and conversations on issues identified from earlier interviews and developments in their lives, particularly those concerning their health and access to treatment and support. The home visits also gave us opportunity to observe patients' interactions with family, friends, neighbours and other community members.

In addition to the extensive home visits, the first author attended two clinic days in each treatment centre for six months. She participated in several activities including counselling sessions and informal conversations of patients. Through participant observation, the thoughts, concerns, interactions and actions of PLHIV relevant to maintaining social support were captured first hand (Murchison, 2010). All the interviews were audio-recorded whilst observations, conversations and encounters in homes and at the health facility were recorded in field diaries on a daily basis.

Data Processing and Analysis

The interviews were transcribed, translated and word-processed. The transcripts of interviews and field notes were imported into NVivo10 qualitative data analysis software package for management. The computer package enabled cross-indexing of material that corresponded with different codes (Mason, 2002).

Analysis was done thematically (Vaismoradi et al., 2013). The process involved a careful reading and coding of relevant texts, sentences and paragraphs according to categories initially developed during transcription and expanded as more data were scrutinised (Pope et al., 2000). The various codes were then compared and collapsed into themes. For example, a theme called 'threat of burn-out' was developed by merging data coded as concerns about burn-out and experience of burn-out. This article draws on patterns identified from a synthesis of data from three broad themes: threat of burn-out, stigma and social support and managing stigma and burn-out.

Ethical Considerations

Permission to access the study sites was first obtained from the District Health Officer of Mukono, then from the respective heads of the two health facilities. Written informed consent was obtained from all participants in the study. Respondents who could not write used a thumbprint. In addition, verbal consent was obtained from the 15 patients selected for follow-up. To protect the interests of patients who had not disclosed to their significant others, their approval was obtained before visiting their homes. At the health facility, the clients were informed that the first author was a researcher. For purposes of observing confidentiality, only pseudonyms are used in this article. The study was granted ethical clearance from Mengo Hospital Research Ethics Committee (679/4-15) and Uganda National Council for Science and Technology (SS 3939).

Analytic Framework

Therapy Management and the Therapy Management Group

In a study of the Bakongo people of lower Zaire, Janzen (1978) documents how kin and non-kin relations of individuals suffering from very serious illnesses emerged to take charge of managing them. These relations conducted diagnosis, selected and evaluated treatment options and provided moral, monetary and other forms of support to the ill person. Janzen calls a collection of kin and non-kin acting with and on behalf of a seriously ill patient 'therapy management group' (TMG), and the process of guardianship that involves treatment decision making and provision of other forms of support to the patient therapy management (Janzen, 1987). The TMG is in effect the set of individuals providing various forms of support for therapy management.

Although Janzen primarily constructs the notion of TMG basing on episodic rather than chronic illness, it provides a useful framework for mapping out the individuals and collectives that provide support for the management of HIV over the patient's life course. In this article, a patient's TMG or treatment support group is conceived to include all the people that provide any form of support for the management of HIV (treatment support), on a more temporal or continuous basis. The support provided may be emotional (love, care, encouragement, understanding), instrumental (money, labour, reminders and food), appraisal (help with decision-making) and informational (advice, information for care) (Berkman et al., 2000).

RESULTS

Out of the 50 PLHIV, 31 were female, and 40 had started ARVs. Their length of period on ART ranged from being newly initiated to nine years. Majority (41) were in the reproductive age group of between 18 and 49 years, seven were between 50 and 60 years and only, two were above 60 years. The majority (33) were married/cohabiting, five were single and four were widowed, while eight were divorced/separated. Eleven of the married respondents had not disclosed to their spouse. In terms of occupation, the majority (26) mainly depended on farming for a livelihood while the rest (7) were unemployed.

Sources of Treatment Support -TMG actors

Our interlocutors obtained treatment support from both kin and non-kin relations. By kin, we mean nuclear and extended family members such as spouses, children, parents, siblings and other consanguine and affines of the patient. The non-kin included fellow patients, health workers, regular service providers (transporters and attendants of drug shops) and other community members including friends, neighbours, religious affiliates and even strangers. In practice, this categorisation of kin and non-kin is not mutually exclusive. For example, there are cases of overlaps where the kin are health workers.

Kins were the primary sources of support for HIV treatment. The support provided by kins was mainly instrumental and emotional in nature. They were the main sources of money for transport to and from the treatment centre and buying food and medicines that were prescribed for the management of OIs and other illnesses but were out of stock. They also provided support in kind, mainly in the form of food and clothing. They further reminded patients to take their medicines, encouraged and counselled them to accept their situation and adhere to treatment. They cared for them when they were ill and regularly helped with picking medicines for patients who were unable to attend scheduled appointments due to ill health, working far from home, busy work schedules and family obligations such as attending burials or taking care of the sick. The kin who owned cars, motorcycles or bicycles often transported clients to and from the treatment centre on clinic days.

The non-kin relations provided varied forms of support. While neighbours mainly provided moral support to patients that were critically ill or incapacitated, health workers and fellow patients were the main sources of information on care and advice for HIV treatment decision making. Advice on feeding, diagnosis and management of side effects and OIs, management of sexual relations and disclosure, particularly in intimate relationships, was mainly sought from and provided by health workers and fellow patients. In addition, both fellow patients and health workers provided emotional support and were often identified as confidantes and the registered treatment supporters of patients who feared to disclose to family and friends due to potential stigmatisation.

Treatment support from transporters, religious institutions and strangers was largely instrumental. Religious institutions and their members were key sources of spiritual and in-kind support such as food and clothing. Transporters and particularly *bodaboda* (motorcycle taxi) riders often took several financially constrained patients to the treatment centre on credit. Strangers usually provided treatment support to patients during crises. For instance, the first author was touched and provided transport and funds for the hospital stay of our interlocutor, Mukasa, who was in critical condition, but his family had failed to mobilize enough money for his transportation and stay in the national referral hospital where he had been referred.

In the following sections, we consider what patients who cannot manage to adhere to treatment without some level of assistance do to sustain the help of supportive relations when confronted with the threats of stigma and burn-out. Their practices are explored under three themes: regulating the frequency of requests for assistance to prevent burn-out; secrecy and lies; and reconstituting the treatment support group.

This time I will not ask them: regulating the frequency of requests for assistance to prevent burn-out

Several dependent patients were mindful of the possibility of wearing their supportive relations down if they made frequent requests for help. These patients commonly employed strategies to regulate the frequency of requests for assistance from their relations to minimise overdependence and reduce the risk of supporter burn-out. This was particularly common among our interlocutors who conceived support from significant others more as a privilege than an entitlement. These patients did not perceive the support of their relations as a given, and thus took measures to prevent overburdening and wearing them down. The strategies employed included occasionally looking for temporary work, sale of assets and rotating among supportive relations.

Looking for temporary work

Some patients opted to look for temporary work to raise money for meeting urgent treatment needs rather than seeking assistance from supportive relations. These patients usually looked for work to meet both predictable treatment costs, such as regular transport to the health facility for review and refill as well as emergency cases such as managing episodic illnesses. Teopista, a widow in her early 50s, opted to work to raise money for medicines prescribed to treat ulcers, palpitations and a skin infection even when she could ask her daughter for financial assistance. She observed that she normally asked her daughter for financial help to meet HIV treatment-related needs when constrained, but would not ask her this time around to avoid overburdening her.

> My daughter is the only one who normally helps me financially… I always call her when I need help. However, this time around I will not tell her. She may start looking at me as a burden. I am going to devise other means. I will ask my neighbour who runs a drug shop to give me medicines on credit, and then look for work on farms around my village to raise money to pay her.

Similarly, 40-year-old Eva, who had enrolled on treatment following a lengthy illness, sometimes, opted to raise money for transport to the treatment centre for refill by working, instead of requesting for assistance from sisters whom she described as very supportive.

> I sometimes work to get money for transport to here [treatment centre]. I have supportive sisters; they are very caring. They always make effort to provide when I tell them I need money for treatment. For example, when I need money for transport, they give it to me. They understand that my life is little [fragile], I cannot manage to do strenuous work. Nevertheless, I cannot ask them all the time, they may get tired of [helping] me.

As shown PLHIV may look for work as a deliberate strategy to regulate requests for assistance and minimise the risk of wearing supportive relations down.

Sale of assets

Other patients opted to sell their assets to raise finances for meeting urgent HIV treatment needs instead of seeking assistance from their supporters. Eighty-three-year-old Sperito indicated that he sometimes sells his assets to meet HIV treatment needs to avoid ‘becoming a burden’ to his supportive children. He explained,

> I thank God that my children are supportive, but they too get tired. I do not want to be seen as a burden, so sometimes I do not inform them about my problems. Instead, I sell my things like coffee, food or chickens to raise money.

On one of our visits to Sperito’s home, he was visibly frail and needed treatment. He observed that he had not sought treatment because he was waiting for traders to buy his coffee. Asked why he had not asked for help from his children, he responded, “I will not inform them this time around. They have just spent a lot of money on my treatment; you know I have been ill for a while.”

Rotating among supporters

Unlike Teopista, Eva and Sperito, some of the PLHIV did not have immediate alternatives for generating funds to meet their treatment needs besides seeking the support of their relations. Even when entirely dependent, some of these patients made effort to minimise pressure on individual supporters. Several of them used what we call a support roster. The strategy involved rotating the individual engaged for support at a time, which enabled the patient to avoid being over dependent on a single supporter. Mutetsi, a mother of two, primarily obtained treatment support from her mother, a brother and an empathetic nurse she had met in the process of seeking care at the treatment centre. She had not disclosed her HIV status to her husband, when she was tested with the sickly child at the discretion of the doctors. However, she always found an opportunity to attend routine visits when the husband was away for work. Mutetsi was perpetually struggling to feed herself and the children, mobilize money to fund routine visits to the treatment centre and buy medicines for her frequently ill child on ART. Her husband did not allow her to work, yet he hardly provided for the family. She reported that he did not occasionally give her money for food and rarely responded when she asked him to buy medicines for her or the child. She usually got the money for transport, buying food and other medicines prescribed for her and the child from the nurse and her mother and brother. Whilst her mother and the nurse knew that she was on HIV treatment, Mutetsi had not disclosed to her brother; however, he was aware of her marital and economic struggles. Therefore, it was easy for her to find an ‘acceptable’ reason to obtain his support. She explained, “For instance, I can tell him that the children are sick, ‘please send me 10,000 shillings to enable me take them to the health centre’. I can also tell him that my husband left no money for food.”

The assistance from the three supporters was solicited on a rotational basis. “If I ask the nurse for money for transport on one visit, the next time I will ask my brother or my mother before engaging the nurse again,” she remarked.

We found that rotating the individual engaged for support at a time allowed a time lag between the point a particular supporter was contacted for help and the next time they were engaged, while assuring Mutetsi of resources from either of the other two. The delay arguably reduced pressure on individual supporters, giving them time to recharge before they were engaged again. Given Mutetsi's case, this study argues that the practice of rotating among supporters may only be feasible for patients with a relatively wide support network.

Whereas Mutetsi and others identified above were cautious and took steps to avoid burning out their supporters, some patients did not. The sub-section below provides insights into the experiences of dependent patients without strategies for regulating their requests for help from individual supporters.

Consequences of unregulated requests for support

Some PLHIV did not take measures to regulate their requests for assistance from supportive relations. These patients tended to view social support as an entitlement; therefore, they indiscriminately placed demands on their supporters. The frequent requests usually evoked resentment from the supporters, who commonly distanced themselves from the patient to avoid being targeted for help. An example was Mukasa who was dependent on his widowed elderly mother. He was advised to return to Mulago Hospital for review after the first author helped to take him there but did not. When she inquired why he had not gone, he blamed his mother for not giving him enough money for transport. He explained, "She said she had no money and gave me only 1,000 shillings (USD 0.2). What could that do for me? I need at least 10,000 shillings (USD 2.7) for a return journey."The first author had earlier engaged the mother and son on the importance of keeping the scheduled appointment. His mother had assured her that they would find money to fund the trip. When the first author engaged her about their failure to mobilize money for Mukasa's review, her explanation suggested that she and other close kin were worn out by his frequent demands for support.

> He sold his things: a woofer, DVD [player] and generator. I did not see any of the money from the sales. However, when I inquired from the person who bought the generator, he told me he had given him 70,000 shillings [USD 19]. I told him to keep at least 10,000 shillings [USD 2.7] for transport, but he did not... He wants to be given everything. It does not seem to matter to him that I have young children to provide for…Now, I understand why his siblings distanced themselves from him

Mukasa's case attests to the reality of burn-out when dependent HIV patients on ART do not take measures to regulate the frequency of requests for assistance from individual supporters. The following section explores how PLHIV overcome the constraints of stigma to sustain access to vital support for meeting their treatment needs.

Secrecy and lies

HIV-status-disclosure is shown to be a critical step in accessing treatment support. However, in a context rife with HIV-related stigma and discrimination such as Uganda, keeping one's status secret is sometimes necessary to maintain and sustain support that is vital in meeting HIV treatment requirements. Stigma can reverse privileges and entitlements to support. In Uganda, spouses, parents, children and close relatives have a cultural and moral obligation to support and care for their spouse, children, parents and other relatives, respectively. Nevertheless, access to such support is commonly disrupted by attitudes of blame and acts of rejection associated with stigma.

It is generally difficult to anticipate people's reactions after disclosure of HIV infection. Several of our interlocutors guarded against blame, rejection and the concomitant loss of support that could follow by using secrecy and lies. They concealed their HIV status from benefactors they expected to withdraw support after learning about it and used lies to continue drawing treatment support from them under the guise of utilising privileges and entitlements mediated by bonds of kinship or other relations. They were further careful to disclose to only relations they trusted to remain discreet to minimise the leakage of information about their HIV status to the benefactors.

A poignant example was Prossy, a 25-year old mother of two who primarily depended on the economic and practical support of her husband, Noah, to meet treatment requirements without disclosing her HIV status to him. Prossy met and married Noah shortly after she enrolled on ARVs. After their marriage, Noah a *bodaboda* rider became central in providing the support that enabled Prossy to adhere to the treatment regimen. Prossy told of how she made savings from money given by Noah to buy food at home. The savings helped her to meet treatment expenses like buying medicines prescribed for the treatment of other infections and meeting transport costs when she did not want Noah to learn about her visits to the treatment centre. She also got Noah to drop her to the treatment centre on some of the scheduled clinic days by lying to him that she was taking their daughter, and later, her son for immunisation. Antenatal visits became her new excuse when she got pregnant with their second child. She shared that immunisation of the unborn baby would become her new excuse for at least the next five years.

Prossy guarded against the leakage of information about her status by disclosing to only her mother whom she trusted to remain discreet. She had close sisters who, like her mother, had cared for her while she was ill but she did not disclose to them. She observed that her sisters were caring and close to her but both she and her mother did not trust them. "You never know. You may get one misunderstanding then they start publicising you [your HIV status]," she explained. She also did not disclose to her close friends including one who occasionally helped her to care for the daughter when she found it convenient not to go with her to the treatment centre. She said that she could not disclose to her friends because she did not trust them. "They are the same people who will gossip about you. I have not told my husband, how can I be sure that a friend will not tell him? The only person I trust is my mother."

Prossy knew it was important to tell Noah the truth; she said that she had considered disclosing her HIV status to him on several occasions, but feared because she was afraid of losing his support and protection if he rejected her. She emphasised how important Noah was in her continued access to HIV treatment and care and why she could not disclose her status to him.

> You see, he gives me money. I eat whatever I want. I get all the good food we are advised to eat. I have never skipped any appointment. I have no problem except that he does not know my status and may leave me if he finds out.

Prossy's fears became a reality when she mustered the courage to disclose to Noah almost a year after our fieldwork, then he ejected her and the children from their marital home. Her experience shows that in a context of widespread HIV-related stigma and discrimination; dependent patients may find it necessary to maintain a hybrid of secrecy and disclosure and cover up with lies if they are to sustain access to support that may be critical to their adherence in the long-term.

The next section describes a strategy that PLHIV employ to manage the consequences of both burn-out and stigma to sustain access to support.

Reconstituting the treatment support group

Our interlocutors normally reconstituted their treatment support groups to match existing situations. New members were commonly brought on board to compensate for the loss of treatment support due to HIV-stigma-related-rejection from and burn-out of existing members. The new members were sometimes existing relations that had initially not been involved in the management of HIV treatment. Dinah continued accessing support to meet her nutritional and medical needs by expanding her support group to include an expert client and members of a local church, when her main benefactor, a brother, appeared to be burnt-out. She had been ill for about three years and mainly depended on her brother for her needs. She had chronic sores in the mouth and throat, which were making it difficult for her to eat locally available food like cassava and sweet potatoes. All she could take were fluids like milk but her brother could not afford to buy it on a daily basis. He had also failed to purchase for her a full dose of Fluconazole, an expensive drug prescribed for her to treat the sores. Citing his increasingly elusive behaviour, she concluded that her brother was tired of providing support towards her endless treatment needs.

> When you call him, he does not answer. He has also not come here to check on me for a while. I think he is tired of my endless problems.Today, it is sores; the following day, I am fainting and need to be admitted. Then there is food. I cannot eat cassava and sweet potatoes because of the sores in my mouth. My brother always complains about the heavy burden of buying milk on a daily basis. It looks like he is tired [of providing for me].

Dinah decided to seek alternative sources of support. She called an expert client whose number she had obtained during a routine clinic visit, explained her situation to him and asked for his assistance. The expert client used his influence to get her the medicine and further gave her money to buy some milk. She also visited a local Pentecostal church and asked for an opportunity to speak to and request for help from the congregation. A couple was moved to offer her a daily supply of two cups of milk from their farm while others mobilized money for her.

By reconstituting their treatment support groups, victims of rejection and blame also found alternative sources to provide the support lost because of stigma. Prossy lost Noah's vital support when their marriage disintegrated, but continued accessing the necessary assistance by bringing the sisters whom she had initially decided to keep out of her HIV treatment issues on board. Without a job and a place to go to, Prossy was compelled to disclose to and solicit the support of her sisters both of whom lived close by in Kampala City. Bringing on board her sisters enabled Prossy to fill the gap left by Noah's exit from her support group.

Hellen, an unemployed woman in her mid-thirties continued accessing support towards her treatment by turning to her church community, when the disclosure of her HIV status spoilt her relationship with her mother and main benefactor. Hellen had returned to her parents' home during a lengthy illness and was being cared for by her mother until she was diagnosed with HIV.

> My mother was openly disappointed. She blamed me for being careless with my life and told me to find another place to live in. I had nowhere to go, so, I went to church and talked to my pastor. He mobilized other pastors; then we went to ask my mother to forgive me, but she refused. I was devastated, but the pastor counselled and offered to house me until I found another place to live in. With the encouragement of the pastor, I shared my experience with the congregation and asked for their help. A couple of [religious] brothers and sisters offered to help me. One gave me a room to stay in, another offered to feed me and the third one offered to cover my treatment costs until I got better and found a job.

As shown, the flexibility with which PLHIV made changes in their treatment support group enabled them to surmount the consequences of stigma and burn-out, thereby assuring them of continued treatment support.

DISCUSSION

The article has described practices that enable dependent PLHIV on ART to overcome the constraints of stigma and burn-out to continue accessing support for long-term treatment. The aim was to identify patients' resilience strategies that could be drawn on to build and/or improve the capacity of PLHIV on ART in a resource-poor setting to sustain access to vital treatment support for a long period.

In consistency with other studies (Nachega et al., 2006; Zachariah et al., 2007; Kunutsor et al., 2011; Kibaara et al., 2016), the article has shown that social support remains important in promoting and sustaining adherence to the ART regimen in a resource limited setting. However, its sustainability in the management of lifelong HIV treatment is threatened by supporter burn-out and stigma. PLHIV's failure to access and/or loss of support due to stigma has been documented elsewhere (Duffy, 2005; Gilbert and Walker, 2009; Gilbert and Walker, 2010; O'Laughlin et al., 2012; Laar et al., 2017). In the context, maintaining support for long-term treatment requires PLHIV to employ deliberate strategies to prevent and sometimes respond to incidences of loss of support due to burn-out and stigma.

The study identified three main strategies employed by dependent PLHIV on ART to surmount the constraints of supporter burn-out and stigma. These include regulating the frequency of requests for assistance by raising finances for treatment through temporary work and sale of assets and rotating among supporters to relieve pressure on individuals. The other strategies are the use of secrecy and lies to continue drawing support from potentially discriminatory benefactors and continually reconstituting their support groups to mobilize alternative sources of assistance in events of loss of treatment support due to stigma and burn-out. The three strategies reflect agency and resilience among PLHIV on ART in a resource-poor setting, as shown elsewhere (Ware et al., 2009; Tuller et al., 2010; Nanfuka et al., 2018). They show that PLHIV on ART in contexts of scarcity do not necessarily succumb to adversity, but often utilise available individual and environmental resources to overcome them to continue with treatment. These findings underline the need to identify and build on the strengths of PLHIV in resource-poor settings if their capacity to sustain adherence to lifelong ART is to be enhanced.

Secrecy has been a constant feature of the HIV/AIDS pandemic world over (Reid and Walker, 2003). Drawing from Posel's (cited in Reid and Walker, 2003) modes of secrecy, our data show that PLHIV use secrecy, as enacted through selective and non-disclosure, to avoid the negative consequences of stigma. However, the study demonstrates that when combined with lies, secrecy can be a formidable strategy for mobilising and sustaining support for causes that may be considered 'unacceptable' by some benefactors, such as the management of HIV. Studies of patterns of HIV-status disclosure among women in developing countries allude to their tendency to use secrecy as a strategy for sustaining support. A synthesis of literature on the rates, barriers and outcomes of HIV-status disclosure among women in sub-Saharan Africa and Asia indicates that several studies identify the fear of losing economic support from intimate partners as a key barrier to disclosure (Medley et al., 2004). In consonance with the above studies, our findings affirm that for dependent PLHIV on ART, selective and non-disclosure may not merely be ways of avoiding stigma and rejection as indicated elsewhere (Hardon etal., 2007; Steward et al., 2008; Rice et al., 2009; Gilbert and Walker, 2010; Vu et al., 2012; Maeri et al., 2016); but also deliberate strategies for negotiating the uncertain outcomes of HIV-status disclosure to sustain access to support that is vital for promoting adherence to treatment.

However, reliance on secrecy and lies to circumvent the effects of stigma may be counterproductive in the end. Besides the health risk that non-disclosure poses to benefactors who double as intimate partners (Wilson et al., 2008), secrecy may limit the patients' opportunities to reconstitute the treatment support group when necessary. This is because both selective and non-disclosure, to an extent, isolate the patient (Carr and Gramling, 2004; Yuh et al., 2014), thereby limiting the breadth of their social network. These limitations reiterate the need to address HIV-related stigma for better treatment outcomes.

It is evident that sustainability of access to social support is not a given even in a highly collectivist setting where values that foster helping like reciprocity, moral obligation and solidarity are the norm (Eaton and Louw, 2000; Basu-Zharku, 2011). Overdependence can wear support networks down. In addition, our data show that HIV patients often depend on kin who are not only poor but also burdened by numerous responsibilities. Supporting HIV treatment increases the strain on their meagre resources, thereby amplifying the risk for burn-out. Therefore, sustaining support for lifelong treatment requires that patients take deliberate strategies to minimise dependence and prevent burn-out of supporters. This further implies that reliance on informal support networks, as the main fall back for HIV patients encountering economic barriers to ART adherence, is not sustainable. Seeley et al. (1993) make similar observations from their study of families caring for HIV patients in south-western Uganda. They found that the majority of patients received limited care from the extended family mainly due to poverty and competing family obligations. A similar trend was also observed in rural Tanzania. In a study of social capital and resilience among households affected by HIV/AIDS, Nombo and Niehof (2008) found that widespread economic decline had rendered it difficult for several willing individuals to assist their infected kin during illness. The study further found that support from other close relations such as neighbours and friends was not forthcoming due to an interplay of poverty and competing family obligations. Engendering sustainable ART adherence in a context of widespread economic scarcity, therefore, calls for the augmentation of informal with more predictable formal channels of support such as health insurance schemes.

Returning to the notion of TMG as briefly discussed in the analytic framework, our data point to differences in the operations and constitution of the TMG from its original conception by Janzen (Janzen, 1978; Janzen, 1988). In managing chronic HIV, the TMG in many cases operates as a dynamic rather than static entity with more or less defined membership as suggested by Janzen (Janzen, 1978). It is evident that our interlocutors were obtaining support from a wide range of actors, who varied overtime as their TMGs were reconstituted to prevent or cope with the consequences of burn-out and stigma. Our data further show that in managing chronic HIV within a context of economic scarcity the TMG may take on a more permanent existence. This is because several patients in resource-poor settings require continuous support to adhere to HIV treatment (Nachega et al., 2006; Ware et al., 2009; Tuller et al., 2010; Okafor and Ekwunife, 2014). However, its membership may change overtime as the needs and situation of the patient evolve. This observation contrasts Janzen's view of a TMG as a temporary ad hoc entity that only emerges when the patient is critically ill and thus disbands when the patient recovers (Janzen, 1978; Janzen, 1978). In addition, in managing HIV, TMG actors may support therapy management unknowingly as patients conceal their status to minimise potential rejection and loss of support due to stigma. Moreover, the TMG can operate in a fragmented manner. Individual actors may support the management of ART more independently without concerting efforts or even knowing each other. This is particularly possible because, as this and other studies (Ware et al., 2009; Tuller et al., 2010; Nanfuka et al., 2018) show, HIV patients tend to play an active role in mobilizing support for their own treatment, and thus constituting their TMGs. Therefore, patients exercise considerable power in determining who to engage for support at a time rather than merely consenting to the support of people who emerge to provide it. ART restores or maintains the health of PLHIV and further emphasises education to empower them to take charge of their health (Gilks et al., 2006). The good health and knowledge of treatment requirements arguably put PLHIV on ART in a better position to take charge of their treatment affairs including who to engage for support. These observations suggest that the TMG is a fluid entity whose constitution and operations may vary with the nature and context of illness.

CONCLUSION

The article has shown that burn-out and stigma are serious threats to sustaining access to vital support for and concomitant adherence to lifelong HIV treatment in a resource-poor setting. Managing the two threats to sustain access to treatment support is a highly pragmatic process. Dependent HIV patients have to work out strategies for preventing or coping with the consequences of burn-out and stigma to sustain support for lifelong ART. Therefore, HIV service providers, particularly social workers and counsellors, need to consider integrating mechanisms to empower ART clients to manage stigma and burn-out. This may involve engaging them to reflect on context specific strategies to sustain the goodwill of supportive relations in the long-term and managing and addressing stigma. The identified strategies can be drawn on to enhance PLHIV's capacity to prevent and manage incidences of supporter burn-out and stigma. This may increase their resilience and ability to sustain adherence to ART in the long-term.

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Foot Notes

1 1 USD= 3700 Uganda Shillings