Sustaining adherence to antiretroviral therapy among HIV/AIDS patients in Uganda
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The Role of Social Support in Sustaining Adherence to Antiretroviral Medication

7.1 Introduction

This last empirical Chapter is one of the products of the qualitative explanatory studies intended to establish the factors facilitating adherence to antiretroviral therapy at the community level. The primary aim of this Chapter is to demonstrate the instrumentality of social support, as a structural factor, in sustaining adherence to antiretroviral therapy among patients seeking HIV treatment services at both the Mission and Public Facilities. It should be recalled that in Chapter 4 social support featured as one of the factors mitigating the economic burden involved in accessing and adhering to ART. Secondly, despite the fact the Mission Facility endeavoured to provide comprehensive care and support, only a small proportion of benefited from micro-credit, OVC support, and Income Generating Activities (see table 4.3, 4.4 & 7.3 here below), and supplies were irregular with food assistance terminated in 2008. Second, the management of HIV related symptoms pre-dates the ART programme itself (Chapter 5).

Evidence from Uganda, India, and Malaw shows that community support and/or home-based care interventions were associated with better ART outcomes in resource-poor settings (cf. Weidle et al. 2006 for Uganda; Kumarasamy et al. 2005 for India; and Zachariah 2005 for Malawi). Even in the developed world, social support is associated with positive treatment outcome (Burgoyne 2005). The utilisation and productivity of social support depends on an individual’s entrepreneurial abilities. According to Singh et al. (1999), patients with high levels of skills regarding obtaining instrumental support have high adherence to ART (in Fisher 2006).

However, such studies do not show the context within which social support emerges, is exchanged, and the implications for adherence to ART. A systematic treatment of the concept of social support must distinguish among: 1) the pre-conditions for seeking and giving social support; 2) the providers of social support
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(Those agreeing to volunteer support); 3) the resources exchanging hands; and 4) the potential benefits accrued from social support. Based on this model, this Chapter expands the notion of the patient-provider relationship. Since social support has not been discussed so far, the second section below presents the conceptualisation of social support. The third section examines the preconditions for seeking and providing social support. The fourth section assesses the nature of support networks available to patients, as well as to the health facilities themselves. The fifth section examines the context within which social support is given, and finally, the conclusion is provided. By discussing the social support available to the health facilities, the key message is that in resource-poor settings, both the patients and providers need social support, albeit in different forms.

7.2 Conceptualisation of Social Support

Social support is regarded as a multidimensional concept with many definitions and meanings (cf. Funch et al. 1986; Hupcey 1998). Among these, O’Reilly’s (1998:863) definition of social support derived from review of other authors’ work is comprehensive, partly because it was synthesised from a review of 33 articles:

Social support is regarded to be an interactive process, in which particular actions or behaviour can have a positive effect on an individual’s social, psychological, or physical well-being.

This definition suggests that social support is both tangible and intangible, involves reciprocity, and yields a wide range of benefits to the recipient. A similar definition is given by Hafen et al. 1996 who defined social support as “the degree to which a person’s basic needs are met through interaction with other people” (in Kritsotakis 2003:46). O’Reilly shows that differences in definition exist regarding what actions, interactions, and effects should be considered as related to social support. Based on other authors, there are two broad types of social support: socio-emotional aid (i.e. affection, intimacy, care, affirmation/approval, self-esteem, respect, empathy, belonging, appraisal), and instrumental or practical aid (tangible aid, money, services, advice, and information), Funch et al. (1986). This implies that social support can be broadly categorised as cognitive and affective, and instrumental behaviour.

The concept of social support is sometimes confused with social capital.38 This confusion arises because both social capital and social support share the common ‘elements’ of social networks and social engagement, and a sense of belonging and

38 For a detailed discussion of social capital issues refer to Coleman (1988, 1990); Portes (1998); Bourdieu (1986); Almedom (2005); Baum (2003); DFID (2005); Seeman & Berkman (1988) in White (2003); Campbell et al. (2001); McLanaham (1981); Stansfeld (1992).
reciprocity. Like social capital, social support operates within an individual’s social networks, which consist of a set of persons who are relied upon for support and who may in turn rely upon the individual. However, social capital debates tend to focus on social structure and community resources (social networks or connectedness) while social support is the supportive behaviour (or functional element) of a given social relationship (Östergren et al. 1991). Therefore, social capital is the structure while social support is the content. Bourdieu, was one of the first authors to analyze systematically the properties of social capital, defining it as “the sum of resources, actual and virtual, that accrue to an individual or a group which are linked to possession of durable network of more or less institutionalised relationships of mutual acquaintance and recognition” (Bourdieu, 1986:248). Similarly, Kritsotakis et al. (2004:46) allude to the same fact by indicating that while social support refers to relations a person develops in his/her social environment, social capital breaks away from this individualistic approach to address more effectively the influence of society on the individual. Therefore, even though social capital and social support have the same theoretical characteristics, they describe two different phenomena.

7.3 Precondition for Seeking Social Support among HIV/AIDS Patients

The need for social support among the patients that were studied can only be understood by assessing the objective conditions for seeking and providing social support. This section will examine those needs, and the problems experienced by the patients and health providers that necessitated seeking external assistance.

7.3.1. Patients’ Needs

The needs experienced by HIV patients in the two facilities tended to vary within the cycle of HIV/AIDS management. Based on patients’ accounts, the HIV/AIDS management cycle can be broken down into three overlapping stages: falling sick, treatment initiation phase, and treatment maintenance phase (also referred to as the persistent phase). The health conditions suffered during the first cycle of HIV management have been presented previously (in Chapter 5, section 5.3.2). I will provide extra information here to that effect.

Based on the qualitative accounts, the stage of falling sick was characterised by a ‘cocktail of illnesses’, a ‘prolonged period of pain and suffering’, ‘helplessness’, and ‘humiliation’, and it was such impaired health conditions that necessitated and attracted social support.
I had high blood pressure and developed a stroke. As a result, my mouth became twisted on one side. Friends and relatives attributed such a condition to witchcraft. I was too weak to talk. The care-givers delivered me to the traditional healer. (Female Focus Group Discussion Participant, UMF)

Aside from severe health conditions, impoverishment during this first phase attracted empathy and social support behaviour.

I moved from one clinic to another. At that time, payment of Graduated Tax was still in force. When I presented my money to the Tax Collector, he became sympathetic. He said to me, ‘Mzee (Swahili for old person), I am exempting you from tax, use that money to buy some medicine’. People used to frighten me by saying that doctor will administer medicine that will kill you. A good friend of mine accompanied me to the hospital. George, who is my son and also serves as my treatment supporter, used to accompany me to the hospital by then. (Male Focus Group Discussion Participant, RPF)

Owing to the deepening economic hardships experienced at this time, some patients became increasingly unable to afford basic necessities and engaged in adverse coping strategies: ‘My daughter dropped out of school, and became pregnant’ (Female Key Informant, UMF). For some, meeting the cost of accessing health services became difficult: ‘I managed to reach the clinic but failed to return home, I was helped by a stranger who gave me 5000 Shillings’ (Female Key Informant, RPF).

This phase attracted both assistance and trouble. Some widows suffered harassment from in-laws during the post-mourning period: ‘In 1994 my in-laws grabbed my property and I ended up putting up in a house as small as a pit-latrine’ (Female Key Informant, UMF). At that same time, the burden of care for their own children and orphans became unbearable, and some patients tried entrusting them to relatives.

My husband had died previously. I had no food, and no money. By then I was too scared to go to Hospital. I also had orphans and three biological children to take care of. I sent them to my brother, but he kept them for only six months and sent them back to me. After some time, my eldest son came and brought me to hospital. (Female Focus Group Discussion Participant, RPF).

The second stage, treatment initiation, was characterised by seeking Voluntary Counselling and Testing (VCT) or Routine Counselling and Testing (RCT), the assessment of clinical conditions, the introduction of multivitamins and cotrimoxazole prophylaxis, the treatment of OIs, and subsequently being initiated on ARVs. Based on patients’ accounts, the first three months were very demanding and required all forms of assistance (money, advice, information, affection, belongingness, affirmation, and approval) in order to manage the costs associated with the mandatory induction
visits and to overcome the anxiety associated with taking up life-long treatment. The subsequent three months after initiation on ARVs were associated with improved appetite, hence heightened dietary costs and social support seeking behaviour.

Finally, during the treatment maintenance phase, patients’ health conditions generally improved dramatically, and the major problem experienced was in meeting the travel costs for regular pharmacy refills, food, and other basic household necessities. This phase also coincides with the resumption of household maintenance responsibilities. In Chapter 5 we saw that the first six months after initiation on ART is associated with clinical and immunological improvement, and such functioning makes it possible to resume or look for livelihood opportunities, especially in the informal sector: “As soon as we recover, we have to start looking for small casual jobs, just to keep us afloat” (Male Key Informant, UMF). However, in some cases, resumption of work becomes difficult due to the previous loss of social networks and contacts, lack of seed money, limited employable skills, and general physical weakness: “A person may have the energy and will to work, but capital to resume work might fail him/her” (Male Key Informant, UMF).

7.3.2. Health Facility Needs

In Uganda’s resource-limited settings, health facilities providing HIV treatment need social support as much as the patients themselves. By May 2009, Mbuya Reach Out (the urban-based Mission Facility, UMF) had 4 doctors and 12 nurses to handle 1644 patients in the four treatment centres. Similarly, at that same time, the HIV Clinic in Kayunga Public Hospital (the rural-based Public Facility, RPF) had 1 medical doctor and 5 nurses serving a total of 800 patients actively on ART. In both facilities, the level of staffing was small compared to the workload, in terms of psychosocial support provision, clinical care and treatment, and general care and support. The number of patients diagnosed with HIV/AIDS and who are eligible for ART has increased since 2005 (Refer to Appendix Figure A.2 and A.3 for 2005/2006 and 2006/2007).

The situation was no better at the national level. Uganda’s National HIV and AIDS Strategic Plan (2008) revealed that while 42% of the population in need was benefiting from ART by 2005, the number in need continued to grow each year, to 129,000 in 2007, and it is projected to rise to 238,000 in 2012 – far outstripping the capacity of the system and the finances available to respond to the demand. This study reveals that health workers’ workload was increasingly becoming unbearable, especially in the Public Facility where the recruitment of auxiliary staff had remained small.
On a typical day of ART clinic, we experience a large volume of work. The most difficult part is processing data for the Ministry of Health (MOH). The MOH requires us to extract the information from the patients’ records to a standardised format. That means that we have to stay behind to make tallies after the patients have left. The advice we received from the MOH is to be committed and to love this kind of work. (Nurse, ART Clinic, RPF)

Given the fact that we (staff) are few, we do not have a fixed time for reporting and leaving the workplace. Instead, the amount of work on a given day determines the number of working hours. (Administrative Assistant, ART Clinic, RPF)

In summary, both the patients and the providers were in need of external sources of social support.

7.4 Overview of Availability of Social Support from Social Networks

The survey included a set of questions to determine the availability of friends and/or relatives, and the dynamics of social support in the form of type, sources, frequency, and satisfaction. In terms of availability of confidants (friends who love unconditionally), results indicated that of the 262 respondents across both health facilities, 99% (257) ‘had close friends and/or relatives they felt at ease with and with whom they talked about personal life, including health problems’. There was no statistically significant difference in terms of availability of confidants between the two sites, with 99% (140) in the UMF and 99% (117) in the RPF having access to confidants ($\chi^2 = .016, \text{df}=1, p= .899$). However, another question interested in patient’s membership of an organisation revealed that few (29%, 74) patients belonged to any formal association, with a bigger (41%, 48) number of urban-based patients being more likely to belong to an association than (18%, 26) rural-based patients ($\chi^2 = 15.567, \text{df}=1, p=.000$).

Of those patients in the two sites who had confidants, a large proportion (97%, 248) usually received care, assistance, and support from the confidant. There was no statistically significant difference in levels of access to assistance between the UMF (97%, 136) and the RPF (97%, 112) ($\chi^2 = .002[b], \text{df}=1, p=.966$). This implies that patients in the rural and urban settings benefited equally from social support resources, which is consistent with results in chapter four, see figure 4.1.

In terms of forms of assistance received from friends and relatives, in descending order, the commonest form of social support was advice 84% (208), followed by emotional support 77% (190), financial support 71% (176), practical support 68%
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(168), food 64% (158); spiritual support 43% (107), a social network 41% (102), compliments 39% (96), and material support 36% (88) [both sites combined]. The 262 ART patients benefited from more than one form of support, reflected in a total of responses that exceed 262 cases.

The sources of social support were spouses, sons, daughters, sisters, brothers, parents, and friends. Yet, the analysis of each of the nine ‘forms of social support’ by ‘source’ shows that the main source of social support was sister/brother – with the highest number (≥52%) of respondents obtaining financial, material, practical support, advice, spiritual support, emotional, compliments, social network, and food from their sister or brother.

In order to assess the frequency of social support, a rating scale was used whereby the respondent was supposed to show whether the mentioned social support was ‘always’ (regular), ‘occasional’, or ‘rare’. For the sake of brevity and clarity, by looking at the highest score for each form of social support, socio-emotional aid was ranked as ‘regular’ while the flow of ‘financial support’ and ‘material support’ was considered ‘occasional’. Results from qualitative studies indicate that social support from wider networks typically became available during the falling sick phase and early part of the treatment initiation phase, and receded once a patient’s health condition stabilised during the treatment maintenance phase.

When I started ART treatment, I informed my brothers. One contributed some money, another one tray of eggs, another bought soft drinks, and another 3 kilograms of sugar, as well as asking the fish vendor to supply fish on Saturdays. They tried their level best. If it wasn’t for that support, I would have dropped out of (HIV) treatment at the very beginning. When I recovered, I started taking care of myself. I reared chickens in order to have a reliable source of eggs. I also grew vegetables. I also convinced my children to buy me a cow, which produces 3 litres of milk. I consume practically all that milk myself. Over a period of 3 months, I had regained weight. I started getting compliments from people about my bodily appearance. The more the compliments, the more I was encouraged to continue taking my medicine. (Male Key Informant, RPF)

In assessing the level of satisfaction with social support, the respondents were simply asked if they were “happy with that kind of assistance?” For each of the nine form of social support between 97-100% of respondents indicated that they were happy. Beyond these statistical figures, the following section examines the forms of treatment support available to the patient as well as the health facilities themselves.
7.4.1. Treatment Supporter

The first source of social support is Treatment Supporters (TSs), also known as Treatment Buddies, or home care-givers. TSs are people, more often than not family members, who participate continuously in the daily management of HIV patients, with a genuine motive to restore, maintain, and promote patients’ health conditions. Understanding the background characteristics of the TSs is necessary because this can have a potential effect on their helping behaviour. As already mentioned in the methodology Chapter, the FGD targeted fifteen TSs, 8 from the Mission Facility and 7 from the Public Facility. While it might be unrealistic to deduce meaningful conclusions from such a sample size, it is still possible to provide information about the characteristics of some of the people who become Treatment Supporters in these settings.

In terms of gender, of the 15 TSs, 9 were female and 6 were male. This may be expected because in traditional African societies women occupy an important position as home care-givers. In terms of social relations, the TSs were: sisters (5), sons (4), wives (2), father (1), mother (1), daughter (1), and brother (1). Table A.5 in the Appendix shows the provider-recipient relationships based on the FGD attendance list. The commonest form of helping relationship was sister-to-sister (5 across both sites), followed by son-to-mother (3). Friends did not feature as Treatment Supporters, possibly because associational ties do not necessarily guarantee ‘daily’ supportive behaviour. Friends appear as Good Samaritans in times of severe need and disappear as soon as health conditions normalise. Daughter-to-father did not feature at all. Daughter-to-father treatment support relations may be difficult to come by because of daughters’ marital engagements and, in the central region of Uganda, it is culturally inappropriate for a daughter to nurse a bed-ridden father, unless in extreme necessity. Similarly, no husband-wife helping relationship was recorded in this particular Focus Group Discussion. Evidence from Individual Patient Interviews indicated that HIV or discordant status is often associated with conflict. Husbands’ failures to meet their breadwinner responsibilities due to sickness and limited economic opportunities sometimes had a stifling effect on the husband-wife relationship.

My wife serves as my Treatment Support but the situation is not good at home. Sometimes she demands basics necessities. Whenever I explain my position, that I am too weak to work, she storms off, saying, “Look, it is none of our business, it was of your free will that you caught the virus.” Marriage, poverty, and medication do not go together well. (Male, (Social Support Recipient FGD, RPF)
In terms of duration of social support, for all the 15 cases, treatment support relationships had lasted between 9 months and 6 years, with almost a half (7) of TSs having served for more than 4 years. This implies that, in some case, the antiretroviral programmes must have built on existing treatment support relationships, presumably the family-based family system, given the fact that the two study sites had only been accredited for just under 4 years preceding this study.

Finally, the treatment support mechanism was based on a weak economic foundation, because TSs were employed in subsistence farming, the informal economy, and some were unemployed, studying, or below the working age (below 11 years of age).

**Intentions for Providing Treatment Support**

The intentions or motivations for providing social support have implications for the quality and, possibly, the duration of support. Ideally, the support provider’s intentions should correspond with the recipient’s needs and the context within which such support is demanded. The consensus was that social support emerged naturally out of the desire to save the life of an ailing relative. This is also the key message in section 7.3.1 in this Chapter. It is at the onset of severe illness that friends and relatives stepped in to reverse the situation, as the following TS indicates:

She (the patient) was living with the husband at the time she fell sick. Despite the fact that the husband never went for a (HIV) test, he was aware of his status. After birth, her baby died from multiple illnesses – vomiting, fever, and cough. The husband abandoned her with her two children in a rented house. I picked her up and took over that responsibility. She was ill, with swollen lymph nodes in her armpits. Because I had gone through the same experience (of AIDS), I advised her to take a test (at Mbuya Reach Out). She resisted. I asked the CATTs (CHW Mission facility) to lend a hand counselling her. On the day she was supposed to take a test, she dressed and, all of a sudden, changed her mind. It was only after some weeks that that resistance waned and she presented herself for test. After being on (cotrimoxazole and multivitamin) for one year, her CD4 went down to 120… She and I underwent education (counselling). After passing the (pre-treatment) interview, she was started on medicine. The doctors asked me whether I could manage. I replied that with the help of the CATTs I would manage. Now she has greatly improved. She takes the medicine on time. Only in a few instances does she seek advice from me. With the exception some simple illnesses, she is doing fine. (Female Respondent, Social Support Provider Focus Group Discussion, UMF) [Brackets my emphasis]

This rather extended account of a ‘sister-to-sister’ supportive relationship demonstrates several more general points. First, a patient’s severe health condition attracts treatment support. Second, the Treatment Supporter simply volunteers to
accord unconditional help to the patient, with such social support behaviour initiated before accessing formal HIV/AIDS treatment. Third, similar health identities generate helping behaviour; the previously infected or affected extended mutual support and health protection skills to fellow relatives living with HIV/AIDS. Fourth, entry into formal healthcare settings expands and formalises treatment support system, with the informal and formal care-givers converging to facilitate entry and utilisation of formal health services. Fifth, helping behaviour wanes as patient’s health condition improves. Six, evidence suggests that providing treatment support is a painful process, involving costs, conflict, resistance, negotiation, and the evaluation of the possibility of continuing.

However, other accounts indicate that, in spite of the volunteering spirit, not everyone’s motives for helping were altruistic. Additional evidence from social support providers suggests that the supportive behaviour is motivated by an evaluation of costs and benefits associated with the survival or death of the HIV patient being helped. According to some TSs, it is more convenient to support a relative to access and adhere to the HIV/AIDS treatment than taking on the extra burden of looking after his/her orphans (after they have died). Some wives feared the loss of their dear ones and the subsequent loss of companionship and mutual support: “I am happy if we both live. Of course two heads are better than one,” (Female, Social Support Provider FGD, UMF). On the other hand, the child Treatment Supporters feared the loss of the economic and social support that would come with the death of a parent: “Of course we love them, but also I take care of my mother so that she will live another day to pay my school tuition,” (Daughter, Social Support Provider FGD, UMF). The little ones shared the same concern of an uncertain future. Luckily, HIV positive parents taking antiretroviral medication were aware of children's fears and concerns. The following discussion took place in a mainly female Focus Group Discussion at the RPF:

Children have special interest in our lives; all of a sudden this child can ask you, “Dad is gone, what will happen to me if you also disappear?” (Female, ( Social Support Recipient, FGD, UMF).

A participant interjects:

I have this little child who constantly reminds me to swallow the tablets. She sometimes wakes up in the middle of the night and asks me, “Mama, are you fast asleep, have you taken your medicine?” I assure her that I already have. Children become happy whenever our health conditions improve, and become downcast whenever our health condition deteriorates. ((Social Support Recipient, FGD, UMF).
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The above quotations also confirm the desire to provide care and support to children as one of the factors driving adherence to ART.

Mother and her Daughter Treatment Supporter

**Appraisal of Treatment Support by the Recipient and Provider**

The survey included a question about patients’ perceptions of the quality of care received from the Treatment Supporters, including both Personal Treatment Supporters and Community-Based Treatment Supporters.

**Table 7.1:** Patient’s Satisfaction with Treatment Support (Both Sites Combined)

<table>
<thead>
<tr>
<th>Level of Quality</th>
<th>Personal Treatment Supporter (n=248)</th>
<th>Community-Based Treatment Supporter (n=152)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Extremely High</td>
<td>55% (137)</td>
<td>46% (70)</td>
</tr>
<tr>
<td>2. High</td>
<td>37% (91)</td>
<td>33% (50)</td>
</tr>
<tr>
<td>3. Average</td>
<td>5% (13)</td>
<td>7% (10)</td>
</tr>
<tr>
<td>4. Low</td>
<td>2% (4)</td>
<td>5% (7)</td>
</tr>
<tr>
<td>5. Negligible</td>
<td>1% (3)</td>
<td>10% (15)</td>
</tr>
</tbody>
</table>

A combination of ‘extremely high’ and ‘high’ rating shows that patients were satisfied with the quality of treatment support, with the rating being 92% (228) and 79% (120)
for both Personal and Community-Based Treatment Supporters. The rest (8% 20) and 22% 32) felt that the quality of support was equal and/or below average. The role of the community-based TS will be discussed below. Qualitative discussions with patients provided confirmatory evidence of this overall satisfaction: ‘They are not bad at all, can’t you see for yourself from our physical appearance?’

While with life-long treatment it is difficult to empirically establish the frequency and duration\(^\text{39}\) of social support, like social support obtainable from wider social networks, the intensity of inter-personal treatment support tends to diminish or becoming intermittent as HIV/AIDS progresses through the persistence phase.

There comes a time when we take our medications without being reminded ... But even when s/he\(^\text{40}\) failed to remind me (as a patient), I am not (a) child, it is my personal responsibility to take care of myself. If a child can take the responsibility of taking the medicine without being reminded by the parent, how could I fail to do so? (Social Support Recipient FGD, UMF)

Provider evaluation of the HIV patient-Treatment Supporter relationship shows a care-giver burden because of the costs, tension, and sacrifices involved in the entire process. Accounts from various TSs demonstrated that such costs and sacrifices varied from one person to another. In the course of illness, some TSs deferred their personal ambitions: “I was attending school but given the fact that I was the only person readily available at that time, I had to postpone schooling for one year” (Daughter, Social Support Provider FGD, UMF). “Even when s/he has biological children you have to take on that responsibility.” (Male, Social Support Provider FGD, UMF)

Family-based treatment relationship is characterised by stress because of the pressure and tension patients impose onto the care-givers. Some patients display a relentless demand for nice food to accompany their medication (kubayiyiiza); seek compliments and approval of the physical functioning and bodily appearance (okubesimisa), like to be showered with praise for having taken their medicine appropriately (kubasuusuuta), or demand attention like babies (kubafaako). If the treatment supporter ignores such demands the patient starts to sulk (entondo) and becomes sullen (kwekyanga). As one female supporter in the rural settings said:

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\(^{39}\) Here, the notion of frequency of social support refers to the occurrence of helping events within a given time period, while duration refers to the length of the period in which help is received.

\(^{40}\) Luganda, the local language in which the investigations were conducted, does not have masculine and feminine pronouns, hence the usage of s/he here.
We have to plead with them about their demands... But when we have some money to spare and return home with what they are looking forward to, that is when they are overwhelmed with joy.

The last form of appraisal that can be made here is the level of reciprocity of supportive behaviour between the recipient and provider. The survey assessed reciprocity between the patient and their social networks (not necessarily only Treatment Supporters). Results indicated that less than a half (46%, 116) of patients across both sites gave something in return for the assistance they had previously received from a confidant. More specifically, the assessment of treatment support itself indicated that patients tended to pay back TSs in simple ways, including with prayers, appreciation, comfort, and practical support, especially during stressful moments (e.g. bereavement) – Hence the frequent travels and attendance of burials, ultimately resulting in non-adherence to treatment. Fortunately, the TSs never expressed many of expectations of their patients.

I don’t expect anything from him/her. This is (a) person who is too weak to produce crops. S/he does not have the energy to board a lorry to go to the market to conduct business (to find money to pay back – my emphasis).

7.4.2 Health Facility Support Systems

Beyond familial or kinship support networks, patients who have been formally enrolled for HIV/AIDS treatment services in the two settings benefited from what can be called Facility-based Social Support. Two variations were identified here: peer-patient support and Healthcare Volunteers.

1. Peer-Patient Support

The second level of social support was among the HIV patients themselves, operating from the health facility and at the community level. This kind of support arose when patients met repeatedly for certain healthcare services (VCT/RCT, ART counselling, pharmacy refill) within a common healthcare setting. Repeated encounters at the general reception and in group counselling (as opposed to less common individualised sessions), brought patients closer together and stimulated peer support.

The most important benefits of such frequent focused encounters and interactions among patients themselves are motivation, a sense of belonging, and behavioural skills. First, interpersonal interaction at the waiting bench involves sharing information, compliments, and encouragement that serve as positive reinforcement:
We are encouraged by the fellow patients who make remarks that we look good. We take the compliments and tell them that our health condition used to be worse before starting medication.

Second, frequent encounters and the associated mutual experiences not only serve as a stress buffer but also reduces stigma (especially the experienced stigma\textsuperscript{41}).

When I come to the clinic I become aware that I am not the only one suffering. ... You stop being haunted by that feeling of individual punishment and eventually you become strong.

Third, sharing information in a healthcare setting is associated with gaining therapeutic skills (see Chapter 6). Patients tend to share individual experiences of falling sick, management of opportunistic infections and drug side effects, coping strategies, and preventive and curative actions.

However, the benefits of such inter-patient interaction are restricted to emotional assistance as it rarely translates into practical and financial support: “One cannot get financial assistance from patients, they are completely poor.”

2. Healthcare Volunteers

The third category of social support system is made up of the HIV/AIDS cadres who operate at the facility and/or community level. During the implementation of community-based healthcare services in the 1980s, these were called Community Health Workers\textsuperscript{42} and they provided primary level care. With the appearance of HIV/AIDS, this primary healthcare approach was revived with the HIV/AIDS infected and/or affected persons transforming into care-givers. These HIV/AIDS caregivers are variously known as Homecare Facilitators (for Uganda Red Cross HIV Project in Uganda), Community ARV-TB Treatment Supporters or CATTS (for the Mission Facility-Mbuya), or simply as volunteers (in the Public Facility – Kayunga). Given the different names in use, Healthcare Volunteer is adopted here to refer to trained patients who volunteer their time and labour to provide care and support to the patients in a healthcare setting. The concept of Expert Patient is less applicable in Uganda’s context because, in the context of the developed world, it refers to patients

\textsuperscript{41} Stigma can be ‘enacted’ (e.g. one is discriminated by the public) or ‘felt’ (e.g. one is shy about oneself).

\textsuperscript{42} According to WHO Study Group (WHO 1989): Community health workers should be members of the communities where they work, should be selected by the communities, should be answerable to the communities for their activities, should be supported by the health system but not necessarily a part of its organization, and have shorter training than professional workers (in Prasad BM 2007).
with long-term illness who can effectively manage their own illnesses in partnership with health care professionals.

It should be noted, however, that while the Mission Facility uses a combination of an outreach model and a community model, the Public Facility uses a facility-based model. The outreach model consists of home-based care teams, comprised of doctors, nurses, laboratory technicians, and counsellors, taking services to communities. The community model entails community members/volunteers/community health workers providing home-based care services to people living with HIV/AIDS. On the other hand, in the case of facility-based model the volunteer perform non-technical work as well providing emotional support to fellow patients at the facility (MOH 2004). Though, in practice, the distinction between all these models is blurred.

**Origin of Healthcare Volunteering in the Two Facilities**

The adoption of the Healthcare Volunteers system for dealing with HIV/AIDS originates from the desire to reduce the effects of staff shortage on the quality of health services and associated potential adverse effects on adherence to ART. Hence, health facilities recruit, train, and empower volunteers to fill the human resource gap. Like the personal treatment support system already discussed above, the current Healthcare Volunteering in the two study sites consisted of spontaneous voluntary action that started as the outreach model in the Mission Facility and as the community model in the Public Facility.

At the Public Facility, healthcare volunteering began as a self-help process. Around the time I started my fieldwork at the Public Facility, I used to see a gentleman who stayed around the patients waiting for clinical consultations. At regular intervals, he rose and addressed the patients thus:

> Fellow patients, kindly listen to me. I ask of you to be patient, the line is moving slowly, but the doctors will certainly attend to you. Do not walk away and return home before you see the doctor. You must realise that the number of health staff is small, but all the same, you will be served.

He would then sit down and, all of a sudden, stand up again and stroll around as if he was an officially appointed usher. He would welcome patients arriving at the HIV clinic, direct them to the relevant waiting lounge, and lead others to the consultation rooms or the pharmacy department. He would line up or ‘jump the queue’ to secure medicines on behalf of the extremely weak. As time went on, he established relationship with professional health workers and he assumed several functions, some of them including; relaying files to the relevant offices, replacing the files in the filing cabinets, and running errands at the request of the professional staff. At the end of
the day, when all his fellow patients had returned to the villages, he would thank the health staff for the day’s work, walk out of the clinic, unlock his bicycle and disappear back home. The following day, he would report to the clinic earlier than the staff to organise the office, and render a hand in pushing the medicine trolley from the main hospital pharmacy.

This gentleman was Mr Nsubuga (true name reproduced with permission). His participation in HIV/AIDS related care and support did not begin as formal healthcare but initiated at the community level. He is the founder of the herbal group mentioned in Chapter 5 that transformed into the Kayunga Hospital ART Association (KHAA) and that served as a monthly forum for talking about adherence issues in Kayunga Hospital.\(^{43}\) Mr Nsubuga also became one of the 6 Healthcare Volunteers fully integrated into the Public Facility to supplement the small number of health staff.

The Healthcare Volunteers underwent training in care and support organised by the Ministry of Health in Kampala. Facilitated by the Makerere University Walter Reed Project (MUWRP)\(^{44}\), the volunteers and the nursing staff benefited from additional training that covered several topics including; adherence, positive living, hygiene, types of ARV regimen, TB management, prevention of mother-to-child transmission (PMTCT), and nutrition. At the time this research was conducted, the MUWRP project met the extra operational costs, including the stipend for volunteers.

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\(^{43}\) Other community based organisations (CBOs) were also emerging in the backyard of Kayunga Public Hospital. I visited one CBO in the countryside called Tulibalamu (Alive and Kicking).

\(^{44}\) MUWRP is a non-governmental not-for-profit HIV research organisation dedicated to finding a safe and effective HIV vaccine. Through PEPFAR funding, MUWRP donated office equipment (telephone and furniture), test kits, a CD4 machine, kidney and liver machines, and training in counselling.
Quite differently, at the Mission Facility, Mbuya Reach Out, the spirit of health volunteering did not originate in the villages but from the Catholic Church, during a 2001 Easter sermon presided over by an Irish priest. Speaking on the theme of salvation, the priest urged fellow Christians to reach out to the sick and needy living in nearby suburbs. The key values that inspired the work of the founding Christian members were ‘hearts and will’, guided by the principles of “Do what you have, with what you have, where you are”. This faith-based ideology was integrated into the training of Healthcare Volunteers. The Volunteer’s Trainer Manual even inscribes a prayer of St Francis of Assisi, asking the Holy Spirit, “Lord, make me a channel of your peace. Grant that I may seek to comfort rather than to be comforted, to love rather than to be loved” (paraphrased). Even a typical HIV Clinic day in the Mission Facility opens with morning prayers and few exercises. During this session, administrative communications are made and new events or members are introduced – which I personally experienced as if being introduced and integrated into a family.

After the Easter Sermon, small Christian communities from Mbuya Catholic Church started visiting the sick and dying people in their homes, and providing emotional and spiritual support. When the workload expanded, more Christians were called out to serve as volunteers in order to staff the weekly clinic (Reach Out Project Document 2005). As time passed, the community outreach project transformed into a strong healthcare organisation, and the programme name was changed from Mbuya Outreach to Mbuya Reach Out. By 2008, the programme had five departments. The community volunteers, CATTS, are now a fully institutionalised sub-department, hosted by the Community Support Department. The first-line supervisor of The Mission Facility tracks CATTS’ performance and the Community Department

45 [http://www.reachoutmbuya.org/volunteers.html]
provides guidance and coordination. Like in the Public facility, monthly meetings serve as forum for discussing individual reports, resolving intra-group conflicts, and planning subsequent activities.

Like the Healthcare Volunteers at the Public Facility, the CATTS are well trained in home-based care activities on the basis of a simplified step-by-step training manual that covers a wide range of topics, including home-based care, the basics of HIV and tuberculosis, ART adherence, psychosocial counselling, and adherence monitoring.

Role of the Healthcare Volunteer System

The role of the Healthcare Volunteer system can be evaluated by assessing the amount and quality of services performed by the volunteers themselves. There are three possible ways of estimating the amount of work performed by the healthcare volunteers namely; by counting the number of healthcare volunteers serving, by taking the working hours per day, and by looking at the functions performed.

The number of healthcare volunteers serving can be understood by using a proxy indicator of provider-patient ratio. Table 7.2 below presents the Level of Staffing and Healthcare Burden with the first three rows presenting the type of health workers at the HIV/AIDS clinic in the form of doctors, nurses, and Healthcare Volunteers in the two facilities between 2009 and 2011. The last two rows present the actual and hypothetical provider-patient ratio. The Health Worker to ART patient ratio on the second to last row reflects the reduced workload as an effect of volunteer participation. Finally, the last row shows the hypothetical increase in workload of professional staff if the Healthcare Volunteers were to be excluded from the healthcare arrangement.

<table>
<thead>
<tr>
<th>Type of Health Worker</th>
<th>Mission Facility</th>
<th>Public Facility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Senior Medical staff</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Nurses</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td>Healthcare Volunteers</td>
<td>250</td>
<td>232</td>
</tr>
<tr>
<td>Total No. of Health Workers</td>
<td>266</td>
<td>246</td>
</tr>
<tr>
<td>Total No. of ART Clients</td>
<td>1644</td>
<td>2099</td>
</tr>
<tr>
<td>Health Worker : ART client Ratio</td>
<td>1:6</td>
<td>1:9</td>
</tr>
<tr>
<td>Professional Staff: ART Client Ratio</td>
<td>1:102</td>
<td>1:150</td>
</tr>
</tbody>
</table>

NB: 1. The data for 2011 is based on a Follow-up Study.

Table 7.2 below shows that Healthcare Volunteers drastically reverse the disproportionate provider-patient ratio. The higher the number of Healthcare

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Volunteers recruited, the more favourable the provider-patient ratio, and therefore the less the clerical and outreach workload for the professionals. The second to last row shows that the Mission Facility with a high number of Healthcare Volunteer tended to enjoy a favourable Health Worker to ART patient ratio (1:6 and 1:9 in 2009 and 2011 respectively) compared to the Public Facility that had fewer Healthcare Volunteers (1:67 and 1:120 in 2009 and 2011 respectively). The last row indicates substantial increase in the number of ART patient that professional staff would have to deal with if the Healthcare Volunteers were not participating in clerical work and outreaches. The table also shows a decrease in the number of professional staff. The reasons for this trend will be discussed later.

The technique of task shifting whereby professional health workers pass on non-technical work to the Volunteers is associated with several benefits, as it:

1. Empowers lay patients in provision of preventive, treatment, and psychosocial support services,
2. Reduces the operational costs in terms of salaries for professional staff,
3. Reduces the workload for professional staff and freeing more time for clinical and adherence activities,
4. Reduces the professional and social distance between professional and lay patients, and common modern scientific medicine,
5. Expands the scope of intervention through facility and outreach services.

The nature of work performed by the volunteers varies depending on the nature of the community-based healthcare model adopted by the facility. In the facility-based model, a model embraced by both the Mission Facility and Public Facilities, volunteers perform non-technical work that takes the form of (among other things): managing reception; retrieving, relaying, and replacing patients’ files; taking and recording clinical indicators (mainly weight); serving breakfast to the patients at the clinic; and (some) dispensing of ARVs and preventive therapies. Beyond the healthcare settings, the Healthcare Volunteers distribute basic care kits (including mosquito nets), participate in outreaches, track lost-to-follow-up patients, facilitate the transfer of patients to newly accredited treatment centres, and accompany and/or visit fellow patients to/in referral centres. The CATTS also visit homes, and administer patient assessment checklist to identify the families needing a given type of socio-economic aid.

At the Public Facility, where a facility-based approach is more pronounced, the Healthcare Volunteers system resulted in community organising. The ART
Association alluded to above organises monthly adherence support meetings within the hospital premises. During these meetings the discussion centres on perceived adherence barriers, adherence to pharmacy refill appointments, and preventive and treatment behavioural change (e.g. use of mosquito bed-nets and nutrition). In principle, a health staff representative is supposed to attend these meetings in order to handle issues of a technical nature. Given the fact that the rural-based Public Facility was not able to implement the socio-economic component of its ART programme due to limited public funding, the ART Association was increasingly exploring the possibility of implementing food and income security projects at the community level.

In addition, the Mission Facility, with a substantial amount of donor funding implements the outreach model whereby the CATT conduct home visits, check the patients’ medical forms, conduct pill-counts, identify adherence barriers including family support, counsel non-adherent patients and/or recommend referral for counselling/treatment, and remind patients about their next refill appointments. The CATTS also screen patients at the community level for treatment enrolment, screen for orphans and vulnerable children, and distribute healthcare kits for needy patients.46

As indicated in Chapter 7, the Healthcare Volunteers implemented counselling. Besides, because they are themselves either infected or affected by HIV, they are keenly aware of patients’ realities and therefore able to tailor the information given, and, using appropriate communication techniques, to address the real adherence barriers. Due to the comprehensive training in HIV/AIDS that the Healthcare Volunteers receive, they can help patients interpret technical information and pass on instructions. Often such interaction is observable at the exit point after meeting the professional. Because Healthcare Volunteers cross borders, they also bridge the professional-patient communication gap, thus receiving information and providing feedback from and to both the patients and the providers. As one volunteer in the Public Facility noted:

> Sometimes patients may come to the clinic with a personal problem but find it difficult to disclose it (to) doctors and end up confiding in us. After s/he has confided in me, I liaise with the doctor to see that such a problem is solved.

As previously indicated, a large proportion of patients were satisfied with the services provided by the community-based Treatment supporter.

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46 Patients in need include those who are bedridden, those referred by major hospitals, the unemployed, the elderly, and those abandoned by relatives. The type of assistance given is in the form of clothes, grants, water guard, starter kits, and water vessels.
Incentives
Lastly, while the principle of voluntarism is emphasised during recruitment, Healthcare Volunteers benefited from a wide range of incentives. These incentives sometimes take the form of an expected reward that motivates certain behaviours.\textsuperscript{47} The volunteers benefit from three types of incentives namely; \textit{intrinsic incentives}, \textit{pecuniary incentives}, and \textit{social incentives}.

The \textit{intrinsic incentives} are connected with doing work because it promotes personal interests and feelings (task enjoyment), or the direct result of the task outcome (e.g. a feeling of achievement). Both patients and staff feel happy when saving lives. The second level of intrinsic incentives is that the volunteers benefit from comprehensive and continuous training and can so expand their functional skills.

The \textit{pecuniary incentives} come in the form monetary or tangible rewards. Volunteers in both facilities earned financial incentives. In the Mission Facility, the Healthcare Volunteers earn a monthly salary whereas in the Public Facility, the incentive takes the form of a transport refund per day worked provided by the Makerere University Walter Reed Project (MURP) contributing Ushs 2500 (US$ 1.6); the Joint Clinic Research Centre (JCRC) contributing Ushs 2400 (US$ 1.5); and Alliance contributing Ushs 100,000 or US$ 62 per month. However small such a financial incentive was, it helped to offset some of the financial obligations of volunteering, especially the travel costs. Unfortunately, by 2011 such financial incentives had been terminated in the Public Facility.

The \textit{social incentives} stem from a particular social system, and are mainly in the form of recognition, approval, and favours from valued others or peers. The social incentives can take the form of playing the role of a model patient when dying and then being saved by the mighty antiretroviral therapy; having associational ties with professionals; participation in planning meetings, and recognition by fellow patients. The role modelling also reduces stigma. In the rural setting, these volunteers were addressed as \textit{Musawo} (doctor), even though the volunteers themselves downplayed this as a flattery.

Challenges to Healthcare Volunteer Services
Overall, the figures in Table 7.2 (3\textsuperscript{rd} and 4\textsuperscript{th} row) shows a drastic increase in the number of patients in 2011 and a slight decrease in the number of health workers.

\textsuperscript{47} Adapted from Track 15: International HRM Turning Knowledge into Action: The Role of Incentives in Organisational Capabilities (p. 15).
An increase in the number of HIV patients enrolling for ART services was attributed to an absolute increase in the number of patients needing HIV/AIDS, as well as the quality of care attracting more HIV patients from neighbouring facilities offering the same services.

That the number of patients enrolling into the antiretroviral programme was likely to rise dramatically is reflected in the large number of patients currently taking Cotrimoxazole Prophylaxis, with 1657 and 900 in the Mission Facility and Public Facility in February 2011 respectively. This expected increase in ART enrolment comes at a time when the number of health workers is decreasing (cf. Table 7.2). A slight increase in staff attrition rates was attributed to the effect of leaving for further studies (both sites), self-imposed retirement, forced dismissal due to inefficiency and/or malpractices (Mission Facility), and withdrawal of financial incentives for volunteers (Public Facility).

7.4.4 Healthcare Services

The last form of social support available to ART patients is the healthcare services. As already indicated in Chapter 4, owing to differences in financial resources, the Public Facility implemented a minimal healthcare package (medical and counselling), while the Mission Facility implemented a holistic package (medical, counselling, socio-economic support and community network of care). Table 4.3 is reproduced here as Table 7.3 to show the proportion of patients who ever benefited from social support.

Table 7.3: Proportion of Respondents who benefited from Assistance at Any Time

<table>
<thead>
<tr>
<th>Type of Assistance</th>
<th>Site</th>
<th>Urban Mission Facility</th>
<th>Rural Public Facility</th>
<th>Total</th>
<th>Chi-Square value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Food</td>
<td>91% (128)</td>
<td>7% (9)</td>
<td>53% (137)</td>
<td>P=.000</td>
<td></td>
</tr>
<tr>
<td>Micro-Credit</td>
<td>40% (56)</td>
<td>0.0% (0)</td>
<td>23% (56)</td>
<td>P=.000</td>
<td></td>
</tr>
<tr>
<td>OVC Support</td>
<td>13% (18)</td>
<td>0.9% (1)</td>
<td>7% (19)</td>
<td>P=.000</td>
<td></td>
</tr>
<tr>
<td>Income Generation</td>
<td>1% (2)</td>
<td>0.8% (1)</td>
<td>12% (3)</td>
<td>P=.664</td>
<td></td>
</tr>
</tbody>
</table>

N.B.: Each item was analysed separately but is presented here in the same table.

In the Mission facility, 91% (128) benefited from food (WFP assistance), 40% (56) from micro-credit, 13% (18) from orphan support, and 1% (2) from income generating activities. Hardly any patient had previously benefited from such socio-

48 The districts served by Kayunga Hospital include; Kayunga itself, Mukono, Jinja, Wakiso, Kampala, Luwero, and Kamuli.
The Role of Social Support in Sustaining Adherence to Antiretroviral Medication

While the amount of support was inadequate, temporary, and the micro-credit not necessarily invested in productive ventures (as indicated in Chapter 4), it was instrumental in sailing urban patients through the extremely demanding treatment initiation phase. Nevertheless, the most important form of assistance has been the psychosocial support accorded to patients by the health staff.:

The Health Workers are our best friends. They give us treatment, handle us with dignity, give us advice, and comfort. They are not rude. There is no black spot in our relationship with them. Counselling was good, we learnt about nutrition, hygiene, dosing hour, mosquito nets, and avoiding fear and worries” (Patient FGD, Kayunga Public Hospital).

7.5 Organisational Context

Success in implementation of participatory approaches in formal health facility settings has depended on the transformation in organisational process. In terms of interpersonal relationships, the expression of power and authority by the top management and by the technical staff is mild. Since a too overt expression of power and authority can stifle volunteering spirit the administrators in both facilities tread a delicate balance between the bureaucratic and collegial type of power and authority. At a Christmas Party at the Mission Facility in 2007, I noticed the absence of a high table for VIPs. No Guest of Honour was present, and there were no (long) speeches, and no separate dining table for the senior staff. The Executive Director was pulled over to the dance floor by the patients and the dominant pronoun was ‘we or us’. The same spirit of collegiality was echoed in the Public Facility, as a volunteer patient noted: “Whenever there is an event like a party we sit together with the doctors.”

The technical staff does not consider the volunteers as a threat but rather as partners in saving lives, which explains why the patient CBO was able to convene its meetings in the hospital premises. Embedded in all this is teamwork and despite the existence of a recognition system in the Mission Facility, CATTS seldom benefit from recognition award because, according to the senior staff, implementation of home based care services requires a group rather than an individual effort.

7.6 Conclusion

The purpose of this Chapter has been to demonstrate that beyond the biomedical interventions, there are social processes that support adherence to ART in the form of social support. The second argument has been that the expanded analysis of such
social support should be approached by assessing 1) the pre-conditions for seeking and giving social support; 2) the providers of social support (those agreeing to volunteer support); 3) the resources exchanging hands; and 4) the potential benefits accrued from social support.

The preconditions for seeking and providing social support are mainly the HIV/AIDS conditions and the associated demands along the health-seeking continuum of falling sick, treatment initiation phase, and treatment maintenance phase. Each phase is associated with different needs. The pioneer patients who endured long, multiple and severe HIV/AIDS related complications, needed substantial amounts of socio-emotional aid and instrumental support during the earlier phase of ‘falling sick’ and ‘treatment initiation phase’. With the stability of health conditions during the treatment maintenance phase, patients’ need shifted to financial and food aid required for accessing and adhering to antiretroviral therapy.

In terms of providers of social support, HIV patients survive on diversified sources of support ranging from kinship (family members and relatives), to associational ties (peer patient support, healthcare volunteers and associations), and institutional support (healthcare services). Because of the physical and social proximity, the family-based support system serves as the most durable sources of social support to the HIV-patient, proving both emotional and instrumental support. At the facility level, the associational support system is in the form of peer patient support, healthcare volunteers and associations. Unlike other forms of social support, the institutional-based social support is not exclusionary but inclusive producing society-wide benefits operating at the facility and community level. As a result, adherence to ART is sustained by multiple sources of social support at various levels.

In terms of the availability of social support measured in as amount, frequency, and timing, social support tends to be inadequate. Three major factors that determine the availability of social support are severity of illness, density of social networks, and poverty itself. Depending on the density of one’s kinship and associational ties, social support comes mainly during the critical period of falling ill and the early phase of treatment initiation, to diminish during the treatment maintenance phase. The family care-givers occasionally step in when patient fail to raise transport money for pharmacy refill, or when patients relentlessly ask for ‘luxurious’ meals.

Even at the health facility, the most important form of institutional-based social support that drives adherence is the medical and psychosocial support, as well as emotional support from fellow patients. However, it is only the philanthropic based
Mission Facility running a large externally funded budget that manages socio-economic aid. Still, only a small proportion benefited from the socio-economic aid, with food aid being subsequently terminated after this study was completed. The peer-patients provide mainly emotional support (sense of belonging), information, and practical support (directing new patients and serving porridge/snacks).

The level of prevailing poverty affects the availability of social support. Hence, commonest form of social support is not financial assistance but socio-emotional aid. Financial assistance comes third after advice and emotional support. Ultimately, in normal times, patients meet their own financial obligations and only resort to external financial support during hard times. The poverty argument might explain the *generalised reciprocity*,\(^49\) whereby social support providers do not expect the patient to pay back quickly and automatically.

Whatever form, amount, and timing of social support improves adherence to ART. This is because social capital is all about social organizing. Sociological and organisational behaviour show group formation and cohesiveness being associated with social control and social facilitation. According to Huczynski *et al.* (1991: 211), “groups invariably establish rules of conduct in order to maintain consistency of behaviour among members.” Once such role expectancy is established, patients fear being evaluated negatively by others. Moreover, adherence to ART is associated with a stream of benefits. Improved health conditions attributable to antiretroviral therapy enables patients to fend for themselves. After all, patients’ appraisal of social support received is positive, regardless of this being irregular or small.

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\(^{49}\) Reciprocity is “cognitive” element of social capital, refers to the provision of resources by an individual or group to another individual or group, and the repayment of resources of equivalent value by these recipients to the original provider (Baum and Ziersch 2003). H is weak.