Master of Public Health

Master international de Santé Publique

Strengthening livelihoods of People Living with HIV/AIDS

A qualitative study of beneficiaries of a French Red Cross food aid program in Nouakchott, Mauritania

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Acronyms

ART: Anti-Retroviral Therapy

BMI: Body Mass Index

FRC: French Red Cross

IGA: Income Generating Activities

MAP: Multi-country Aids Programme

MRC: Mauritanian Red Crescent

OPC: Out Patient Center

PLWHA: People Living With HIV/AIDS

PTMCT: Prevention Transmission of Mother to Child Treatment

SCAC: Service de Coopération et d’Action Culturelle de l’Ambassade de France

SENLS: Secrétériat Exécutif National de Lutte contre le VIH/SIDA

UNDP: United Nations Development Programme

WFP: World Food Program

Abstract

Context: The French Red Cross (FRC) has implemented a nutritional support program in Nouakchott, Mauritania, providing a monthly supply of basic foodstuffs to improve the nutritional status of People Living with HIV/AIDS (PLWHA) and their adherence to the treatment, while lessening the burden of food expenses. After carrying out this program for six years, the FRC sought to understand its beneficiaries better so as to respond more effectively to their needs and challenges and to develop additional aid programs that would be more sustainable and would encourage autonomy from Non-Governmental Organizations (NGOs) support. This qualitative study sought to identify how PLWHA expressed their needs and the challenges they faced in securing their livelihoods.

Method: A qualitative study was conducted from February to June 2012 in Nouakchott, Nouadhibou and Kaédi. Using focus group discussions, semi-structured interviews and observations, we collected data from ninety-eight informants (PLWHA recipients of the project, medical and paramedical staff and members of NGOs working with PLWHA)

Results: Recipients of the FRC nutritional support program revealed that the adverse effects of HIV on their livelihoods began with their diagnostic itineraries and continued with the burden of healthcare needs and stigmatization, which resulted in their social exclusion, or heightened its risks.

Conclusion: The various impacts that HIV has on the livelihoods of PLWHA, reported by our respondents, must be considered when devising sustainable aid programs. The extended diagnosis itineraries of HIV/AIDS could be reduced through education and the strengthening of the Mauritanian health care system. Aid programs should create and support income production activities in order to reduce the burden of healthcare needs placed on PLWHA livelihoods. Lastly, the empowerment of local NGOs and associations in the fight for advocacy and education over HIV/AIDS issues would tackle the stigmas associated with the disease and thus reducing the risk and fear of social exclusion.

Keywords: Food aids support, HIV/AIDS, social support, stigmatization, Mauritania, health care.

Résumé

Renforcer les moyens d'existences des Personnes vivants avec le VIH/SIDA

Une étude qualitative des bénéficiaires d'un projet d'assistance alimentaire de la Croix-Rouge française à Nouakchott, Mauritanie

Contexte : Depuis six ans, la Croix-Rouge française (CRF) gère un projet d'appui nutritionnel et d'aide alimentaire à Nouakchott, Mauritanie, qui consiste en la distribution d'une ration alimentaire mensuelle aux Personnes vivants avec le VIH/SIDA (PvVIH). Ce projet cherche à améliorer le statut nutritionnel des bénéficiaires et leur observation au traitement, tout en diminuant la charge des dépenses alimentaires qui s'imposent à eux. A ce jour, la CRF désire encourager l'autonomie des PvVIH envers les organisations non gouvernementales (ONG) en développant des projets d'assistances à caractère durable. Cette étude consiste à identifier les besoins et les défis exprimés et affrontés par les PvVIH pour assurer leurs moyens d'existences.

Méthode : Une étude qualitative a été menée de février à juin 2012 à Nouakchott, Nouadhibou et Kaédi. Les données ont été collectées auprès de 98 participants (PvVIH bénéficiaires du projet, personnel médical et paramédical et membres d'ONG travaillant auprès des PvVIH) au travers de groupes de discussions, d'entretiens semi-structurés et d'observations.

Résultats : Les bénéficiaires du projet d'assistance alimentaire de la CRF ont révélé que leurs moyens d'existences étaient affectés par l'itinéraire vers le diagnostique du VIH/SIDA, suivi du poids des besoins de santé et de la stigmatisation, augmentant les risques d'exclusion sociale.

Conclusion : Les multiples impacts du VIH sur les moyens d'existences des PvVIH doivent être considérés lors de la conception et révision de projets d'assistances à caractère durable. Renforcer le système de santé mauritanien pourraient contribuer à l'amélioration de l'itinéraire vers le diagnostique du VIH/SIDA. Appuyer les PvVIH à créer et maintenir des activités génératrices de revenus pourrait réduire le poids des besoins de santé. Accompagner les ONG nationales et les associations de PvVIH dans la lutte pour le plaidoyer et la sensibilisation du VIH/SIDA favoriseraient la réduction de la stigmatisation associée au VIH/SIDA et la diminution du risque d'exclusion sociale.

Mots clés : Autonomisation, PvVIH, VIH/SIDA, Mauritanie, moyens d'existences, stigmatisation, lien social.

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Introduction

HIV infection provokes a person's immunological decline, permitting life-threatening opportunistic infections and cancers to thrive and provoking weight loss. But human immunodeficiency virus not only entails medical consequences; it has important socioeconomic consequences for people living with HIV/AIDS (PLWHA) and their families. Particularly in places where prevalence is low, where populations have relatively little experience with people living with HIV, the potential for social, economic, and political exclusion may escalate. In response to both nutritional needs and socioeconomic exclusion of PLWHA in Nouakchott, Mauritania, where HIV prevalence is 0.7%, the French Red Cross (FRC) has put into place a nutritional support program, which provides a monthly supply of basic foodstuffs to improve the nutritional status of patients and their adherence to antiretroviral (ARV) treatment and to decrease the burden of food expenses. After carrying out this program for six years, the FRC sought to understand better its beneficiaries, Mauritanians living with HIV, so as to respond more effectively to their needs and challenges and to develop additional aid programs that would be more sustainable and would encourage autonomy from NGO support.

In order to respond to this question, I worked with a team of nine people to investigate how HIV diagnosis and living with this chronic illness has affected the livelihoods of recipients of this nutritional support program, how they meet their own daily and long-term needs, and how the FRC can adjust or reorient its interventions to meet the expressed needs of this population. Based on evidence collected through interviews, group discussions, and observations, recipients of the FRC nutritional support revealed that the adverse effects that HIV had on their livelihoods began with their diagnostic itineraries and continued with the burden of healthcare needs and the risks of social exclusion which, resulted from stigmatization of those afflicted with this chronic illness. Therefore, any sustainable HIV intervention that seeks to encourage autonomy must consider these concerns expressed by PLWHA themselves.

This thesis will first address the published literature concerning the wide-ranging effects that HIV has on the livelihoods of people and their families. It will evaluate program recipients' interpretations of how diagnosis itineraries affected their livelihoods. It will then assess the program recipients' appraisals of their own healthcare needs and of the health care system's capacity to respond to them. Finally, the thesis examines how recipients describe the risks of social exclusion and its effects on their livelihoods.

The research was conducted in Nouakchott, Nouadhibou and Kaédi, where we collected evidence through focus group discussions, semi-structured interviews and observations. Based on the analysis of information collected from ninety-eight informants, we developed recommendations for a more effective use of FRC resources for program recipients.

Research question

How has HIV diagnosis and living with this chronic illness affected the livelihoods of People Living with HIV/AIDS recipients of the French Red Cross nutritional support program, how do they meet their own daily and long-term needs, and how can the FRC adjust or reorient its interventions to meet the expressed needs of this population?

Objectives

1. To evaluate program recipients' interpretations of how diagnosis itineraries affected their livelihoods.
2. To assess the program recipients' appraisals of their own healthcare needs and of the health care system's capacity to respond to them.
3. To examine how recipients describe the risks of social exclusion and its effects on their livelihoods.
4. To draw sustainable HIV intervention that seeks to encourage PLWHA autonomy from NGOs aid considering their expressed concerns.

Background

Mauritania is one of the poorest countries in the world, ranking 159 out of 187 countries for the Human Development Index elaborated by the UNDP. The population is mainly young; 50% of the population is under 18 years old, while only 4% is older than 60. Life expectancy at birth for men is 57 years old and 60 years old for women. The birth rate is 4.36 children per woman. The HIV prevalence is 0.7% for the general population and of 7.64% for populations with high-risk behaviors (including sex work and Men having Sex with Men).

Mauritania's ability to provide support to PLWH has fluctuated considerably over the past six years. In 2006, it received fifteen million US dollars from the Global Fund to fight AIDS, Tuberculosis and Malaria. The first installment, managed by the Secrétariat Exécutif National de Lutte contre le VIH/SIDA (SENLS), suffered from significant management problems, which led in September 2009 to the suspension of the grant's second phase, along with interruption of World Bank sponsored "Multi-country Aids Programme" (MAP) funding. Suddenly, Mauritania found itself without any international financing for the fight against HIV, and thus its capacity to respond to the needs of PLWHA was greatly reduced. The Global Fund sustained the antiretroviral therapy supply throughout the suspension as a commitment to PLWHA survival. In July 2011, after a three-year interruption, the Global Fund reversed its earlier decision and recommenced financing a reduced package of activities.

The French Red Cross actively sought to respond to PLWHA needs, even prior to these global health-financing schemes for HIV care. In 2004, the FRC opened an outpatient center dedicated to care for people living with HIV/AIDS. As of now, it is the only center in Mauritania where PLWHA can find the complete range of care that they require. Within the outpatient clinic, patients can be tested for HIV, receive biological exams and antiretroviral therapy (ART), be treated for opportunistic infections and receive psychosocial support. Three other health units in the country offer ART supply and treatments for opportunistic infections as well as medical consultations. They are not, however, equipped to perform biological exams or provide psychosocial support. Therefore, every patient has to travel every six months to the Nouakchott clinic, regardless of his/her geographical location, in order to receive the full biological exams.

The Nouakchott outpatient center is attached to the Ministry of Health and is supported by the FRC for technical and administrative management, as well as for the management of the ART supply for the entire country. In addition, the FRC has implemented a food assistance program for PLWHA under the care of the Nouakchott clinic. This food assistance program, which aims to improve the nutritional status and adherence to treatment of PLWHA, began in 2006 with funding from the World Food Program (WFP) and since June 2011, has received funding from the Service de Coopération et d’Action Culturelle de l’Ambassade de France (SCAC). This latter grant of 600,000€ allowed 1,415 people to enroll and to receive a monthly package of nutritional support from June 2011 through May 2012.

The FRC designed two different food packages for recipients. The first nutritional package targeted individual PLWHA who presented a Body Mass Index (BMI) of 18.5 and under, and/or who suffered from one or several opportunistic infections. Patient enrollment in the program took place once a physician in the Nouakchott outpatient clinic provides a written medical prescription. The ration constituted of twenty kilos of rice, five kilos of black-eyed peas, 1.8 liters of oil, one kilo of sugar and 350 grams of salt. Between June 2011 and May 2012, the FRC distributed 2,612 of these rations.

The second food package was a family ration, distributed to those facing financial difficulties. Enrollment for these recipients took place through a written prescription by social worker at the Nouakchott outpatient clinic. The ration consisted of 25 kilos of rice, five kilos of black-eyed peas and three liter of oil. Some 11,844 family rations were distributed between June 2011 and May 2012. Some PLWHA enrolled in the FRC program received both types of food rations.

The FRC food supplement program is clearly designed to respond to the needs of Mauritanians living with HIV. But responding more effectively to their expressed needs also requires insight into the wide-ranging consequences that this chronic disease, its diagnosis and treatment has had on their social relations and their capacities to earn their livelihoods over time. Social scientists studying Mauritanian society have characterized both stratified social relations, as well as practices of assisting impoverished and vulnerable community members. But in order to explain why Mauritanians living with HIV cannot avail themselves to these mechanisms of community support, I draw from social scientists' insights into stigmatization and social exclusion.

The Haalpulaar'en organization:

- The high-caste is the « Rimve » = nobles
- The middle-caste is the « Nyeenyve » = artisans
- The low-caste is the « Maacuve » = Slaves.

The 2 first castes are divided by several groups.

(Equipe de recherches sur les Mutilations Génitales Féminines, 2011)

Table 1 - The Haalpulaar'en organization

Mauritania's multiethnic population includes Maure, Haalpulaar'en, Wolof and Soninké peoples. Each of these groups of ethnic affiliation is highly socially stratified, into castes, but also engages in particular practices to assist community members.

Many of Mauritania's major ethnic groups organize their populations into hereditary castes (see Table 1 entitled "The Haalpulaar'en organization"). Certain hereditary castes, such as the Maacuve, tend to be impoverished and have low social status (Ballet & Hamzetta, Formes sociales de la pauvreté en Mauritanie, 2006). According to the sociologist Salem Ould Mohamed El Moctar (2006), in Mauritania, social status can shape the extent of one's social relations and thus the material, financial, and/or emotional support that a particular person might be able to draw on to counter losses of livelihood. People belonging to the higher caste (nobles) have extended social relations and therefore higher opportunities to benefit from assistance. ((El Moctar, 2006);(Obrist & Wyss, Lier la recherche en mileu urbain avec l'approche "livelihood": défis et perspectives, 2006))

At the same time, Mauritanian populations engage in several social and religious practices that assist family and community members experiencing financial or other difficulties. The *"lawha"*, for instance, is a community mechanism through which all community members contribute money to resolve a problem that one member faces. (Ould Taleb, et al., 2006). Group chiefs or traditional healers may initiate contributions and fix contribution amounts. They may set contribution amounts independent of the economic status of the poorest community members. Consequently, while certain individuals clearly benefit from these contributions, others may find themselves financially strapped; they must make these donations, no matter how large, in order to maintain their honor and ties to the community. Also, because the decision of who is to benefit is made community elites, the chief and the traditional healer, it has been observed that the wealthier and higher ranking members of the community are most likely to benefit from this practice (Ballet & Hamzetta, Le capital social comme protection sociale? Le cas de la Mauritanie, 2003).

Mauritanian social groups also draw from Islamic principles and practices of charity to support impoverished people. According to Bilal Ould Hamzetta, in his study about begging in Nouakchott, there exist different forms of charity in Mauritania. At the end of Ramadan, every wealthy Muslim should donate *zakat*, a fixed percentage of his or her financial or natural assets (livestock or cereals), and the proceeds go to non-wealthy Muslims. In addition, the *koubs* or *waqf* and *mniha* are other forms of charity that make the use (though not the ownership) of certain assets, including palm trees, houses, or livestock available to destitute individuals, so long as they preserve and ensure the continuity of these assets. These forms of charity help to alleviate economic destitution of particularly vulnerable people, such as orphans and widows (Hamzetta, 2006).

Why does it appear that Mauritanians living with HIV/AIDS do not have reliable access to these mechanisms of social support? I have found that the sociological literature on stigma or social exclusion is helpful in understanding how our informants explained their loss of livelihood and at times, their inability to rely on this support. Sociologist Erving Goffman (1963) described stigma as ''the situation of the individual who is disqualified from full social acceptance." As Goffman and subsequent analysts have described it, "stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group" (Weiss, Ramakrishna, & Somma, 2006). Stigma, or what some call social exclusion, is a critical consideration for the FRC's social and health policy; stigma exacerbates the physical, psychological and social burden of chronic illness. It can profoundly affect a person living with HIV. It can, for example, delay appropriate help-seeking, force a patient to terminate much-needed medical treatment, disrupt antiretroviral therapy, increase HIV symptoms, or provoke the onset of depression (Sayles, Ryan, Silver, Sarkisian, & Cunninghma, 2007).

Below, we show that recipients of the FRC program reported that social exclusion can come from inside familial networks, denying individuals of existing forms of support. By the same token, our research also reveals that kinship networks can constitute an important source of emotional and material support.

Methods

This qualitative study, carried out between February and June 2012 in Nouakchott, Kaédi and Nouadhibou in Mauritania (see map below), was conducted by a team of nine people, including a study manager, six interviewers and two transcribers. Funding was provided by the Service de Coopération et d'Action Culturelle de l'Ambassade de France (SCAC).

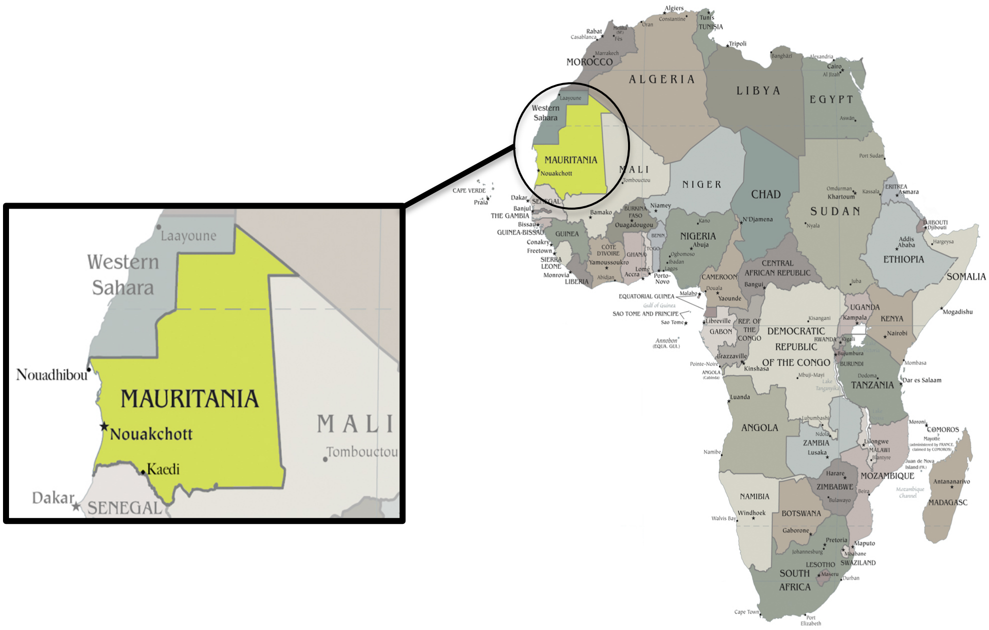

Figure 1 - Map of Africa and Mauritania

We adopted a qualitative approach in order to develop a better understanding of the study population's past experiences, as well as their daily lives and challenges. We used focus group discussions, semi-structured interviews, and observation to collect data. We performed seven focus groups with six to eight PLWHA, forty semi-structured interviews with PLWHA beneficiaries of the project (30 in Nouakchott, five in Kaédi and five in Nouadhibou), four PLWHA habitat observations, 14 semi-structured interviews with medical and paramedical staff working with PLWHA, eight semi-structured interviews with Non Governmental Organizations (NGOs) working with PLWHA.

The study population represents all the PLWHA beneficiaries of the project. Ninety-eight participants were enrolled in the study, including 76 PLWHA beneficiaries of the project, 14 medical and paramedical staff working with PLWHA and eight NGO leaders working on HIV/AIDS in Mauritania. We interviewed 40 PLWHA using semi-structured questions, and 36 people participated in focus group discussions.

Based on house visits to 1 125 beneficiaries (out of 1 421 enrolled in the project) on the 1st of March 2012, 78% (881/1125) of this population is based in Nouakchott, 5% (54/1125) in the Gorgol region (region of Kaédi) and 4% (46/1125) in Nouadhibou. The rest is spread over the country. Living conditions are different in these three regions. Nouakchott is the administrative capital, whereas the Gorgol region is a rural region on the Senegalese border, and Nouadhibou is an economic capital, centered on a fish exporting industry and the presence of foreign companies. We sought to account for variations in beneficiaries' experiences in these different locations. Study participants were selected on a weekly basis for the following week. All the study participants received reimbursement for their transportation expenses. Written Informed consent was obtained from all participants prior to the interview.

Four staff members in charge of health and hygiene education sessions were selected to conduct interviews, focus group discussions, and home visits among PLWHA. They attended a two-day training in order to learn to use the interview and focus group guides. All of these interviewers are HIV infected; they are well accepted among the beneficiaries, who know their HIV status and appreciate the guidance that they provide. These research assistants spoke the languages spoken by the beneficiaries. The study manager, the head of the nutrition program and the FRC health coordinator conducted the interviews with medical, paramedical and NGO's staff.

The research team elaborated semi-structured guides for different study participants (see Annex). For recipients of the nutritional support package, we included questions concerning: demographic and household characteristics, the diagnostic and treatment process that informants pursued, and the livelihood consequences of HIV diagnosis and chronic illness perceived by informants. Focus group discussions were organized around a guide that collected information concerning availability and access of health care, HIV acceptance and stigmatization, income and social support. Semi-structured interviews with medical and paramedical staff and NGO representatives aimed to collect information on their perceptions of the availability of care and patient access to health care, social support for program recipients, as well as recipients' income and stigmatization that they faced.

We conducted interviews and focus group discussions in the languages Hassanya, Pulaar, Wolof, Soninké and French and recorded all of them. Two assistants transcribed and translated all interviews into French, and subsequently we checked these transcriptions for quality control.

Results

The table below presents the characteristics of the 40 informants living with HIV beneficiaries from the food support program.

Table 2 - Characteristics of 40 PLWHA participating to interviews

Characteristics (N = 40*)	n	%	Median	Range
Age (years)			43	[28,63]
20- 35	10	25		
36- 50	24	60		
51 - 65	6	15		
Sex				
Females	22	55		
Males	18	45		
Ehnic group				
Haalpulaar'en	23	57.5		
Maure	8	20		
Soninké	4	10		
Wolof	4	10		
Bambarin	1	2.5		
Polygamous				
Monogamy	25	62.5		
Polygamy	15	37.5		
Education				
Primary	14	35		
Secondary	13	32.5		
Professional	3	7.5		
Literacy				
Literate	19	47.5		
Illiterate	21	52.5		
Income generating activities				
Activities	34	85		
Formal sector**	3	7.5		
Informal***	31	77.5		
No activities	6	15		

* n = number of PLWHA interviewed in one to one interviews

** Formal sector: employed in a company, teacher, military

** Informal sector : retail selling, field work, services (hairdressing, cook, cleaning), construction work, clothes dying, mechanic, Calligraphe, wood worker, painter.

Diagnosis itineraries

At the time we interviewed PLWHA beneficiaries of the nutritional project, a certain number indicated that the diagnostic and treatment process was complex, that it involved shuttling between healers and biomedical centers, and that it entailed considerable costs.

Many, though not all symptoms (diarrhea, skin rashes) associated with HIV are common to other diseases. Ten of our informants indicated that they consulted traditional healers to diagnose and to treat their early symptoms, and sometimes to address what are perceived as problems within the patient's broader social relations (Ould Taleb, et al., 2006). Seven began their diagnosis itineraries with traditional healers; one reported visiting traditional healers after being diagnosed with HIV, and two reported consulting them at the same time that they were visiting biomedical centers.

One of our informants, Moussa, followed this last itinerary. He is 42 forty-two years old, is married with 2 children and lives in Nouakchott. He is literate and holds a professional degree as an electrician. He is the head of a twelve-person household and is the sole breadwinner for the family. His wife was first to present HIV/AIDS signs. Moussa and his wife tried to treat her symptoms for about a year and a half. He recounted, "*We sought for care everywhere, there is no health center where we didn't go to. We spent all of our money".* They first sought care from traditional healers and continued to see them while visiting different health centers that failed to properly diagnose her. Their search to treat Moussa's wife symptoms brought them to Mali and Senegal to seek the most well known traditional healers. Moussa observed,

> *You know in Africa, we have traditions and whenever we are sick, we have to see traditional healers, so a lot of people here don't go to modern medicine in the first place. The problem is that traditional healers don't exist anymore; they say they can treat you, but they only want to eat your money and let you go. You go to see them and they say "you have this or this disease, you bring that amount of money and I will treat you". So for a person who wants to be healed, he/she would sacrifice to find money. So you bring the money, he gives you something and then…nothing happens… in the meantime it looks like your health is getting worse. So you go from one traditional healer to another one, from clinics to hospitals, you spend everything you had. It is so expensive, especially for a head of a household who has numerous persons to feed and not enough revenue. You are sick and you need care but people exploit you and you loose everything you had to be able to live. This is what exhausts a lot of people. I had to give up on everything to find care for my wife. If you would have seen her before, you would have not recognized her, she was like a dead*

> *person, lying down for an entire year. I supported her and I was feeling ok at this time but they diagnosed me as HIV positive. I finally said, "Yes I will take the medicines".*

Moussa and his wife finally received their diagnoses at the national hospital a year and a half after they started seeking care. In the meantime, they sold two parcels of land and some of their livestock. His wife who had been a hairdresser sold all of her hair dressing tools and closed her salon. "*If we had known that the outpatient center existed,"* Moussa lamented, *"we would not have lost all of that. Traditional healers ate all our money".*

This testimony illustrates the lengthy time and high expenses reported by some of our informants. Not only did our informants acknowledge that they depleted their financial assets, but they also reported that their health worsened. According to medical doctors at the Nouakchott outpatient center who participated in the study, it is harder to improve the health status of a person who is at an advanced stage of the disease. The earlier a person is diagnosed, the better effect ART can have on the infection, which improves the recovery of health and implies less adverse effects of the virus.

Thirty other informants reported visiting biomedical centers after experiencing HIV related symptoms. Coura, forty-eight years old, does not know how to read and write, and previously worked as a shepherdess. She has lived in Nouakchott for about 18 years. Like Moussa, her diagnostic itinerary was lengthy. She started to feel tired while she was working as a fish seller at the market. She went to the national hospital in Nouakchott; they performed a blood test, but did not find that she was infected with HIV and gave her medicine to treat her symptoms. This medication did not alleviate her symptoms, so she decided to seek treatment in Senegal. She sold her jewelry to pay for her travel, care and food expenses. This second round of blood tests led to a diagnosis of *Dokhoum Sitti* (skin rash). Once more, she received treatment, and yet again experienced no improvement in her condition. Finally, she returned to the Nouakchott national hospital where blood tests finally revealed that she was infected with HIV. She explained that she felt relief at this diagnosis, particularly because she had exhausted her wealth to pay for her medical care.

Six other informants recounted having similar experiences to Coura; they had visited several health centers, sometimes traveling across borders to Morocco, Senegal, Lybia and Tunisia, before receiving a diagnosis of HIV infection. One woman, Djeinaba, maintained that she spent over 250,000MRO (689€) on health care before being diagnosed with HIV. She first received care in Morocco for a month and spent twenty days at the hospital in Nouakchott. Medical doctors participating in the study and working at the Nouakchott outpatient center reported that HIV test is not systematic in the Mauritanian health care structures, and that the Mauritanian health care providers lack training to care for patients with HIV. These accounts show that the itineraries that people follow to receive a diagnosis can be lengthy and costly. Even when PLWHA visit biomedical centers, their efforts to obtain a diagnosis can exhaust their financial resources.

Eighteen participants in our study reported that they live off retail trading and clothes dyeing, but these activities require capital to purchase supplies. Eight of our informants indicated that their funds to invest in their work had been depleted during the diagnosis and treatment of their illness, or that they had to sell their work assets (boutiques, restaurants or hairdresser salon) like Moussa's wife. Djeinaba lost her job as a retail trader because she had spent her savings on seeking a diagnosis for her illness. Since then, she reported that she has not worked because she has no capital to invest in traded goods.

The diagnostic and treatment itineraries can represent unpredictable, but also very costly processes. According to both patients and health care workers, these processes can deplete material and financial assets and incur a decline or loss in income-producing activities.

Healthcare needs

At the same time that diagnostic processes have depleted their material and financial assets, our participants also reported that their expenses increased because of chronic illness exacerbated the burden of healthcare needs. They indicated that they had to shoulder several medical and associated expenses.

The availability of HIV health care is unequally distributed throughout Mauritania. Only four centers devoted to HIV care at the national level exist; these centers are located in Nouadhibou, Kiffa, Kaédi and Nouakchott. The Nouakchott outpatient center is the only center that offers both social and medical care and is the only site that can perform the required blood tests every six months. Consequently, all patients diagnosed with HIV must travel to Nouakchott at least twice each year, undertaking voyages that incur considerable transportation and housing costs. In Mauritania, medical care for PLWHA is free of charge, consisting of free medical consultations at the Nouakchott outpatient care and HIV care units in other regions of the country, antiretroviral treatment (ART), and medicines to treat opportunistic infections. But frequently, our informants reported, they face difficulties acquiring medicines for opportunistic infections because of lengthy supply shortages. In such cases, the recipients must pay for these medicines at private pharmacies at their own expense.

Our informants also suffered from secondary diseases, including heart disease and cancers, and thus required specialized care. Specialist care is not free of charge, and several of our informants indicated that their treatment was a significant economic burden. Mohamed is a sixty-three year old study participant who suffers from hypertension. When he worked in the military, he received health care insurance provided by the state and was followed by a cardiologist, who provided him with treatment for treating his hypertension. Now retired, Mohammed no longer has this health care insurance. Therefore, he explained that he cannot face the cost of cardiologist consultations and is not able to buy the medicines either. He added that he was really careful to monitor his diet to do what he could to manage his hypertension. Sokhna, is a 34 year old teacher, and two of her children are HIV positive. She explained that she sometimes needs to consult a specialist, but cannot afford to do so because in addition to rent and food expenses, she must buy medicine for her children.

Some study participants indicated that they cannot afford these costs and seek diverse solutions to meet the expenses. Moussa reported that he and his wife sometimes did not eat because they just had bought their medicines for opportunistic infections (because the country was suffering from a supply shortage). Another informant, Samba, explained that she asked the president of a PLWHA Association to buy medicines for her, and in exchange, she gave him the food package she received from the FRC. Others maintained that they did not purchase the prescribed medicines. As one woman, Binta, a widow who sells peanuts and some dyed clothing explained, *"Me, when I don't have money, I tear up the prescription and I throw it away. If you don't have enough to eat, you will not have enough to pay for your medicine"*

In addition to the medical and specialized care costs, participants must pay for transportation to health care centers. Every six months, PLWHA must visit the Nouakchott outpatient center for blood tests, which are only available in the capital city. Some study participants indicated that they can save enough money to travel to Nouakchott, but others delayed or missed their appointments because they could travel only after saving sufficient funds to make the trip. A round trip ticket to Nouakchott can cost up to 20,000 MRO (55€) for a person who lives in a remote area of Mauritania.

Alioune and his wife are HIV infected. They live in Sélibabi, close to the Senegalese border. He reported that *"Sometimes, we need to go to the Nouakchott outpatient center but we cannot because we don't have enough money to pay for the transportations. Transportations* *from Sélibabi to Nouakchott cost 10,000 MRO (25€) for one person one way. It is a huge challenge for us and we don't want to interrupt our treatment".*

Some program recipients lived with family members who were also suffering from HIV. Out of 40 study participants, 24 had at least one other family member (spouse or children) diagnosed with HIV-related illness. They indicated that the health expenses that they faced were exceedingly heavy. Their care expenses are higher, and their capacity to earn income through labor is considerably reduced. For these households, their capacities to earn their livelihoods and to withstand particular unexpected crises have been dramatically reduced. One of our informants, Fatou, explained that she has three children who are all HIV positive. Her husband divorced her when she told him she was HIV positive. He has never been tested himself. When he divorced her, she struggled to meet all of the needs of her children. She has since remarried and her living conditions have improved. Her current husband, however, does not know that she and her children are HIV positive. Therefore, she does not ask him to assist her with health expenses. She explains that she struggles greatly to pay for these health care expenses. One of her first challenges involves finding money for travel to and from the health center. *"I come from Sinthiane tallal in the Maghama region,"* Fatou said. *"It is far from the Nouakchott outpatient center. For reaching care, I need to pay for transportation for my children and myself, which is complicated for me. Sometimes, I can't come because I don't have enough money to pay for the tickets".* Because of these travel expenses, then, she cannot always get the care that she needs. *"Sometimes, I'm sick but I don't have any money. I lie down in my house, I can't seek for care, so I stay in this situation and wait for when I would be able to get care...Sometimes, I'm sick and my kids are too, so I treat them and I forget myself".*

Healthcare expenses are a considerable burden that can challenge the ability to meet daily/life expenses. An overwhelming majority of the study participants claimed to have serious difficulties affording the costs of rent, food, and transportation. Mothers who have been widowed or divorced are in a particularly difficult position, as they are responsible for providing for an entire household. Coumba, a 44-year-old woman and mother of eight children, is in a polygamous union; her husband lives far away with his other wife. He never comes to see her and does not help for the household expenses, so Coumba assumes sole responsibility for all of her children. One son is a fisherman and assists her with household and care expenses. Although Coumba wants a divorce, her husband refuses.

Coumba explained that sometimes she cannot seek the care that she needs because she cannot afford food for her children. She acknowledged, *"I prefer suffering from my health* *and instead satisfy my kids needs. I can't bear having an empty pot when my kids come back from school for lunch".*

Other informants recounted much the same. One man, Sidi, commented, *"The first thing that I think about in the morning is how much money I have in my pocket to know if I'm going to be able to eat today."* Another, Djiby, maintained, *"If I find money, I eat, if I don't, I don't eat… I don't work and I don't have anyone who gives me anything… this is the way I live, sometimes I fall, sometimes I get up. Sometimes at night, I'm hungry and I go to bed without eating".* Still another, a married 52-year-old man with two young children, explained that he and his family are frequently evicted from their houses because he is unable to pay the rent.

Study participants used different strategies to cope with the expenses of daily life. Some prioritized their expenses; certain informants purchased food first, while others pay their rents first. Some people sold their physical assets to pay for food, whereas others expanded their income-generating activities. Mariam is 45-year-old divorced woman with seven children. Only one of her children lives in her household; the others are married and live with their spouses. She explained that she is forced to sell her monthly food ration from the FRC in order to afford her rent and to keep a roof over her head. On the days she lacks food, she counts on neighbors to give her their leftovers. But this source of assistance is highly uncertain, and she reported that sometimes she does not eat and goes to bed with an empty stomach.

While a few of our participants, all male, refused to borrow money because they found the process humiliating, 35 out of 40 informants borrowed money in local boutiques or from their relatives. These loans range between a few ouguiyas to 50,000 (140€). Borrowers paid back their loans over time without interest; installments depended upon their income.

Some of the participants with school age children reported cutting back on educational expenses to cover health care costs. Four informants reported that they had to remove their children from school, and three explained that they transferred some or all of their children from private to free public schools. Penda is 35 years old; she is divorced and has five children, only one of whom is in her charge. Three live in Gambia with their father, while another is a Talibé[1] in Senegal. Penda explained that she cannot always keep him in school

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[1] Talibés are religious student, particularly students of Islam with a religious teacher. In Senegal, they are often living with a marabout religious teacher and beg for money on the street for giving to the marabout in exchange for their education. Some teachers take advantage of this education to exploit children, keep them against their will and unfeed them.

"Often he learns in school for 2 months and then he stops. If I find money again, he goes back to school".

Our interview and group discussion results concerning PLWHA expenses show that although HIV treatments are free of charge, our PLWHA acknowledged that they faced many daily life expenses as a result of their HIV status, and that these expenses were exceedingly difficult to meet. Participants indicated that familial support was an important source for assuring their daily expenses, but was not an option available to all participants due to stigma.

For most of our informants, the diagnosis of HIV infection was a shock, one that disrupted their capacities to pursue their livelihoods. Fourteen informants, equally men and women from different ethnic groups, described that they were profoundly discouraged after receiving this diagnosis, and that it discouraged them from imagining a future other than death for themselves. Sidi, a 38-year-old man, reported *"I was devastated for a while, like someone who is not a person anymore, who is waiting to die at anytime".* Another study participant, Amadou, experienced diagnosis similarly, but explained that he spent a year thinking he would surely die at the year's end. A 34-year-old teacher and the mother of two HIV infected children, Sokna, explained that when she discovered that her newborn was HIV infected, she realized the virus also infected her. She recalled, *"This day, I cried to the point that I wanted to hang myself"*. For some informants, this discouragement led to the loss of work. Thirty-five year old Samba, who owned a food store in Senegal at the time of his diagnosis, reported that he felt so discouraged that he stopped working his store, which subsequently went bankrupt. The emotional impact of a diagnosis was enough of a factor to cause the reduction or elimination of income generating activities for many study participants, greatly impacting livelihoods.

A psychologist working at the Nouakchott outpatient center explained that *"many PLWHA lose their jobs due to their health. Most PLWHA in Mauritania work or worked in the informal sector; they are butchers, fish sellers, cleaning ladies, cooks, retail traders, etc. This socio-economic group is more exposed to job insecurity and more vulnerable to psychological distress. The loss of work, the depletion of financial assets, the impossibility of meeting their and their families' needs can lead to depression. Psychosocial care is an essential need for this population."*

Living with this chronic illness, according to our informants, often limited what jobs they could take and how much they could work. Some participants decided to decrease their job activity in order to maintain their health; others could not continue their income generating activities because of poor physical health. As Mohamed recounted, *“Before, I used to work like a robot, but now when I force it, I get sick”.* Because our informants had to limit their work, they indicated that they ended up relying on family support and eventually depleted their material and financial assets.

Social relations

Social support can come from kin group members, religious communities, other corporate social groups, non-profit organizations and associations for PLWHA. Professor Abdoulaye Doro Sow, who teaches at the University of Social Sciences in Nouakchott, reported to us that people seek for support first from their close social relations. If they find no support there, they will seek it within their communities, and as a last resort, from NGOs and associations. Although stigma and fear of social exclusion can disrupt the mechanisms of social and kinship support networks, 32 out of 40 PLWHA informants have received material, financial or/and psychological support from close social relations, their broader communities, or an NGO or association. However, HIV/AIDS represents a major challenge for program recipients in the maintenance of their varied social relations, and yet these relations constitute an important source of support for PLWHA. We heard much discussion about the importance of material (and emotional) support between kin group members, religious communities, and other corporate social groups, but our informants also suggested that there was considerable disparity between rhetoric and actual practice. PLWHA reported that they suffered greatly from social exclusion.

Our informants (PLWHA, medical, paramedical and social workers interviewed in this study) explained that a person living with HIV/AIDS in Mauritania is often considered to be “*sexually deviant”*, in the same category as a prostitute or an adulterer. Some informants reported feeling ashamed of being HIV positive, that it was a shameful disease. Some did not understand why they were infected, as they did not commit adultery or work in the sex trade. As Haby, a 37 year old divorced woman with three children, explained, *“I learnt that the disease was transmitted through sexual relations, but me, I’ve never had any sexual relations outside of my marriage, so I believed I could not have this disease.”* Penda also was shocked she was HIV positive: *“Me, I thought only prostitutes could get AIDS and me, I did not play”.*

Medical doctors reported that they advised PLWHA to disclose their status to only one or two people they could trust. Some of our informants reported taking this advice, sharing their

HIV status with a limited number of people whom they trusted such as their spouses; others decided not to divulge their HIV status to protect their social relations. According to our informants, revealing one's status can easily destroy these links as kin, friends, and religious community members may refuse to offer social and economic support out of fear and condemnation of a PLWHA. Announcing serologic status to a spouse can represent a significant risk for the infected person, whose spouse could ask for a divorce. However, this risk is different for women than it is for men, according to our informants. In the Islamic Republic of Mauritania, both men and women can get divorced, but women must ask the permission of a *Cadi, a Muslim judge who adjudicates disputes over marriage, divorce, succession, and inheritance.* Men, however, can divorce at any time without seeking authorization. Both Mariam, 48 years old with four children, and Leila, 45 years old with eight children, were divorced by their husbands, who left them and their children when these women informed them that they were HIV positive. Neither woman has seen her husband after he left. Mariam, Leila and other women with whom we spoke indicated that they found themselves in especially precarious situations, because they did not work when they were married. When their husbands divorced them, these women had to struggle to find income generating work. It is this risk of divorce that compels some women to hide their HIV status from their spouses, as Fatou did (see page 18).

Another informant, Moussa, explained that he and his wife do not want to tell anyone about their status because *"everyone sees it differently. To avoid having the word spread to people who would think they have to run away from us, it's better to keep it to ourselves and to do everything for getting treatment. We live in a really really difficult society".* And the 60-year-old widow Sokhna explained, *"I've told only my sister because she works at the hospital and she can understand. I could tell my children, but they might prohibit to their kids from seeing me. This is what I avoid".*

Still another study participant, 32-year-old Harouna from Senegal, distanced himself from his social relations. He reported, *"I take my medicines, I eat well, I pray. Everything I can do in order for people to not notice that I'm sick, I'm doing it. When I pray, I thank God that nobody knows I'm sick".* Harouna suddenly abandoned his wife and his son and his family when his brother found his ART in his bag. The brother asked in the presence of Harouna's parents what the medicines were for. Harouna claimed that the medicines were not his. He left home the following day and has not returned for more than six years.

But disclosing one's HIV status can sometimes reinforce social relations, as in the case of Alassane, a 45 year old man who reported that his friends were still more supportive after he informed them of his HIV status: *"they became more than my friends, now they are brothers"*.

Study participants acknowledge that social exclusion or fears of social exclusion had important economic consequences. Some study participants indicated that they did not dare ask their kin for assistance because they feared too many questions about their conditions. Others hid their HIV seropositivity, instead claiming to kin and friends that they suffered from a less stigmatized chronic disease, such as diabetes or hypertension, in order to avoid their social exclusion. Some participants so feared rejection by their communities that they refused to visit the local HIV health care unit, preferring instead to travel (and thus to incur travel expenses) to attend consultations at the outpatient center in Nouakchott, where nobody would know them. Although acquiring the money to pay for transport was a considerable struggle for some informants, they preferred to pay this money rather than to risk losing the support of their broader social networks. Nine out of 10 informants living permanently outside of Nouakchott recounted that they travelled to Nouakchott to find treatment but to hide their chronic illness from kin, friends, and neighbors. One informant, Fatou, pays travel expenses for herself and her three children to seek treatment at the Nouakchott outpatient center, instead of the closer Kaédi health unit, because *"there are no secrets over there".*

This support manifests itself in different forms among study participants; we observed some receiving full support, extended support and occasional support. Six informants are fully supported by family members. Of these six, two are married men; four are women (two divorcées, one widow, and one married woman). All of these informants except one (see p.18) shared their status with at least all or some of the people who support them. Among the six informants who are fully supported by family members, we observed no distinction in support between ethnic groups.

Among the 32 informants receiving support from social networks, nine informants receive partial support for housing, food, and health expenses; they must maintain some form of income generating activities to make ends meet. Eight of these informants are women and one is a man, aged between twenty-three to fifty-seven years old.

Seventeen informants (seven women and ten men) received occasional support in the form of donations (including charity) or loans. Our respondents explained that they sought this occasional support, to cover health expenses or unexpected expenses.

Our results suggest that women appear to benefit more from full and extended support than men. In contrast, men appear more likely than women to seek out and receive occasional support.

The practice of providing support plays an important role in Mauritanian society. Among the many different forms of giving, the practices of charity prescribed by Islamic principles are one form of support that PLWHA can receive. Among our informants, seven reported having received this type of charity. Three received cash donations, two reported being the recipients of the *mniha (see page 6)*, through house and livestock lending, and two others reported having benefited from the *lawha* (see page 6) in their community.

Other forms of support come from NGOs and associations providing assistance to PLWHA in Mauritania. Since 2008, eighteen associations, all headed by PLWHA, provide occasional financial support to other PLWHA; each forms a single node within a national network to cover different regions of the country. However, the funding they receive is limited and comes exclusively from the SENLS (see page 7) so their activities are severely constrained. According to the study participants, associations also lack of management capacities, which could otherwise assist them in securing additional funding.

NGOs suffer similarly from a lack of adequate funding. Nevertheless, they seek to assist individual people living with HIV, by informally supplementing their incomes to pay for medicines, medical exams or housing rents. These NGOs were mainly created after the country received a fund from the World Bank (the “Multicountry Aids Programme” MAP) but since the fund was closed, few interventions could be implemented because of a lack of financing. A few programs are still in place, mainly targeted to orphans (funded by the UNICEF) or HIV screening. Out of 40 informants, ten reported receiving NGO support at least once in the past (including compensation for transport and assistance in covering medical costs). But all of these informants received this support only occasionally or just once. One informant, Salimata, a 57 year old woman, explained not going to any NGOs or association because *“this town is small, it is like a mirror. If you go, people would say you came to look for charity”.* Our informants working in NGOs and associations acknowledged that their assistance to PLWHA is miniscule compared to their needs.

As a consequence of stigmatization, PLWHA can lose or suffer from a lack of support from their social relations. Fifteen PLWHA informants claimed having been stigmatized for their illness, either by family members, friends, or acquaintances. Study participants admitted that the fear of social exclusion has isolated them and reduced their working opportunities. Sidi, a married, childless man, was working at the national electricity company when he received a letter transferring him to Néma, a remote town on the Malian border. He realized that he would be unable to find appropriate healthcare for HIV in Néma and refused the transfer, without providing any justification for it. He lost his job for not justifying his refusal. He explained, *“If I had done so, the reasons would have been shared with everyone. I preferred to not tell them and accept the discharge. They decided I refused to work with them and this is the way it ended”.* Stigmatization therefore can not only rupture ties between kinship and other social networks, but can also lead to the loss of employment due to fear of social exclusion.

Study participants also recounted that they received poor treatment from health care workers when they divulged their HIV status; they therefore refuse to inform health personnel of their HIV status outside of the HIV unit. One study participant recalled that he had to threaten a dentist in order to receive a dental examination.

Stigmatization also appears to be a daily social burden in the lives of PLWHA. One 52-year-old man, Amadou, recounted to us, “Some people in my community do not eat and drink with me. Even when I pray in groups (at the mosque), people next to me leave the row and I’m left alone”. He explained that he felt isolated; he cannot ask anyone for help for buying medicine or for transportation expenses. Another woman, Binta, recounted that she was driven out of her sister’s home by her nephew’s denigrating treatment. She could not to find another place to live, so she had to place her children in the care of friends.

Health care and social workers with whom we spoke indicated that stigmatization and social exclusion of PLWHA has decreased in recent years, but our evidence suggests that the weight of stigma continues to prevent PLWHA from benefiting from full social support and adds an additional burden to their daily lives.

Discussion and recommendations

This study has examined how people living with HIV and health care workers in Nouakchott, Nouadhibou, and Kaédi describe the burdens that patients must shoulder on a daily basis. Our qualitative investigation shows that the itineraries of diagnosis and treatment can represent an unpredictable and very costly process, one that can deplete material and financial assets and incur a decline or loss in income-producing activities. Study participants explained that chronic illness, too, affects their livelihoods over the long term. Some claim that they have had to reduce or cease their work efforts because they do not have sufficient capital or physical strength. As a consequence, program recipients indicate that they face significantly reduced income at the same time that their expenses (including medical expenses) are increasing. Thirty-five out of 40 informants borrowed money from local boutiques or from their relatives to cover food expenses. This underlines that at least according to our informants; the majority of them find that their primary needs are not met.

Equally important to program recipients are various social networks (kin, religious community) that could provide a significant source of financial and emotional support. But divulging HIV status, our informants maintained, can result in social exclusion and the loss of this support. In addition, stigmatization can rupture social relations, which represent an important livelihood asset for PLWHA.

In supporting PLWHA to be more autonomous from NGO support, it is important to reduce the varied impact that HIV/AIDS can have on their livelihoods. Providing monthly food aid for PLWHA immediately after they are diagnosed, and maintaining support for a fixed length of time would help them to recover from the diagnosis itinerary with its many adverse impacts, to reinforce their nutritional status and overall health. Food aid could also target pregnant women under Prevention Transmission of Mother to Child Treatment (PMTCT) for maintaining their nutritional status and improving their treatment adherence. In addition, adapted food portions could also be distributed to newborns during the transition from breastfeeding to solid food. PLWHA suffering from a physical or a mental handicap, PLWHA in the final stages of the disease, elderly PLWHA and orphans should receive monthly and sustained food support.

To reduce the HIV/AIDS impact on livelihoods, advocacy for people living with HIV would help these people to be better informed about their rights and responsibilities, so that they may stand up to stigmatization and discrimination. In addition, wider public education on the importance of HIV screening could encourage people to seek care more quickly in biomedical centers. Early diagnosis and treatment would not only help to restore the health of these patients, but would also greatly reduce the financial impact of care seeking on their livelihoods. Education about HIV/AIDS prevention and transmission contributes to the reducing of the spread of HIV, but can also address stigmatization. Reducing stigma could diminish the threat of social exclusion and leave PLWHA with greater access to their networks of support.

Among our study participants, only three worked in the formal sector, whereas others did not work (6, or 15%). Thirty-one participants (77.5%) worked as vendors, day laborers or service workers (hairdressing, food service and cleaning). Some pursued multiple activities, while others worked occasionally. They contended that several factors limited their work activities. First, many experience the limitation of their physical capacities as a consequence of HIV/AIDS symptoms. Second, the significant costs of their diagnosis itineraries added with the burden of care expenses often-exhausted financial capital. And lastly, the emotional shock of an HIV/AIDS diagnosis, along with the difficult realities of stigmatization, often led often to debilitating emotional states. Informants also noted that these impediments to working reduced their ability to acquire and save capital to cope with daily expenses. Being able to generate and/or maintain income-production activities was observed to be of the utmost importance for the majority of our informants who do not benefit from social support. Supporting income-generating activities could reinforce PLWHA livelihoods and help them to cope with daily challenges in a sustainable way. The creation of a partnership between the FRC and a microfinance loan agency could provide people with the professional experience and skills necessary for a sustainable IGA through prime-rate micro-loans. Beneficiaries could be trained in management and business skills with routine follow-ups from the FRC or the loan agency to monitor and consult on the progress of their income-generating activities. Installments would be stretched out over a long period of time for avoid effecting PLWHA revenues. As people from their community will inevitably inquire about where their start up capital came from, microfinance loans could offer an explanation that does not disclose their serologic status.

PLWHA medical needs are not covered equally throughout the country, and certain healthcare expenses represent a huge burden on PLWHA livelihoods. Strengthening the national health care system and systems of aid provided by local NGOs and associations have been identified through the expressed concerns of health workers and PLWHA as main factors that would significantly contribute to the reduction of this burden. The decentralization of PLWHA care should be total, so that blood tests, social and psychological care are available in all the country units. An efficient medical supply and management system should be implemented in order to tackle shortages and eliminate the economic strain that it can place on PLWHA. The training of medical and social care workers should be reinforced in all health care centers to promote HIV screening and reduce stigmatization of HIV patients in health centers. The respect of medical practitioner-patient confidentiality also needs to be enforced to eliminate the fear of PLWHA in visiting the HIV units closest to their homes.

These recommendations do not claim to represent all possible interventions that could be implemented in the encouragement of autonomy from NGO support, but were derived from the expressed needs by our divers informants (PLWHA, Medical, Paramedical and Social workers). A study on PLWHA mental health should be implemented in order to better design projects with a deeper understanding of the recipient population.

Limitations of the study

This study is based on PLWHA perceptions crossed with health and social workers perceptions. We recruited interviewers from among the project staff because they had good access to the beneficiaries and they spoke all languages spoken in Mauritania. Knowing that our study was linked to the FRC and to the food aid program could have biased participants' responses to our questions. They might have at times overemphasized particular aspects of their testimonies in the hopes of receiving additional support from the FRC in the future. In addition, they may have suppressed certain criticisms of the FRC program because they feared some form of retribution, or the suppression of future support. Finally, the translation process may have occasioned the loss of some information conveyed by our informants; we insisted, however, that transcribers transcribe and translate every recorded word so as to reduce this risk.

We had originally planed 12 discussions with two to three PLWHA family members who were aware of their status, but we could not perform any of these discussions. This effort was stymied by the fact that only a few respondents had shared their status with more than one person. Moreover, many of our informants were not comfortable with the research team coming to their house to speak with family members because they feared arousing neighbors' curiosity. For this same reason, we were only able to conduct four observations at PLWHA households.

Conclusion

This study aimed to improve the understanding of the PLWHA recipients of the French Red Cross food aid program, in order to enhance the ability to respond more effectively to their needs and challenges and to develop additional aid programs that would be more sustainable and would encourage autonomy from NGO support. The various impacts that HIV has on the livelihoods of PLWHA need to be specifically addressed in the design of any new sustainable form of aid. The extended diagnosis itineraries of HIV/AIDS that have such adverse impacts on PLWHA livelihoods could be reduced through education and the strengthening of the Mauritanian health care system. In addition to reducing negative effects on income generating activities, more efficient diagnostic itineraries help preserve the health of PLWHA and increase the efficacy of treatment. Additional aid programs should create and support income production activities in order to reduce the burden of healthcare needs placed on PLWHA livelihoods. Lastly, the empowerment of local NGOs and associations in the fight for advocacy and education over HIV/AIDS issues would tackle the stigmas associated with the disease and thus reducing the risk and fear of social exclusion. A study on the cost for the government of a PLWHA with no external support would highlight the need to invest in further interventions for PLWHA.

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Annexes

Semi-structured interview guide: People Living with HIV/AIDS

GUIDE D'ENTRETIEN SEMI-STRUCTURE
--
PVVIH

Numéro de l'entretien:
Date :
Heure de début :
Heure de fin :
Lieu d'entretien:

Remarque :

- Expliquer l'étude à la personne que nous voulons interviewer avant sa sélection. Expliquer de nouveau brièvement en début d'entretien et demander si la personne a des questions.
- faire signer une fiche de consentement à chaque personne interviewée.
- Faire signer un accord pour enregistrement de l'entretien.
- Demander si la personne est d'accord pour que l'on organise une discussion avec 1 ou quelques membres de son ménage.

Données démographiques

1. Patient

- Sexe :
- Age :
- Lieu de naissance :
- Groupe Ethnique :
- Situation matrimoniale :
    - *Penser à la polygamie*
- Nombre d'enfants/ Nombre d'enfants à charge :
    - Age des enfants
    - Niveau d'éducation des enfants
- Lieu de vie :
    - *Demander si pendant toute l'année, la durée, si déplacement entre différentes régions et en fonction de quoi.*
- Bénéficiaire du projet :
    - *Ration individuelle*
    - *Complément familial*
- Langue(s) parlée(s) :
- Education :
    - *Primaire (1ère à la 6ème année)*
    - *Secondaire (7ème à la terminale)*
    - *Université*
    - *Formation professionnelle*
    - *Medersa*

- *Analphabète/alphabète*

Estimer la capacité à lire et à écrire : demander au patient d'écrire son lieu de naissance

2. Ménage

Définition d'un ménage : *un ménage est constitué des personnes qui partagent régulièrement le même repas. Définition utilisée en Afrique en général.*

- Nombre de personnes :
- Liens avec ces personnes :
- Sexe et âge des personnes :
- Langues parlées par les différents membres du ménage :
- Personne chef du ménage : (sexe et âge)
- Niveau d'éducation des différentes personnes du ménage :
  - *Primaire (1ère à la 6ème année)*
  - *Secondaire (7ème à la terminale)*
  - *Université*
  - *Formation professionnelle*
  - *Medersa*
  - *Alphabète/analphabète*

Vécu de la maladie et stigmatisation/discrimination

Nous aimerions mieux connaître le niveau de stigmatisation/discrimination subit par les PVVIH. Connaître ce niveau peut nous permettre de comprendre les conséquences de la maladie sur la situation économique et le statut social des patients mais aussi sur leur santé mentale (état dépressif/anxiétés). Nous voulons également avoir une meilleure connaissance sur la part du secret dans le vécu de la maladie des PVVIH. La confidentialité sur le statut auprès du ménage voir du conjoint peut créer un environnement de stress et de mal être important chez le PVVIH (état dépressif).

- Aviez vous déjà entendu parler de votre maladie avant de recevoir votre diagnostic ?

- Comment avez-vous connu votre statut ? Lors de quelles circonstances ?
  - *Discuter de l'itinéraire thérapeutique du patient jusqu'au CTA*
- Comment avez-vous réagit à l'annonce de votre statut ?

- Est-ce que vous l'avez partagé avec vos proches ?
  - *Si oui, qui ? Quelle a été la réaction ?*
  - *Si non, pourquoi ?*
- Comment est perçue une personne atteinte du VIH/SIDA dans votre communauté ?
  - *Comment les gens pensent que la maladie est transmise ?*
- Vous sentez-vous stigmatisé ? Comment ceci se manifeste ? Quelles sont les conséquences ?

<u>Remarque</u> : La stigmatisation et les discriminations peuvent réduire voir annuler/empêcher les activités professionnelles.
MICS 2007 à Nktt chez les hommes et femmes :

- *5.7% (H) et 16.2% (F) ne prendraient pas soin d'un membre du ménage malade du SIDA*
- *29.5% (H) et 35,7% (F) aimeraient garder le secret si un membre du ménage a le SIDA*
- *44.7% (H + F) pensent qu'un enseignant ayant contracté le VIH sans être malade du SIDA ne devrait pas être autorisé à enseigner à l'école*
- *57% (H) et 62,9% (F) n'achèteraient pas des légumes frais à un marchand/vendeur malade du SIDA*
- *76.8 (H) et 81.9% (F) sont d'accord avec au moins une attitude discriminatoire.*

Santé

Nous aimerions évaluer l'accès financier et géographique des soins de santé pour les PVVIH et estimer la capacité de réponse aux besoins de santé de ces patients. Il est important également d'évaluer le poids de l'état de santé sur le ménage. Des questions sur les contraintes financières sont proposées dans la section « revenus ». Il est important de discuter des soins apportés par un membre de la famille car ceci peut affecter l'activité professionnelle de ce proche (diminution du temps de travail du *caretaker*, changement

d'activité professionnelle lorsque la prise de soin est trop lourde). Ceci peut avoir d'importantes conséquences sur les revenus du ménage.
La santé mentale est également un aspect important à prendre en compte.

- Comment va votre santé ?
    - Etes-vous sous traitement ?

  Si sous traitement :
    - Où trouvez-vous les ARV?
    - Avez-vous tout le temps des ARV ?
    - Comment supporter-vous le traitement ?
    - Est-ce que vous arrêtez de le prendre des fois car le traitement est très lourd ?
- Que faites-vous quand vous vous sentez malade ?
    - Comment vous traitez-vous ?
    - où allez-vous ? auprès de qui ? Pourquoi ?
    - Avez-vous eu besoin de venir vivre à Nktt pour trouver des soins ? Expliquer cette décision.
- Avez –vous des infections opportunistes ?
    - Arrivez-vous à vous soigner ?
    - Trouvez-vous les médicaments ?
    - Avez-vous accès aux spécialistes quand vous en avez besoin ?
    - Avez-vous accès aux examens complémentaires lorsque vous en avez besoin ?

  Il y a t-il une autre personne infectée par le VIH dans le ménage ? liens?
    - *Conjoint*
    - *Enfant*
    - *Autre*
- Devez-vous prendre soin d'une autre personne malade dans votre ménage ? Discuter du lien avec cette personne, de la maladie et de l'énergie que cette prise en charge demande

Alimentation et hygiène

- Nombre de repas par jour et si pas 3 repas/jour demander pourquoi
- Composition des repas et demander pourquoi
- Est-ce que vous avez l'eau courante ? Avez-vous accès à de l'eau potable ? Si oui, sous quelle forme ?
- Avez-vous des latrines et si oui de quel type ?

Remarque : l'observation du milieu de vie sera important pour avoir une meilleure vision de l'environnement de vie. Faire vos commentaires après chaque entretien.

Revenus

- Estimer les biens avant la maladie et après:
    - *Bétail (type et nombre de têtes)*
    - *Véhicule (type et savoir si fonctionnel)*
    - *Terres (superficie)*
    - *Or*
- Logement :
    - *Propriétaire de son logement? D'autres logements ?*
    - *Locataire ?*
    - *Logé à titre gratuit?*
    - *Logement spontané ?*
- Quelles sont les sources de revenus du ménage?
    - *Activité professionnelle ?*
    - *Activités agricoles ?*

    - *Appartenance à une organisation (coopérative) ?*
    - *Vente informelle ?*
- Est ce qu'une personne de votre famille ou autre vous envoie de l'argent pour subvenir aux besoins du ménage ?
- Est-ce que les activités professionnelles du ménage ont changé depuis votre maladie ? pour vous et pour les autres membres ?
    - *Enfants qui travaillent ?*
    - *Femme qui travaille ?*
    - *Personne de la famille envoyée en ville pour gagner de l'argent ?*
    - *Personne qui prend soin du malade à dû adapter son travail ? changement, diminution du nombre d'heures ou arrêt*
- Comment les revenus du ménage ont évolué depuis la maladie ?
    - *Si baisse, estimation de la baisse de revenues*
- Quelles sont les mesures prises pour faire face aux problèmes de revenus?
    - *Diminution du nombre de repas? diminution de la consommation viande/poisson – compensation avec les légumineuses?*
    - *Diminution des coûts de transports?*
    - *Vente de biens? De quel type?*
    - *Arrêt de la scolarisation des enfants?*
    - *Demande aux enfants de travailler pour apporter de l'argent au foyer?*
    - *Emprunt ? estimer le montant, auprès de qui ? quelles sont les conditions ?*
- Comment faites-vous face aux dépenses en lien avec la maladie ?
    - *Vente de biens ?*
    - *Emprunt ? estimer le montant, auprès de qui ? quelles sont les conditions ?*
    - *Aide nationale aux indigents ?*
    - *Gratuité des soins essentiels ?*
    - *Mutuelle pour les fonctionnaires ?*
    - *Caisse communautaire ?*

Dépenses

- Dépenses quotidiennes
    - *quoi ? qui ? quand ? comment ?*

    - *Est-ce que vous devez emprunter de l'argent parfois ? où ? Combien ?*

    - *Comment remboursez-vous vos emprunts ?*

    - *variation des dépenses dans l'année ;*

- Dépenses occasionnelles
    - *quoi ? qui ? comment ? quand ?*

    - *Est-ce que vous devez emprunter de l'argent parfois ? où ? Combien ?*

    - *Comment remboursez-vous vos emprunts ?*

Besoins

Nous aimerions que le/la participant(e) exprime ses différents besoins (besoin de scolariser ses enfants, besoin d'acheter à manger, besoin d'acheter des vêtements…) et que le/la participant(e) classe ces besoins selon ses priorités. Enfin, il serait intéressant de savoir si cette personne est en mesure de répondre à ses besoins.

- Quels sont les besoins que vous devez satisfaire ?
- Comment vous les priorisez-vous ?
- Aujourd'hui, de quelle façon arrivez-vous à répondre à vos besoins ?

Soutien

Les informations ici recherchées doivent nous permettre de mieux comprendre et d'évaluer le soutien communautaire des différents PVVIH. Il faudra alors questionner le patient sur toutes les formes de soutien, que ce soit traditionnel, religieux ou autre... Par la suite, nous aimerions identifier à partir des commentaires des patients eux même, les différentes formes de soutien qu'ils estiment avoir besoin.

- Quel type de soutien pensez-vous avoir besoin ? Pourquoi?
    - *Prise en charge des enfants (nature : médicale, nutritionnel, appui scolaire...)*
    - *Psychologique*
    - *Formation professionnelle*
    - *AGR*
    - *Prêt (microfinance)*
    - *coopératives*
    - *Mutuelle de santé*
- Recevez-vous un soutien financier et/ou alimentaire d'autres personnes ou organisation ?
    - *Si oui, quoi ? par qui ? depuis quand ?*
    - *De quel ordre ? montant ou quantité*
- Est-ce qu'il y a des personnes ou une personne en particulier qui prennent soin de vous?
    - *Parents*
    - *Enfants*
    - *Frère ou sœur*
    - *Partenaire*
    - *Agent de santé communautaire*

  Estimation du temps consacré.
  Caretaker dans le ménage ou en dehors du ménage.
- Aimeriez-vous recevoir un soutien dans l'entreprise d'une activité ?
- Que pensez-vous du soutien alimentaire qui vous est apporté ?

En dehors de ce que nous venons de parler juste avant, partager avec nous un événement de vie que vous désirez. (Récit de vie)

Pour terminer, si la personne a partagé son statut avec des membres de sa famille, demander si il/elle est d'accord pour que l'on s'entretienne quelques minutes avec 2 ou 3 personnes du ménage.

Semi-structured interview guide: Medical and paramedical workers

GUIDE D'ENTRETIEN SEMI-STRUCTURE
--
PERSONNEL DE PRISE EN CHARGE

Numéro de l'entretien :
Profession :
Date :
Heure de début :
Heure de fin :
Lieu d'entretien :

Remarque 1: Ce guide concerne les personnes impliquées dans la prise en charge médicale et paramédicale des PVVIH:

A Nouakchott :

- le personnel du CTA (4 médecins, 1 assistante sociale, 1 psychologue, 3 infirmiers, 1 pharmacien, 1 secrétaire médicale, 1 laborantin),
- les 4 sensibilisateurs travaillant avec les PVVIH ciblés dans cette étude,

A Nouadhibou :

- 1 médecin
- 1 pharmacien
- 1 infirmier

A Kaédi :

- 1 médecin (Dr Wagé si pas de remplacement du médecin partis)
- 1 pharmacien

Soit au total 23 personnes sous réserve de l'acceptation de participation.

Remarque 2 : Les entretiens seront plus ou moins poussés sur certains aspects en fonction du poste de la personne interviewée (parler plus du soutien psychologique avec le psychologue par exemple)

Profession de l'enquêté

Comment sur ces aspects permet de mettre la personne au centre de la conversation et d'introduire l'entretien d'une façon moins directe.

Depuis quand êtes-vous à ce poste ?
Aviez-vous déjà travaillé avec les PVVIH avant ce poste ?
Quelles difficultés rencontrez-vous dans votre exercice de tous les jours ?

Santé

- Quel est l'état de santé de la majorité des patients avec qui vous travaillez ?
  - *Etat de santé physique*
  - *Etat de santé mentale*
- Que font-ils quand ils ont besoin de soins?
  - Où vont-ils ? Auprès de qui ? pourquoi ?
  - Est-ce que certains partent vivre à Nktt pour trouver des soins ?

Remarque : A cause de la maladie certains PVVIH quittent la ville pour aller dans les village pour recevoir le support de la famille. D'autres PVVIH quittent le village pour chercher des soins médicaux dans la ville. Certains patients qui vivent dans les régions viennent aussi jusqu'à Nktt pour échapper à la stigmatisation dans leur région.

- Discuter de l'accès aux soins des malades (consultations, traitement, examens complémentaires)
  - *Accès financier*
  - *Accès géographique*

    - *Capacité physique*
    - *Offre et disponibilité*
- Discuter de la prise de soin du PVVIH par la famille.
    - *Mobilisation*
    - *Conséquence de cette mobilisation*
- Discuter du besoin de soins des patients
    - *Aide à la prise d'ARV*
    - *Aide lors des IO*
    - *Soutien psychologique*

Stigmatisation/discrimination

- Quelles sont les réactions des PVVIH à l'annonce de leur statut ?
    - Déni de la maladie, anxiétés, stress, dépression
- Comment selon vous est perçue une personne atteinte du VIH/SIDA dans sa communauté ?
    - *Comportement des gens vis à vis des PVVIH*
    - *Discours des gens envers les PVVIH*
- Quelles sont les conséquences de la stigmatisation sur les PVVIH et la famille du PVVIH ?
- Existe-t-il des discriminations envers les PVVIH ?
    - *Si oui de quel ordre ?*
- Comment les familles réagissent à l'annonce du statut ?
- Qu'est-ce qui selon vous pourrait faire évoluer les mentalités ?

Revenus

- Discuter du poids de la maladie sur les revenus des PVVIH
- Discuter des mesures prises par les PVVIH pour faire face aux problèmes de revenus et de la façon dont les PVVIH pourraient être soutenus
- Discuter de l'exode rural ou urbain en fonction des problèmes de revenus ou de la maladie

Soutien

- Que pensez-vous du soutien alimentaire ? Quelles sont vos recommandations ?
- Quel autre type d'appui pensez-vous nécessaire pour aider les PVVIH à subvenir à leurs besoins afin qu'ils soient à terme indépendant
    - *Prise en charge des enfants*
    - *dons*
    - *Prêt*
    - *Mutuelle de santé*
    - *Formation professionnelle*
    - *Création de coopératives*

  Discuter de chaque possibilité avec l'interviewé en terme de réponse aux besoins et de faisabilité.

Semi-structured interview guide: NGOs and associations

GUIDE D'ENTRETIEN SEMI-STRUCTURE
--
ORGANISATIONS DE LA SOCIETE CIVILE

Numéro de l'entretien:
Nom de l'organisation :
Lieu de l'organisation :
    Siège :
    Zone d'intervention :
Position dans l'organisation :

Date :
Heure de début :
Heure de fin :
Lieu d'entretien :

Organisation

- Quelles sont les activités de l'organisation ?
    - *Type (agents de santé communautaire?)*
    - *Fréquence*
    - *Déroulement*
- Combien de personnes appartiennent à l'organisation ?
    - *Nombre de membres du bureau*
    - *Si Agents de santé communautaires, nombre ?*
    - *Nombre de bénéficiaires*
- Depuis quand existe l'organisation ?
- Depuis quand appartenez-vous à cette organisation ?
- Quelles sont vos relations avec le CTA ?

Santé

- Quel est l'état de santé de la majorité des patients avec qui vous travaillez ?
    - *Etat de santé physique*
    - *Etat de santé mentale*
- Que font-ils quand ils ont besoin de soins?
    - Où vont-ils ? Auprès de qui ? pourquoi ?
    - Est-ce que certains partent vivre à Nktt pour trouver des soins ?
- Est-il fréquent qu'un PVVIH ait dans son ménage une autre personne infectée par le VIH/SIDA ou d'une autre maladie ?
- Discuter de l'accès aux soins des malades
    - *Accès financier*
    - *Accès physique (disponibilité des transports, mobilité des patients)*
    - *Offre et disponibilité*
- Discuter de la prise de soin du PVVIH par la famille.
    - *Mobilisation*
    - *Conséquence de cette mobilisation*

- Discuter de la prise de soin d'un autre membre du ménage (si autre membre malade) :
    - *Mobilisation*
    - *Conséquence de cette mobilisation*
- Discuter du besoin de soins des patients
    - *Aide à la prise d'ARV*
    - *Aide lors des IO*
    - *Soutien psychologique*

Stigmatisation/discriminations

- Comment selon vous est perçue une personne atteinte du VIH/SIDA dans sa communauté ?
    - *Comportement des gens vis à vis des PVVIH*
    - *Discours des gens envers les PVVIH*
- Quelles sont les conséquences de la stigmatisation sur les PVVIH et la famille du PVVIH ?
- Qu'est-ce qui selon vous pourrait faire évoluer les mentalités ?

Revenus

- Discuter du poids de la maladie sur les revenus des PVVIH
- Discuter des mesures prises par les PVVIH pour faire face aux problèmes de revenus et de la façon dont les PVVIH pourraient être soutenus
- Discuter de l'exode rural ou urbain en fonction des problèmes de revenus ou de la maladie.

Soutien

- De quel type d'appui les PVVIH peuvent t-il disposer ?
    - Alimentaire,
    - Financier,
    - Social,
    - Etc…
- Quel type de soutien pensez-vous être nécessaire pour les PVVIH ?
-
- Que pensez-vous du soutien alimentaire ? Quelles sont vos recommandations ?

Focus group discussion guide: PLWHA

FOCUS GROUP
--
PVVIH

Nombre de participants:
Genre du groupe : H / F
Date :
Heure de début :
Heure de fin :
Lieu :

Remarque 1 : Commencer par réaliser 4 focus groups : 2 avec des femmes + 2 avec des hommes. Les groupes ne devront pas dépasser 6 à 8 personnes. En réaliser plus selon les *outcomes* des focus groups. On ne cherche pas forcément à être représentatif de la population d'étude car la culture commune peut fonder une base commune au travers des différentes populations.

Remarque 2 : Ils pourraient permettre également d'identifier des récurrences dans les discours, des sujets à approfondir lors des entretiens ainsi qu'une façon culturelle de parler du VIH/SIDA (termes particuliers à reprendre lors des entretiens). Enfin, ils permettront d'avoir une meilleure conception du contexte dans lequel l'étude va s'effectuer.

Remarque 3 : les différents points qui sont déclinés sous chaque thème sont des questions à titre indicatif pour guider et lancer les discussions. Ils ne sont pas forcément à utiliser si la discussion se lance facilement au sein des différents focus group. Il est intéressant de laisser les participants animer la discussion et de se mettre en retrait un maximum afin de ne pas influencer les discours. La discussion peut ainsi évoluer vers des sujets que nous n'avions pas anticipé.

ATTENTION : Lors de la constitution des groupes, il est important d'expliquer les objectifs de la cette étude ainsi que ses différents principes éthiques. Ces différents points pourraient être rappelés au début de la discussion.

Santé

- Accès au traitement et les difficultés
- Prise du traitement/observance

Vécu de la maladie et stigmatisation

- De quelle façon les gens parlent du VIH/SIDA ?
- Est-ce que la maladie est stigmatisante? Quelles sont les différentes formes de stigmatisations ?

- Avez-vous été sujet à des discriminations à cause de la maladie?
- Rejet de la famille? Rejet par le/la conjoint(e)?
- Est-ce un frein dans l'activité professionnelle ?
  - *Si la discussion ne se lance pas, donner l'exemple si besoin du refus d'acheter des produits frais chez un marchand ayant le VIH/SIDA. (cf MICS 2007)*

Revenus et évolutions

- Quel est le poids de la maladie sur les revenus?
  - *En terme de perte si diminution des activités*
  - *En terme de dépenses de santé*
- Quelles sont les mesures prises pour faire face aux problèmes de revenus?

  - *Diminution du nombre de repas? diminution de la consommation viande/poisson? Augmentation de la consommation de légumineuses ?*
  - *Diminution des coûts de transports?*
  - *Vente de biens?*
  - *Arrêt de la scolarisation des enfants?*
  - *Demande aux enfants de travailler pour apporter de l'argent au foyer?*

Soutien

- Est-ce vous recevez un autre soutien que le soutien alimentaire?
- Est-ce que vos proches vous aident?
- Est-ce qu'il existe un soutien communautaire? (Nantis qui offrent des repas aux voisins les plus démunis)
- Que pensez-vous de l'appui alimentaire?
- De quelle façon aimeriez-vous être soutenu? Pourquoi?

Observation tool for PLWHA housing

GRILLE D’OBSERVATION
--
PVVIH

Numéro de l’entretien:
Nom de l’enquêteur :
Date :

Géographie	Ville/village	
	Quartier	
	Situation géographique de l’habitat : • Entourage de l’habitation (Habitations/ terres) • Niveau d’isolation de l’habitat (commerces) • Distance des structures de santé (CTA) • Accessibilité	
Habitat	Type d’habitat	
	Composition (matériaux) des murs, du toit et du sol	
	Etat général de l’habitat • Propreté • Aération • Lumière	
	Nombre de pièces	
Equipements	Moyen d’approvisionnement en eau Moyen de conservation de l’eau	
	Type de latrines	
	Electricité • Source	
	Equipements (demander de visiter la maison) • Mobilier • Radio/télévision	
	Moyen de combustion pour alimentation	
	Nombre de personne dans le ménage pendant l’entretien Vas et vient au sein de l’habitat	