

# Giving Voice to Patients in Rural Haiti: An Assessment of Retention in HIV Care

Marguerite Susich<sup>1,2</sup>, Patrick Ulysse<sup>1,2</sup>, Alain Casseus<sup>2</sup>, Annie Michaelis<sup>1</sup> and Joia Mukherjee<sup>1,3\*</sup>

<sup>1</sup>Partners in Health, Boston, Massachusetts, USA

<sup>2</sup>Department of Global Health and Social Medicine, Harvard Medical School, Boston, Massachusetts, USA

<sup>3</sup>Zanmi Lasante, Cange, Haiti

## Abstract

**Objective:** Initiatives aimed at improving patient retention in HIV care in Haiti have focused on a wide range of tactics for identifying individuals who are lost to follow-up yet the patient perspective is often missing from efforts to understand and address the root causes of lost to follow-up.

**Methods:** As part of a routine quality control audit of the HIV program, structured interviews were conducted with 100 patients who had returned to care after previously being lost to follow-up at three rural health centers in the Lower Artibonite region of Haiti supported by the non-governmental organization Zanmi Lasante. These interviews uncovered factors that contributed to patients' previous lack of follow up and elucidated factors that influenced their return to care. The interviews sought to capture the patients' preferred communication methods and their suggestions for improvements in HIV care at the health facility.

**Results:** As part of a quality of care audit, 100 patients were interviewed in November and December 2014, and their reasons for loss to follow-up were identified. The common factors noted were socio-economic barriers to remaining in care, challenges affecting case management at both provider and the facility level, and patient perceptions of good health. 74% of the respondents identified increased communication by health care professionals through telephone calls and home visits as the reason they chose to return to care. Respondents suggested increase in economic and transportation support, improved communication between providers and patients, improved clinic experience, and increased medication management as factors that would decrease lost to follow up in the future.

**Conclusion:** Reasons for loss to follow-up in this rural Haitian population reflect similar social and structural barriers common to lost to follow-up populations globally, however patients participating in these interviews reported unique barriers in communication as inhibiting factors to remaining in care. By utilizing this feedback from end users of the health system as an essential component in the design and implementation of service improvements, health systems can more effectively diminish loss to follow-up.

**Keywords:** HIV/AIDS care; Global health; Loss to follow-up; Haiti; Antiretroviral therapy

**Abbreviations:** LTFU: Loss to Follow-Up; ART: Antiretroviral Therapy; PLHIV: People Living with HIV; PIH: Partners in Health, EMR: Electronic Medical Record

## Objective and Background

The advancement of HIV treatment and access to antiretroviral medications has enabled over 11 million people to receive treatment in low and middle-income countries [1]. While this has dramatically improved the health of people living with HIV (PLHIV), challenges of retaining patients in care persist, especially in communities where the most vulnerable populations reside. Identifying reasons why PLHIV are lost to follow-up (LTFU) is a critical part of efforts to improve program performance, it allows healthcare managers to more thoroughly monitor program strengths and weaknesses (e.g., tracking trends in CD4 counts and viral loads over time) [2]. Remaining in care is critical for PLHIV as ART will halt or slow disease progression, allow for immune recovery and decrease the probability of the development of resistant virus at an individual level. In addition, retaining patients in care promotes sexual health—from protecting discordant partners, to the timely treatment of co-morbid sexually transmitted diseases to increasing opportunities to promote condom use and family planning [3,4]. Retention in care also has a positive influence on the overall health of communities [5,6]. When people recover from advanced illness in communities, their survivorship and good health encourage others to come forward and decreases stigma [3]. Finally, some analyses in resource-limited settings

have concluded that initiatives to reduce HIV LTFU are cost-effective as they prolong the use of less expensive first line therapy and reduce costly hospitalizations [7]. In combination, these reasons provide compelling justification for investment in initiatives aimed at reducing LTFU in the fight to enhance the wellbeing of PLHIV and their communities in Haiti.

Many previous efforts to examine reasons for LTFU in resource-limited settings have revealed problems in retention due to socio-structural barriers. Major themes in LTFU studies include the economic and structural burdens of transportation to clinic and opportunity costs associated with the provision of childcare and lost days of work [8-13]. This paper seeks to supplement the current literature by sharing the patients' perspectives which were collected during a routine quality of care audit in an HIV program in rural Haiti. The audit was performed

**\*Corresponding author:** Joia Mukherjee, Partners in Health, Department of Global Health and Social Medicine, Harvard Medical School, Boston, Massachusetts, USA, Tel: 617-998-0181; E-mail: [jmukherjee@pih.org](mailto:jmukherjee@pih.org)

**Received** February 05, 2016; **Accepted** March 03, 2016; **Published** March 11, 2016

**Citation:** Susich M, Ulysse P, Casseus A, Michaelis A, Mukherjee J (2016) Giving Voice to Patients in Rural Haiti: An Assessment of Retention in HIV Care. J AIDS Clin Res 7: 553. doi:10.4172/2155-6113.1000553

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to understand and integrate the patient voice into the process of improving care. We believe this provides unique opportunities to design interventions that best meet the needs of the intended population.

## Settings

Haiti accounts for 55% of all PLHIV in the Caribbean, with a prevalence rate of 2% among adults ages 15 to 49 nationally [14]. The 140,000 PLHIV reside in a country where over half of the population lives below the national poverty line [15,16]. In the Artibonite region of Haiti, the female HIV prevalence rate is 3.0% and the male rate is 1.6%, for a total prevalence of 2.3% [17]. This rate is almost three times greater than the current global prevalence of 0.8% [18].

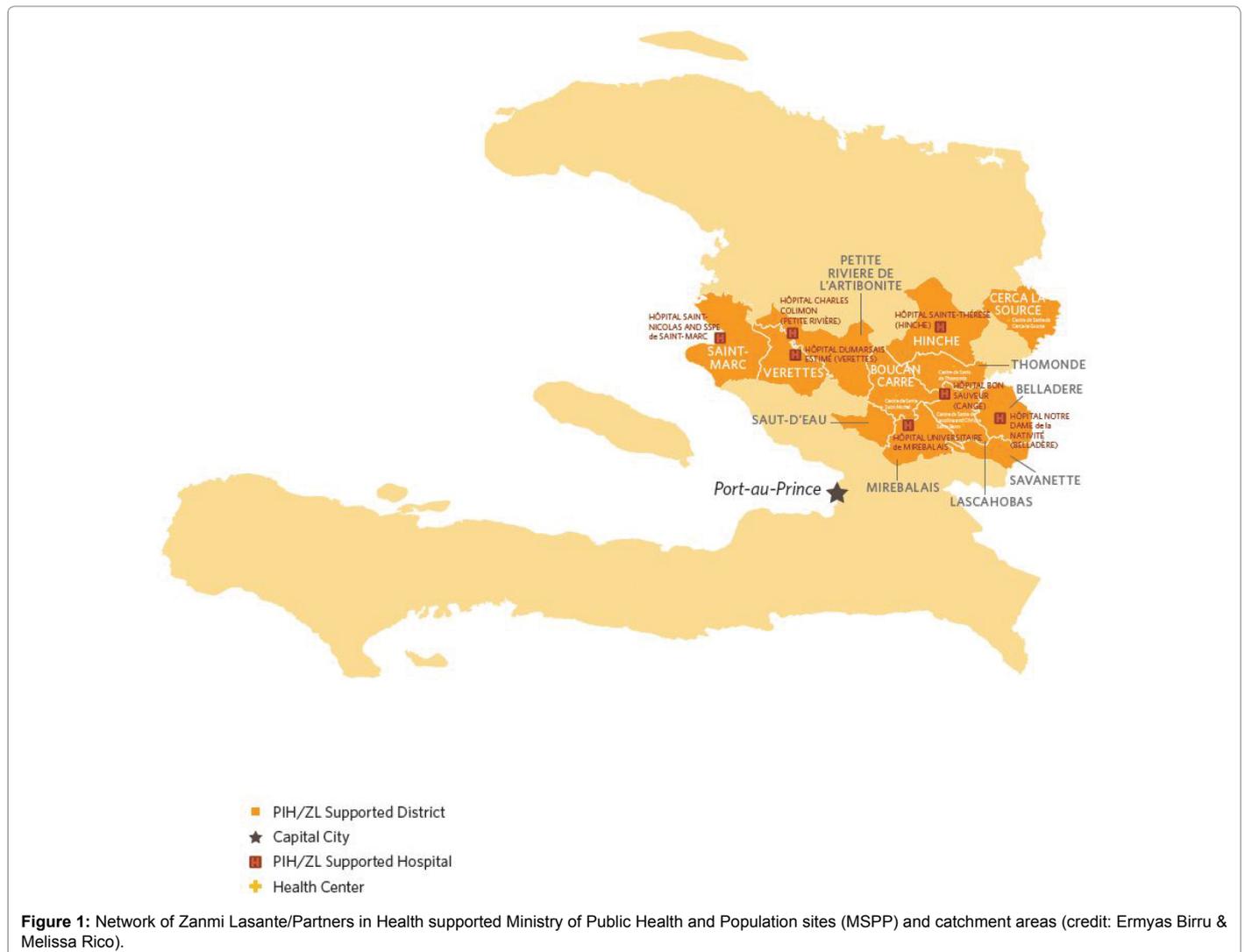
This paper profiles findings from a routine quality of care audit that was performed to better understand barriers to long-term retention in care among patients receiving HIV care and treatment services at three facilities supported by Zanmi Lasante/Partners In Health in the Artibonite region.

Partners In Health (PIH) was founded in the 1980s to provide medical and social services to the residents of Cange, a rural squatter settlement in Haiti's Central Plateau. ZL/PIH began to treat PLHIV with antiretroviral therapy in 1998 [19,20], using a package of services—

from community health workers to conditional cash transfers to support adherence and retention in care [21]. With the advent of large scale HIV funding through the Global Fund to Fight AIDS, TB and Malawi (GFATM) and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) PIH and its Haitian sister organization Zanmi Lasante began to expand HIV prevention, care and treatment to support the public facilities in Central and Artibonite Departments, serving a primary catchment area of over 1.2 million. By 2015, the network of ZL supported facilities supported more than 10,000 patients on ART (Figure 1).

## Methods

November-December 2014, as part of a routine quality of care audit, program managers reviewed the electronic medical records system and chose the first 100 patients among those who had returned to care after being lost to follow-up. These patients were asked to participate in a qualitative survey. The survey instrument was a structured questionnaire with both close-ended and open-ended questions was administered after receiving consent. Demographic information, including treatment status (pre-ART or ART) and date of last visit were obtained in a structured format. The open-ended portion of the survey included questions on factors that contributed to patients' previous



abandonment of care, factors that influenced patients to return to care, their preferred communication methods, and perceptions on how to improve the system of HIV care at Zanmi Lasante-supported sites.

Through querying the electronic medical record system for the quality of care audit, adults over 18 years of age with an established diagnosis of HIV, were selected if they were previously enrolled in care at one of the three selected sites and were attending their first visit after being lost to follow-up for at least 3-6 months. Patients were considered lost to follow-up if they had been enrolled on antiretroviral therapy (ART) and did not return to care for a period of three or more months. If the patient was not yet on ART (pre-ART), they were considered lost to follow-up if they had not attended clinic for six months or more. Identified patients were asked to participate in an interview to improve patient retention in care. Verbal informed consent was obtained prior to interviews.

Nurses and physicians conducted all interviews in Haitian Creole. Written instructions were included on each form, including an explanation of the purpose of the survey to be read to each participant. Interviews occurred privately on the hospital grounds.

Each interview was transcribed and translated from Haitian Creole into English. The original and translated versions were used in analysis. The interviews were analyzed using standard qualitative methods to identify content and themes [22,23]. This process included open coding to identify central concepts and categories.

## Results

All of the 100 patients selected from the EMR query consented to be interviewed. One hundred respondents participated in interviews across the three sites. Table 1 contains the descriptive statistics of this group. Thirteen of these subjects received care at a community referral hospital and 87 received care at community health centers. Of the surveyed participants, 44% (n=44) were male. Eighty-four percent (n=84) were initiated on ART prior to becoming LTFU. The mean age was 37 years (SD: 11.3 years) and mean CD4 count was 387 cells/mm<sup>3</sup> (SD: 313 cells/mm<sup>3</sup>). The average time since recorded diagnosis for the patients studied was five years. The mean length of time since last facility visit was 11 months (SD:9 months).

## Reasons for Leaving Care

Many recurring themes were seen in subjects' reasons for failing to return to care. Some patients cited errors socio-economic barriers including hunger, opportunity or out of pocket costs, other sited communication gaps with clinic, not feeling physically ill or not believing they were sick. Table 2 outlines the themes that were found.

Even though consultation, medications and laboratory tests are free at these facilities, 35% reported socio-economic barriers as their main reason for stopping care. For example, one respondent noted,

"I did not return to the hospital before because I have five children, I do not have help and I need to work in the Dominican Republic" (54 year-old Female, ART, LTFU for 20 months).

	All patients (n=100)
Age (mean years±SD)	37 ± 11.3
Gender (% male)	44
Initiated on ART prior to becoming lost to follow-up (%)	84
CD4 count (mean cells/mm <sup>3</sup> ±SD)	387 ± 313.8
Time since last facility visit (mean months ±SD)	11 ± 9

Table 1: Descriptive statistics of interview respondents.

	All patients (n=100)
<b>Reasons for Return to care:</b>	74
• Community health worker	
• Feelings of Illness	12
<b>Reasons for LTFU</b>	
<b>Socio-economic factors</b>	
• Transportation	1
• Childcare	8
• Work and other time commitments	20
• Out of pocket cost	6
<b>Management of clinic</b>	
• Communication of treatment plan	28
<b>Individual factors</b>	
• Feeling well	21
• Seeking alternative treatment	4
• Stigmatization	4
<b>Patient suggestions for Improvements</b>	
• Social economic support	14
• Reminders	14
<b>Improved clinic management</b>	
• Wait times	15
• Customer service	12

Table 2: The results of the questionnaire grouped by major themes that emerged.

"Economic problems, when I take my medications they make me tired all day and there are days I cannot eat when I am hungry" (27 year-old Female, ART, LTFU for 24 months)

"I do not have money to come to the appointments, I cannot find lending, it is not a choice [I make] to not come to the appointments" (32 year-old Male, ART, LTFU for 14 months)

Twenty-eight percent of respondents cited communication errors as their main contributing factor to defaulting. Communication errors reported included patients not knowing they had a follow-on appointment, not knowing when their next appointment was scheduled, or not having a follow-up appointment scheduled. For example, patients often reported confusion about when they were expected to return:

"Because I did not know when to return" (52 year-old Female, ART, LTFU for 6 months)

"Because I lost my appointment (time)" (48 year-old Male, ART, LTFU for 13 months)

Twenty-one percent of patients stated they left care because they did not feel they were ill or did not believe they were ill.

Other respondents noted the negative influences of stigmatization against PLHIV (4%), spiritual beliefs (4%) or other non-specific personal decisions (2%) as reasons for leaving care. For example:

"Because I have a sister in law (working) at the hospital and I do not want her to see me" (24 year-old Female, ART, LTFU for 4 months)

"Because, people around my house were watching me [gossiping]" (70 year-old Female, ART, LTFU for 5 months)

Those citing spiritual beliefs as reasons for previously defaulting perceived that only spiritual leaders' have the ability to improve their health or that the cause of their illness is due to a spiritual dilemma and not a physical disease process. Representative responses included:

"I did not know what I had. I believed the Boko [traditional healer] could heal me" (51 year-old Male, pre-ART, LTFU for 6 months)

"[I] felt [I] was very sick, [I] think this problem is not of the hospital. [It is] spiritual sickness" (34 year-old Male, ART, LTFU for 6 months)

The remaining 6% of respondents did not report a reason for leaving care.

### Reasons for Returning to Care

74% of respondents cited communication initiated by healthcare professionals as the reason they decided to return to care. These communications included community healthcare workers making home visits and nurses or social workers calling patients. Responses included:

“They [the community health worker] came looking for me and therefore, I came” (36 year-old Male, ART, LTFU for 4 months)

“I could not do this, I did not accept when they told me I was sick; my community health worker talked with me and I accepted to return” (32 year-old Male, ART, LTFU for 7 months)

Twelve percent of respondents cited feelings of physical illness as their main contributing factor for returning to care. The remaining respondents cited a nonspecific personal decision (n=12) or had no recorded response (n=2). Those citing personal decisions stated there were no external factors relating to their decision to return.

### Communication Preference

Eighty eight percent of respondents verified that the healthcare center was using an accurate mode of communication to contact them. These responses included verifying telephone numbers, home addresses and indicating whether they preferred the healthcare center to contact them via telephone or home visits. 7% of respondents requested that community health workers not visit their homes and 5% of participants gave no response.

### Improvement Suggestions

Respondents were asked for suggestions on how to improve adherence to care.

45% of respondents stated that they did not have a suggestion or felt that the services at the health center were satisfactory.

14% of patients spoke of the additional services they wished to see at the care center, such as increased economic assistance, more transportation assistance and medication management services.

“Finding medicine for me that does not make me feel worse” (29 year-old male, pre-ART, LTFU for 3 months)

41% of respondents requested improved efficiencies in the clinic--14% asked for improvements in communication-- appointment reminders, such as written cards or telephone calls. 15% of respondents felt that the health center could achieve better appointment attendance by decreasing wait times for patients. These respondents reported challenges with long queues, high patient volumes at clinics, and not enough providers to meet demand. For example:

“Do not leave people waiting at the hospital for a long time because we have work to do” (40 year-old female, pre-ART, LTFU for 8 months)

“To have more nurses and doctors to decrease wait times” (34 year-old male, ART, LTFU for 6 months)

An additional 12% percent of respondents mentioned concerns related to customer service practices. These respondents generally asked for the facility to improve health care professionals' welcoming practices and interpersonal engagement with patients.

“Yes, [improve] the way in which you speak to people” (51 year-old male, ART, LTFU for 6 months)

“Give me a good welcoming” (37 year-old female, ART, LTFU for 23 months)

“Always encourage me” (32 year-old male, ART, LTFU for 8 months)

### Conclusion

Targeting lost to follow-up populations as they re-enter care gives a clearer understanding of this at-risk population. Through this project, we were able to better understand patients' reasons for missing appointments and their suggestions for ways that the health facility can better support patients in adhering to treatment plans. This information is crucial to assist in planning future initiatives to bolster long-term retention in care.

Reasons for loss to follow-up in this population reflect similar social and structural barriers common to LTFU populations in previous studies [3,10-13]. These factors include transportation, financial and child care/work responsibilities [8-13]. However, direct interviews with patients attending care at multiple health facilities in rural Haiti reveal unique barriers in communication as major inhibiting factors to patients remaining in care.

The communication theme is not often referenced in the literature on retention in care. There is mention of communication barriers in HIV-positive patients with severe mental illness, but we see from the current project that communication challenges can also be an important barrier for the general population of HIV patients in rural Haiti [13]. Initiating efforts to augment communication between healthcare professionals and patients is an achievable goal within the current healthcare system. The strategy at the three survey sites already includes a team of community health workers capable of further enhancing communication with patients. Indeed, the large percentage of patients citing contact initiated by community health workers as their reason for returning to care reiterates the positive outcomes that can be accomplished by a community health worker system.

Outside of communication, patients often cited social and structural barriers to care. In resource-limited settings, accessing health care is often only one competing need in a spectrum of priorities where commitments to work and children may take precedence over personal health. These reasons for failure to attend medical appointments indicate that socio-structural factors are sometimes more important in determining retention in care than individual-based psychosocial factors.

Several patients reported returning after experiencing symptoms of illness while others noted failure to return because of feelings of good health. Although many programs have focused on efforts to enhance adherence to appointments and medication through patient education, a meta-analysis conducted in 2009 shows that HIV peer education programs in low and middle income countries have no significant positive physiological effect on patients and have not been examined for their ability to increase rates of retention in care [24]. In our project and others like it, the substantial rates of patients citing economic and systems-related barriers to appointment adherence support the argument that health delivery implementers should aim to address structural and systemic barriers to care, rather than focusing predominantly on patient education.

Identifying the unique needs of populations through this cross-sectional survey process helps increase knowledge of factors inhibiting

long-term retention in care, but only targeted interventions will truly aid the fight to improve the health status of individuals and communities. Our hope is that the structure of this process can be helpful to others interested in examining the unique needs of specific populations and increase the inclusion of patient input, especially in low and middle income countries, in efforts to improve care systems.

## Study Limitations

Because this was part of a routine quality of care audit, patients were administered the survey by healthcare professionals, and therefore may have been less forthcoming with criticisms of healthcare professionals and the healthcare system than they would have been with third-party interviewers. By capturing patients at a physical appointment, the patient population in this survey may also have more means and ability to return to care than others. Future investigations may be needed to understand the similarities and differences in the experiences of patients who never return to care even after community health worker outreach or other support efforts.

## Ethical Review

This project was reviewed and approved by the Zanmi Lasante Research and Ethics committee and that the work also was exempted from IRB review by the Partners IRB in Boston, Massachusetts because it is a dissemination of lessons learned from routine clinical quality improvement processes, not a human subject's research investigation.

## Authors' Contributions

All authors have made substantive intellectual contributions to the study. MS and PU conceived of the study, and participated in its design and coordination. AC and PU assisted in translation of data. MS performed statistical analysis. JM has been involved in the design of the HIV program and the PI of the PEPFAR grant that supports it. All authors helped to draft the manuscript. All authors read and approved the final manuscript.

## Acknowledgements

We would like to acknowledge the patients who participated in the project and the staff at Zanmi Lasante sites in the Lower Artibonite region. We are especially thankful to Dr. Jean Paul Joseph, Dr. Ruth Joseph, Dr. Surzie Santiago and Dr. Chenet Celicourt. The work at Zanmi Lasante has been made possible in large part through the generosity of private foundations and donors.

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