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Patient–provider perceptions on engagement in HIV care in Argentina

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Abstract

Approximately 30% of patients participating in the national antiretroviral therapy (ART) program in Argentina fail to achieve an undetectable viral load, and approximately 25% are not retained in care. This qualitative study was designed to explore and identify factors associated with engagement and retention in public and private health care in Buenos Aires, Argentina. Qualitative data from key informants ($n = 12$) and focus groups ($n = 4$ groups) of patients and providers from private and public HIV treatment facilities were recorded and transcribed. Predetermined and arising themes related to adherence, engagement, and retention in care were coded and analyzed using qualitative data analysis software. Reasons identified for patients' lack of adherence or engagement in care differed between patients and providers, and patients attributed limitations to low self-efficacy, fear and concerns about HIV, and lack of provider involvement in treatment. In contrast, providers viewed themselves as decision-makers in patient care and patients as responsible for their own nonadherence due to lack of commitment to their own health or due to medication side effects. Patients reported health care system limitations and HIV concerns contributed to a lack of engagement, and providers identified limited HIV literacy and stigma as additional problems. Both agreed that chronic illness and substance addiction impacted adherence and retention, and agreed on the importance of trust, honesty, and communication in the patient–provider relationship. Results support the incorporation of system-, provider-, and patient-focused components into interventions to facilitate patient engagement, adherence, and retention in public and private settings in Argentina.

Keywords

HIV; adherence; engagement; communication; Argentina

Introduction

Antiretroviral therapy (ART) for the treatment of HIV infection has improved steadily over the past decade, offering more potent, and effective medication, dosing convenience, and better-tolerated combinations. With a population of over 40 million people, Argentina has an estimated 130,000 persons living with HIV (UNAIDS/WHO, 2012; National AIDS

Program), with an estimated prevalence of 0.4% of the adult population (UNAIDS, 2012). In order to provide universal access to ART, the government of Argentina has distributed ART medications to 72% of eligible HIV patients (UNAIDS/WHO, 2012). Yet, despite this effort, approximately 30% of patients participating in the national ART program in Argentina fail to achieve an undetectable viral load, and approximately 25% of those diagnosed with HIV are not retained in care (Crabtree-Ramirez et al., 2011). Adherence, including engagement and retention in care and optimal use of ART, is necessary to maximize the benefits of HIV treatment. Late presentation and initiation of treatment, suboptimal medication adherence, and poor retention in care have been identified as major challenges to successful long-term care in Argentina (Crabtree-Ramirez et al., 2011; Mocroft et al., 2008).

The role of the patient–provider relationship is central to engagement and retention in care and the achievement of optimal health outcomes (Mills et al., 2006). Barriers to the patient–provider relationship, such as patient concerns or beliefs about HIV medication, poor understanding, or lack of knowledge of the disease, attitudes about treatment, adjustment to chronic illness, and treatment side effects have been associated with nonadherence to ART (Fogarty et al., 2002; Ickovics & Meisler, 1997). Treatment success has been described as the shared responsibility of providers and patients (Burns & Vermund, 2010), resulting, in part, from the efforts of both patients and providers to enable the patient to achieve and maintain adherence (Thrun et al., 2009). Communication between patients and providers may be a critical component in facilitating the therapeutic relationship (Beach, Keruly, & Moore, 2006; Clucas et al., 2011; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004). Increased social support by medical professionals, friends, family members have been found to improve adherence to HIV medication and linked to quality of life for patients living with HIV; (Ncama et al., 2008; Peltzer, Friend-du Preez, Ramlagan, & Anderson, 2010; Reilly & Woo, 2004), while a lack of familial and social support have been demonstrated to be a barrier to care (Nachega et al., 2004).

Stigma and its psychological effects have been identified as a barrier to engagement and retention in care and to medication adherence (Murray et al., 2009; Nachega et al., 2004; Varni, Miller, McQuin, & Solomon, 2012). For example, HIV/AIDS patients may fear disclosure of their serostatus by other patients residing in their community, or by providers at their local hospital, or clinic (Bogart et al., 2013). Patients may avoid being associated with the HIV/AIDS health care facility in a local hospital or clinic, negatively impacting engagement and adherence (Mill, Edwards, Jackson, MacLean, & Chaw-Kant, 2010). Health service delivery can also inadvertently promote stigma through the structural organization of health care facilities by, for example, assignment of specific areas or departments within a hospital or health care facility as solely for HIV-positive clients (Church et al., 2013). Stand-alone clinics may be particularly stigmatizing, labeling clients as they walk through the door, resulting in an immediate and involuntary disclosure of their serostatus. Reduction of stigma within the health care setting is, therefore, also a critical goal due to its influence on health service utilization and treatment adherence.

Qualitative research generates in-depth information from the respondent's unique perspective, informing the development of culturally tailored interventions, which may, in turn, be more likely to lead to successful and sustainable programs. The current qualitative study was designed to explore and identify factors associated with patient engagement and retention in care in public and private health care institutions in Buenos Aires, Argentina, to provide the foundation for an intervention to enhance engagement among patients not adhering to treatment. It was hypothesized that patient–provider communication and stigma would be identified as the key elements in engagement and retention in care.

Methods

This study was collaboratively developed and implemented by investigators in the USA and Argentina; the activities presented were conducted May–September, 2012. Prior to the initiation of study procedures, ethical approval was obtained from the University of Miami Institutional Review Board and ethical review committees affiliated with Fundación Huésped and Helios Salud. All study participants provided informed consent prior to engagement in study procedures.

Sites

Participants were recruited from two clinics located in urban Buenos Aires, Fundación Huésped, and Helios Salud. Fundación Huésped is a public nonprofit institution that provides outpatient HIV health care services to over 3000 patients in Greater Buenos Aires. Helios Salud is a private nongovernmental organization that provides outpatient HIV health care services to 3500 patients in Greater Buenos Aires.

Procedure

Key informant interviews (KIIs) and focus groups discussions (FGDs) were conducted by Fundación Huésped and Helios Salud study staff. Types of key informants were selected by the overall team as representative of a broad range of both providers and patients. Twelve key informant interviews were conducted, six at each organization. Six of the key informants were health care providers: four physicians, one laboratory technician, and one administrator, employed at the clinic sites, and six key informants were HIV-positive members of the community. All participants were over 18 years of age and included representatives from all patient populations, including men, men who have sex with men (MSM), sex workers, substance users, and women. A total of four focus group discussions were conducted, two patient focus group with six mixed-gender patients and two mixed-gender focus groups of medical providers (four physicians per group). Fundación Huésped and Helios Salud each conducted one patient and one provider focus group and each conducted six interviews.

KIIs and FGDs were 60–90 minutes in duration and conducted at each clinic site in Spanish by trained and experienced study staff, i.e., psychologists and HIV counselors. All interviews and groups were audio recorded with the explicit consent of all participants, and recordings were transcribed and translated by native, Spanish-speaking study investigators in the USA. Stem items and topics associated with adherence, engagement, and retention were created using an iterative, collaborative process between the USA and Argentina teams at the study sites; primary themes for items were drawn from previous pilot research (Jones et al., 2009; Waldrop-Valverde, Jones, Gould, Kumar, & Ownby, 2010; Waldrop-Valverde et al., 2009), feedback from site staff, and site surveys. Proposed focal themes were then reviewed and refined by the entire team; stem items were presented as open-ended questions, see Table 1 and 2, and time was available in interviews and focus groups to address additional topics as they arose. Predetermined questions about medication and treatment adherence were tailored to patient and provider groups (e.g., definition, practical application, provider awareness of patient understanding and discussion of treatment of options, side effect, and test results, the importance of disclosure and social support, time spent with patients, strategies used to improve adherence, perceived barriers, and working with difficult patients). In-depth, one-on-one key informant interviews addressed similar topics related to medication adherence with questions designed to assess patients' and community members' understanding and attitudes about ART, medication adherence, challenges, and solutions to adherence problems, the perceived role of medical providers in

promoting HIV health literacy and treatment adherence, and the provision of feedback to patients by providers regarding their health status (i.e., viral load and CD4 count).

Coding and analyses

Qualitative data was analyzed using QRS Nvivo9[®] qualitative data analysis software. Themes were identified from transcripts and a project committee consisting of four investigators in the USA, two of whom were bilingual in English and Spanish, coded discrete segments. Clinic study staff then reviewed themes and the entire team to ensure adequate coverage of themes of all topics. The themes summarized below represent challenges and opportunities to establishing treatment adherence and linkage to care among HIV-positive patients in both public and private health care settings.

Results

The primary themes that emerged from patients and providers were obtained from the open-ended questions developed for providers and for patients (Table 1). Communication between patients and providers, treatment commitment, the roles of patients and providers in achieving optimal health outcomes, providing feedback regarding laboratory testing, stigma and social support were discussed.

Patient–provider communication

Both patients and providers agreed that a strong therapeutic alliance was the most important factor in achieving treatment adherence and engagement in care and optimal health outcomes. However, confusion and a lack of congruence existed between patients and providers regarding treatment adherence. Providers asserted that nonadherent patients were a source of frustration in their medical practice and identified patients' poor communication skills and passive attitudes toward their treatment as factors influencing nonadherence. Providers perceived and considered their traditional roles as "authoritarian or paternalistic" with patients, although some felt this had changed over the years. For example, participants in the provider focus group noted:

The paternalistic way of practicing medicine limits or lays aside the patient's opportunity to participate in a more active way and take responsibility for medical decisions. This is a model that runs against adherence. Doctors need to give patients the opportunity to get involved in care and ... to discuss health/personal problems with their doctors.

Providers reported that when patients took an active role with regard to their HIV status and care, patients were more in control of their ART treatment, had better overall understanding of the illness, treatment, and laboratory results and were more engaged in care. For example:

This authoritarian or paternalistic type of practice has been changing over the years and there is more active role from patients. When patients take an active role over their condition, patients do better clinically and have better adherence to medication.

Providers predominantly relied on "intuition" to evaluate their patients' adherence, lacking specific feedback tools, or not using them consistently to evaluate their patients' understanding of medical information. While providers were keen to discuss the long-term nature of illness and treatment with HIV with patients, patients felt a heightened awareness of the chronicity of HIV and overwhelmed by the prospect of a lifelong chronic illness. However, patients asserted that the long-term relationship with their health care providers was an important component for engaging in care and being adherent. The long-term relationship not only offered the opportunity to evaluate laboratory results over time and

consider treatment options but created confidence and a feeling of “trust” with their provider, an important factor for treatment adherence.

Division of responsibility

Patients and providers acknowledged the importance of acceptance of HIV status as a very important factor in engagement and retention in care.

Patients affirmed a sense of personal responsibility for engaging in lifelong treatment:

Acceptance of the disease is crucial for engaging in long-term treatment.

However, they shared experiences of distress related to the burdens of disease management, especially when faced with the term “treatment for life.” Providers accepted responsibility for treating patients, but nonadherence was perceived as patients’ failure to follow medical instructions or to incorporate medication schedules into their lives. Conversely, patients expressed frustration with their provider’s expectation of treatment adherence accompanied by a lack of shared responsibility for achievement of that goal. Intravenous drug users were perceived by providers as the most challenging group due to high loss to follow-up, missed appointments, and treatment nonadherence.

Stigma

Patients and providers agreed that stigma was a major barrier to engagement, care, and treatment adherence. Nondisclosure of HIV status and the fear of being victimized or rejected by families, friends, or community were reported as negatively impacting treatment adherence.

In addition, complicated medication schedules interfering with daily activities such as job/school schedules were of great concern. For example, patients felt that medication regimes were associated with poor adherence when they interfered with their social activities and/or inflexible working schedules:

- If I am in my work or in a public place I am afraid of being watched taking medication.
- Stigma is not as strong as it was years ago, but still is present in the general public.
- It has been very difficult for me to accept my HIV status psychologically, but when I accepted I was HIV I had to confront discrimination. Now I have accepted being a carrier.
- The greatest complication is oneself.

In addition, patients were troubled when the side effects affected their bodies, causing them to be “identified as HIV” by family and friends, specifically when visual signs would appear such as lipodistrophy.

Both patients and providers agreed that patients’ acceptance of their HIV status stimulated family and community support and enhanced adherence. Patients and providers perceived family and social support, as well as understanding of medication side effects, prior to initiating antiretroviral treatment, as both important and helpful components for maintaining ART adherence. However, providers failed to address the potentially negative consequences of HIV status disclosure.

Structural barriers

Patients reported having adequate time to discuss treatment options during the medical visit, review test results and treatment outcomes, and to address side effects almost exclusively when seen by their usual primary physician. However, when patients experienced frequent changes of primary care specialist or physician, those changes were perceived as a strong barrier to adherence. In addition, difficulties obtaining physician appointments or other health care services in hospital settings, such as laboratory tests and pursuing direct access to providers in the emergency rooms or at different community settings were also considered powerful barriers to adherence. Patients reported concerns about confidentiality in clinic settings which involved segregated clinics created to establish separate areas to provide services to HIV-positive patients, identifying patients attending as positive to other clinic patients and personnel:

- Residents and working personnel frequently violate the confidentiality. One time I was told: “don’t worry, every patient here is HIV positive.”
- Personnel (secretaries, nurses and physician assistants) are typically unfriendly.

Facilitators of adherence

Patients felt that practicing acceptance, integrating medication ingestion into daily routines, such as meals and other daily routine activities, were useful to maintaining adherence. In addition, the use of pillboxes and reminders (e.g., calendars, alarms, and written reminders), and creating a daily routine, along with family/partner support, were the most important enhancements to adherence:

- The medicines organized my life.
- The use of reminders such as a calendar and the use of a pill box has helped me take my medication.
- “Before, with the large number of pills I was taking it was too complicated to take my medication, but now that I take two pills twice a day is much better” where some of the comments from the participants.

In addition, patients noted that participating in the study focus groups improved familial and social support, as well as helped patients’ process and overcome perceived stigma and accept their own HIV serostatus and consider the importance of engagement in their own care.

Discussion

This qualitative study was designed to explore providers’ and patients’ experiences and attitudes regarding engagement, adherence, and retention in care. As hypothesized, patient–provider communication and stigma were important factors in adherence to treatment. In addition, concerns about the division of responsibility for treatment adherence and structural barriers arose as important challenges. Both patients and providers agreed that HIV disclosure and familial and social support played an important role in adherence, though the apparent disagreement between patients and providers on responsibility for health outcomes presents an opportunity to open the dialog between patients and providers that may improve engagement in care. While patient’s acceptance of their illness and improved treatment options have been shown to be important aspects of adherence to care, a shared sense of responsibility for treatment may be needed between patients and providers.

Results support previous research regarding the association between communication between patients and providers and improved adherence, quality of life, patient’s satisfaction

with care and reduction of medication-related problems (Boehme et al., 2012; Clucas et al., 2011; Jones et al., 2012; Schneider et al., 2004). Shared responsibility between patients and providers may offer an opportunity to improve communication and problem-solving skills, such as adaptation of patient medication schedules to their daily routines. Furthermore, adaptation of clinic systems to patient schedules and appointment flexibility need to be further evaluated as important opportunities to enhance adherence, facilitating better access to providers.

Stigma has been identified as a major barrier to adherence to HIV care by both patients and providers and results are consistent with previous studies (e.g., Kalichman et al., 2009). Providers highlighted the importance of overcoming stigma as a critical step toward increased responsibility for obtaining care and maintaining adherence but seemed to discount the negative effects that patients faced as a consequence of disclosure. On the other hand, patients perceived that participating in focus groups not only provided a way to obtain information and education on HIV-related issues but also proved beneficial for considering the importance of attending appointments and medication adherence. Patients also found the groups to be helpful in overcoming stigma through peer communication and support. This suggests that group interventions may be an important strategy to reduce stigma in this population.

This study was conducted with a small sample of participants and, therefore, these results may have limited generalizability. However, results elucidate important factors that may contribute to understanding the dynamics between patients and HIV care providers. Results of this study provide a starting point for future research and development of multilevel interventions targeting engagement and retention in HIV care. This broader understanding of the challenges related to adherence and, therefore, potential solutions to nonadherence, presents opportunities for the development and incorporation of system-, provider- and patient-focused strategies into interventions to facilitate long-term adherence and retention in care.

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Table 1

Providers focus group open-ended questions.

1	How to define adherence? What does that mean? What are the difficulties that can be encounter?
2	How do you know that your patient understand your explanations about treatment How important is for patients to know how treatment works?
3	What are the frustrations you experience with your patients?
4	How many of your patients know what they are being prescribed and know how to express how are they feeling?
5	How much time you spend with your patient during the visit?
6	What strategies do you use to improve adherence?
7	What type of questions you ask your patient about treatment and how frequently you ask them?
8	How important is the discussion of the laboratory results with your patient? On each visit or when there are problems? Do patients understand what you are talking about?
9	How important is it for the patient to discuss their HIV status with family of friends? Do patients need to have support from family, friends, work, etc.?

Table 2

Patients focus group open-ended questions.

1	What is adherence and how you define it?
2	What barriers do you identify that affect adherence?
a.	Have you ever had a problem taking your medication?
b.	Have you ever had a problem going to your appointments?
c.	What are the obstacles of adherence?
3	How important are the side effects for you? What are the limitations you have to maintain adherence?
4	Who is the most important person to discuss your medication with and help you on your health care? Who do you go to in order to get more information? What resources are helpful to you in taking your medication on a regular basis?
5	What does not help, i.e., health system, emotional situations, and frustrations?
6	How is a typical visit with your doctor? How much time you spend with your doctor discussing treatment issues? Does the provider ask about treatment?
7	How can you describe your positive and negative aspects in your relationship with your doctor?
8	Have you ever changed your doctor? Why? Do you know someone who has changed the doctor?
9	Have you taken medication? Who decides? How is the process on treatment decisions?
10	Who is in charge now about your treatment?
11	What do you know about CD4 and VL? Do you know what it means?
12	Do you think there are people that do not know their VL/CD4 results and what do they mean?
