

'Staying alive' with antiretroviral therapy: a grounded theory study of people living with HIV in Peru

Juan Manuel Leyva-Moral,^{1,2} Patrick Albert Palmieri ,^{3,4} Blanca Katiuzca Loayza-Enriquez,^{2,5} Kara Lynette Vander Linden,^{6,7} Ursula Elisa Elias-Bravo,^{8,9} Genesis Masiel Guevara-Vasquez,^{2,10} Lucy Yonmey Davila-Olano,¹¹ Mariela Patricia Aguayo-Gonzalez^{1,2}

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For numbered affiliations see end of article.

Correspondence to

Professor Dr Patrick Albert Palmieri;
patrick.palmieri@uwiener.edu.pe

ABSTRACT

Background To achieve an optimal quality of life through chronic disease management, people living with HIV (PLHIV) must adhere to antiretroviral therapy (ART). ART has been available throughout Peru since 2004 without cost in all regions; yet only 60% (43 200) of PLHIV receive ART and 32% are virally suppressed. Despite the low adherence, little is known about the experience of PLHIV with ART adherence in the context of Latin America.

Methods A constructivist grounded theory design was used to understand the ART adherence experiences of PLHIV in Northern Peru. Unstructured interviews were conducted with 18 participants resulting in theoretical saturation. All interviews were recorded, immediately transcribed and analysed concurrently with data collection using constant comparative analysis with Atlas.ti (V.8) software. Rigour was maintained through openness, reflexivity, audit trail, memo writing, debriefings, member checks and positionality.

Results The core category 'staying alive' emerged through the interaction of four categories, including: (1) overcoming barriers; (2) working with the healthcare team; (3) tailoring self-care strategies; and (4) appreciating antiretrovirals. Adherence is not a spontaneous outcome, instead, the surprise of HIV diagnosis transitions to living with HIV as a chronic disease. The healthcare team helps PLHIV realise ART is their life source by enhancing, supporting and facilitating self-care and overcoming barriers.

Conclusion Adherence emerges from experiential learning as PLHIV recognised ART as their life source in balance with their desire to continue living a normal life. Social support and healthcare team interventions help PLHIV implement tailored self-care strategies to overcome personal, social, and structural barriers to adherence. Healthcare professionals need to recognise the challenges confronted by PLHIV as they learn how to continue living while trying to stay alive.

INTRODUCTION

Globally, about 40 million people are living with HIV (PLHIV) with two million in Latin America.¹ In Peru, there are at least 72 000

Key questions

What is already known?

- Antiretroviral therapy is effective at maintaining an undetectable viral load for people infected with HIV essential for the long-term management of HIV as a chronic condition.
- Individual and collective social beliefs provide a wide range of meanings to antiretroviral therapy with some beliefs limiting adherence.
- Existing evidence suggests HIV care is not person centred as there is unidirectional communication and a lack of mutual respect that negatively impacts adherence.

What are the new findings?

- People infected with HIV learn to appreciate antiretroviral therapy as their life source through experiential learning as they try to maintain their quality of life.
- Authentic presence, effective communication and mutual respect offered by healthcare professionals motivate people infected with HIV to tailor self-care strategies to fit their lives.

What do the new findings imply?

- Adherence to antiretroviral therapy evolves from individual beliefs and personal perspectives about HIV to a shared framework with healthcare professionals providing mutual support.
- Person-centred care for people infected with HIV needs to focus on developing trusting relationships with authentic presence, effective communication and mutual respect.
- Future interventions should be tailored to people and situations to maximise adherence while concurrently respecting their strong desire to maintain a good quality of life.

PLHIV including 16 000 unaware of their infection.² HIV accounts for 1.8% of the total disease burden and 1.9% of the total annual deaths (2200) in Peru.^{3 4} Since 2010, prevalence has risen by almost 25%, and

AIDS-related deaths have increased by 15%.⁵ PLHIV need to adhere to antiretroviral therapy (ART) in order to reduce the risk for transmission and to manage HIV as a chronic disease. Despite ART being available without cost in all regions of the country,⁶ Peru has achieved only moderate progress in managing PLHIV⁷ as 60% (43 200) know their status and 60% receive ART. Furthermore, only 32% of Peruvians living with HIV are virally suppressed.⁸ These data are estimates as there is not a national monitoring system.⁹ Peru has not provided data for the newest country score card.¹⁰

As PLHIV attribute meaning to their interactions with people and objectives as a social process,¹¹ they select, organise, reproduce and transform the meaning of living with HIV. Although ART adherence is negatively impacted by the realities of daily living, PLHIV can be adherent between 80%¹² and 95%¹³ to maintain viral suppression. This means there is some room for omissions, oversights, and errors. Adherence is complicated as PLHIV report negative perceptions about ART side effects,¹⁴ efficacy¹⁵ and healthiness.¹⁶ Furthermore, adherence risk has been associated with concerned about dependency,¹⁷ body changes¹⁶ and fatigue.¹⁸ Due to past experiences, some PLHIV associate ART with approaching death.¹⁹ In the context of Peru, one small study with data from 2006 focused on facilitators and barriers to ART adherence reported risk was also related to concern about side effects (74%), perceived danger (19%) and doubts about efficacy (16%).²⁰ Despite these negative perspectives, many PLHIV realise ART keeps them alive.^{21–24}

Previous grounded theory studies related to PLHIV and ART adherence have largely focused on access to care,²⁵ physician practices such as communication,²⁶ counselling strategies such as by community pharmacists²⁷ and symptom management.²⁸ Other studies have focused on targeted populations such as HIV-positive drug users,²⁹ sex workers,³⁰ young people³¹ and asymptomatic people infected with HIV.³² While most grounded theory studies about ART adherence are from an African context,³³ none were identified for Latin America. Furthermore, in the context of Peru, little is known about the experiences of PLHIV with ART. As such, the purpose of this study was to develop a theory about the meaning of ART adherence from the experiences of PLHIV in the Northern region of Peru.

METHODS

Study design

This study adopted a constructivist grounded theory approach^{34 35} to understand ART adherence as a social process for theory development. According to Charmaz,³⁶ constructivist grounded theory provides 'a method of conducting qualitative research that focuses on creating conceptual frameworks or theories through building inductive analysis from the data.' Through this study design, the methodological flexibility originally proposed by Glaser and Strauss³⁷ is maintained as the

theory evolves from the multiple realities, positions and subjectivities of the participants are explored through a constant comparative approach. As such, the interpretative understanding results in a theory grounded in the words and experiences of the participants.³⁸ The study is reported according to the criteria recommended by the³⁹ Standards for Reporting Qualitative Research (online supplemental table 1).

Setting

The study was conducted in Chiclayo, a city in Northern Peru in the department of Lambayeque, with a population of 645 000. Due to the decentralised public health system and the fragmented HIV reporting in Peru, regional data are not readily available from the central government.⁴⁰ However, the HIV unit at the regional hospital where this study was conducted manages about 250 PLHIV each year; more than half non-adherent with ART.⁴⁰ PLHIV receive free health services from a core team composed of a clinical nurse coordinator, an infectious disease physician, and a midwife with support services provided by laboratory, nutrition, pharmacy and psychology professionals. Similar to most Latin American countries, Peru is officially a Catholic country with most people identifying as Catholic. As a result, PLHIV often feel stigmatised and experience discrimination⁴¹ as their HIV infection is considered a divine punishment for sin.⁴²

Sample

Theoretical sampling⁴³ was used to select participants as the interviews progressed. The strategy sought to achieve maximum variability⁴⁴ while the analysis provided the participant profiles necessary to achieve theoretical sensitivity.⁴⁵ The nurse responsible for coordinating the HIV unit verbally invited patients to participate in the study during their normally scheduled visit. The nurse coordinator was well known to the HIV community for her professionalism, community engagement and commitment to improving the quality of life for PLHIV in the region. In addition, the research team was familiar to the HIV community due to multiple interactions during previous studies. After receiving a verbal explanation about the study accompanied by written materials, patients opting to participate in the study were able to schedule an interview appointment, at their discretion, with the principal investigator. This provided potential participants with an opportunity to review the written materials prior to the informed consent process at the time of the interview. The initial inclusion criteria were adults with an HIV diagnosis, clinically managed at the HIV unit, presenting with sufficient mental capacity to participate in an interview. The sample size was determined by the theoretical saturation of the data,⁴⁶ estimated for scheduling purposes between 15 and 25 participants.^{36 47 48} At the end of the interview, each participant was provided with a supermarket gift card with a value of US\$25.

Data collection

Interviews were conducted from September 2018 to May 2019 by experienced qualitative researchers (JML-M, BKL-E) in a secure private location of the hospital. At the beginning of each interview, participants were provided detailed information about the study and questions were answered prior to the interviewer obtaining the written informed consent. Then, demographic information was collected during a short conversation prior to moving into the interview. Data were collected in Spanish through an unstructured interview to explore the meaning of ART, health system experiences, relationships with healthcare professionals, self-care practices, adherence weaknesses and strengths, and challenging experiences related to adherence.

Typical for a grounded theory study,^{49 50} whether classic,⁴⁶ Straussian⁵¹ or constructivist³⁶ approach, the unstructured interview⁵² begins with a single grand tour question⁵³—‘Tell me about your experience with taking your antiretroviral medication each day.’ From this single question, participants described their experience. Brief field notes were collected to note potential areas for additional inquiry or requiring clarification. The interviews, lasting 45–90 min (most about 70 min), were digitally recorded and immediately transcribed for continuous analysis by the research team.^{35 54} Theoretical saturation was achieved with 18 interviews, and no interviews were repeated. The COREQ⁵⁵ checklist, Consolidated Criteria for Reporting Qualitative Studies, was used to guide the reporting of this process (online supplemental table 1).

The participants were informed about the voluntary nature of their participation, their ability to withdraw from the study at any time without providing a reason, the confidentiality of their participation, and the deidentification of data for reporting. Once all questions were answered, each participant was asked to sign an informed consent. Given the sensitivity of the research topic, participants were instructed during the informed consent process to report any feelings of emotional distress during the interview. Although there were no unanticipated situations, the interviewer was prepared to contact the healthcare team, if necessary, to protect participant safety within the context of the confidentiality agreement.⁵⁶ Physical study documents were secured external to the HIV unit while digital files were maintained on a password-protected laptop. No data that could result in participant identification was collected during the interview. A pseudonym was chosen by each participant to facilitate their ability to learn how their data contributed to the grounded theory.

Data analysis

The data were analysed concurrently throughout data collection using constant comparative analysis³⁴ with the Atlas.ti (V.8) software. This analytical process resulted in each interpretation and associated finding being compared with the existing findings emerging from the constant comparative analysis.⁵⁷ Interview debriefings

were completed after each session to summarise discussions, identify potential areas for clarification, note congruences and incongruences with other interviews and inform sampling. Transcripts were independently reviewed multiple times by the researchers (BKL-E, JML-M) to become familiar with the content prior to coding. Data analysis involved open, axial and selective coding as phrases, expressions and words that denoted specific content were assigned a descriptive code.⁵⁰ Through a process of continuous critical reflection, the 106 initial codes were organised by researchers (BKL-E, JML-M, MPA-G, PAP) into 13 subcategories and grouped into four categories with an interpretative meaning.⁵⁸ No deviant cases were observed. Memos captured important information for discussion, questions and reflection as the codes and categories emerged from the data, including properties and dimensions.⁵⁹ With constant comparative analysis and collaborative conversation,⁶⁰ the research team (BKL-E, JML-M, KLV, MPA-G, PAP) developed a deep understanding about the relationships between the categories. Finally, a clear core category emerged to explain the phenomenon with theoretical sensitivity.^{61 62}

The credibility, originality, resonance and usefulness³⁴ of the results were demonstrated through openness, immediate transcription, memoing, constant comparative analysis, theoretical sampling, saturation and sensitivity, and a substantive theory.^{63 64} Two experienced qualitative researchers with diverse backgrounds interviewed the participants to limit bias, while recordings, transcripts and memos established an audit trail. Member checking was completed at the end of each interview through a brief discussion with participants to confirm the accuracy of the interpretation captured from their interview. Verbatims were translated into English and verified by two bilingual research team members, applying a previously reported process,⁶⁵ to insure the translated verbatims retained not only syntax but also the original meaning. The results were verified with external consultation, with minor refinements for two category names. The core category was collectively noted to define the central meaning without further recommendations.

Reflexivity

For a grounded theory to be methodologically rigorous⁶⁶ the two interviewers and the other researchers engaged in the data analysis need to be reflexive⁶⁷ as categories emerge from the data⁶⁸ rather than preconceptions forced into the data. In this regard, the research team (multidisciplinary, multilingual, multicultural and multinational) recognised their interactions with participants and discussions with colleagues can influence the study design, data collection and analysis, and interpretation as written results.⁶⁹ The team maintained an open dialogue with ample opportunity for self-reflection. Open communication and reflexive practices resulted in the team achieving a deep understanding of the data.

RESULTS

In total, 18 participants living with HIV were interviewed, including 11 men, 7 women and a transgender woman, between the ages of 18 and 59 years. The participants reported actively taking ART and acquiring HIV through the sexual route. Most of the participants reported an undetectable viral load (12) with four detectable and two uncertain. Sociodemographic characteristics for the sample are presented in [table 1](#).

The core category ‘staying alive’ represents adherence through experiential learning as PLHIV develop strategies to achieve an equilibrium in living, socially and healthy, despite their HIV infection. Staying alive emerges from four interconnected categories, including: (1) overcoming barriers; (2) working with the healthcare team; (3) tailoring self-care strategies and (4) appreciating antiretrovirals. As a substantive theory underpinning the experience of PLHIV with ART adherence, staying alive necessitates PLHIV overcoming a series of personal problems and external barriers to care for themselves. Largely focused on ART adherence, survival needs to be balanced with maintaining a meaningful quality of life.

[Adherence] It is like my pass to be able to survive day by day, because if I do not take it [the pills] I feel that I am going to decline and I would not continue my life, at least as I had planned, since my defenses are going to fall, it can affect me and I can die (Oscar).

Rather than simply obeying medical advice, adherence is the personal understanding about what is happening, realising there is an effective treatment and access to health and social resources. PLHIV seek autonomy despite their dependence on the health system. In this regard, healthcare professionals maintain a critical role in helping PLHIV understand their disease, access their medications, and manage their new reality through personalised care with a humanised approach. Once the personal problems and external barriers are overcome and trusting relationships with healthcare professionals are consolidated, self-care strategies emerge as effective ART to manage the HIV infection as a chronic disease. [Figure 1](#) is the visual interpretation of the theory to explain how PLHIV are staying alive with ART.

Overcoming barriers

Establishing a favourable relationship with ART requires PLHIV to face the HIV diagnosis, accept the changes to their lives, and learn to live with the feelings of guilt and regret. For the most part, these feelings are based on the discriminatory and stigmatising experiences they reported following diagnosis. Consequently, they fear infecting their partners, a fact that on many occasions results in celibacy or feeling obligated to reveal their serostatus before beginning a new relationship. Similarly, PLHIV with children or expected to have them, struggle with the possibility of their children becoming infected. Ultimately, managing their fear and guilt results in an

opportunity to consolidate ART adherence and remain vigilant in protecting their family.

He [my husband] also knows that he has to protect himself, although I remember a doctor telling us both that if I was undetectable, I couldn't hurt him. But I don't want to risk it. I do not dare. It's been 4 years now and we have always taken care of ourselves. Although he wanted to make it normal [condomless] because the doctor said so, but I keep saying no (Catherine).

I feel relieved, happy, because I am taking my treatment. Thanks to this NGO I had my son and I hope that my son does not have this disease, they are still studying him. I'm dying to think that I might have infected him (Margarita).

The health system presents a myriad of barriers that must be overcome to achieve adherence. This acceptance is characterised by PLHIV simply obeying, or submitting, to the norms, including consciously resigning themselves to the consequences of norms. Wait times, privacy, anonymity, visit length and bureaucracy are all barriers limiting access to care and interfering with activities of daily living, such as working and caring for children.

I think that attention must be faster. The procedures are very cumbersome. We have responsibilities and asking permission from a company [employer] for several days affects you (Antonio).

A major concern for PLHIV is privacy violations are uncontrollable. They become ‘visible’ in the waiting room clearly identified as ‘infectiología’ (name of the infection area in Spanish) in the same vicinity as other medical specialties when seeking care. Although they want to keep their diagnosis hidden, PLHIV believe anyone who sees them waiting in this area will be suspicious about their diagnosis. This generates discomfort which they are forced to accept as there is no other option to stay alive. These medical visits are essential because their ART prescriptions are provided at this time.

I always say to my wife, what are they [the other patients waiting in the room] going to think? Of course, they will know that I have HIV if I come to the door where they say infectious diseases [...] If you meet someone you know and ask you what you are doing here in infectious diseases, you have three or four options to say: I have tuberculosis, I have a virus, a parasite, or HIV and any of those are frowned upon. The name [infectiology] is wrong for me (Jorge).

Another concern of PLHIV is the excessive number of students, including interns and residents, entering and exiting the ‘infectiología’ area during their appointments. This is an additional barrier related to balancing privacy concerns with the required monitoring for medication distribution. PLHIV feel uncomfortable and vulnerable when revealing confidential information with so many bystanders. The environment and policies place them in a difficult position where they often submit to make things simple. They emphasise; however, they really dislike this disrespect of their privacy.

Table 1 Participant characteristics

Name (Pseudonym)	Age	Sex	Relationship status	Year of diagnosis	Transmission route	Education	Profession	Viral	
								Load	Sexuality
Antonio	36	Male	Single	2015	Sexual	Secondary	Industry	Undetectable	Heterosexual
Carlos	42	Male	Single	2014	Sexual	College	Commercial	Does not know	Homosexual
Caterine	38	Female	Cohabiting	2006	Sexual	Elementary	Grocery	Undetectable	Heterosexual
Flor	59	Female	Cohabiting	2016	Sexual	Secondary	Housewife	Undetectable	Heterosexual
Florence	44	Female	Single	2015	Sexual	Secondary	Housewife	Undetectable	Heterosexual
Gustavo	35	Male	Single	2015	Sexual	Secondary	Construction	Detectable	Heterosexual
Jorge	24	Male	Cohabiting	2016	Sexual	College	Business	Undetectable	Heterosexual
Juan	49	Male	Single	2015	Sexual	Secondary	Cook	Does not know	Bisexual
Margarita	22	Female	Cohabiting	2016	Sexual	Elementary	Housewife	Undetectable	Heterosexual
Michael	35	Male	Cohabiting	2014	Sexual	Secondary	Construction	Undetectable	Heterosexual
Micky	33	Male	Single	2017	Sexual	Secondary	Cook	Undetectable	Homosexual
Miguel	23	Male	Single	2018	Sexual	College	Architecture	Detectable	Homosexual
Monica	23	Female	Cohabiting	2016	Sexual	Secondary	Bus	Detectable	Heterosexual
Oscar	18	Male	Single	2017	Sexual	College	Student	Undetectable	Bisexual
Ricardo	27	Male	Single	2015	Sexual	College	Engineer	Undetectable	Heterosexual
Rosen	46	Transgender	Single	1993	Sexual	College	Tourism	Detectable	NA
Tulipan	25	Female	Single	2015	Sexual	Secondary	NA	Undetectable	Heterosexual
Walter	20	Male	Cohabiting	2018	Sexual	College	Student	Undetectable	Homosexual

NA, not available.

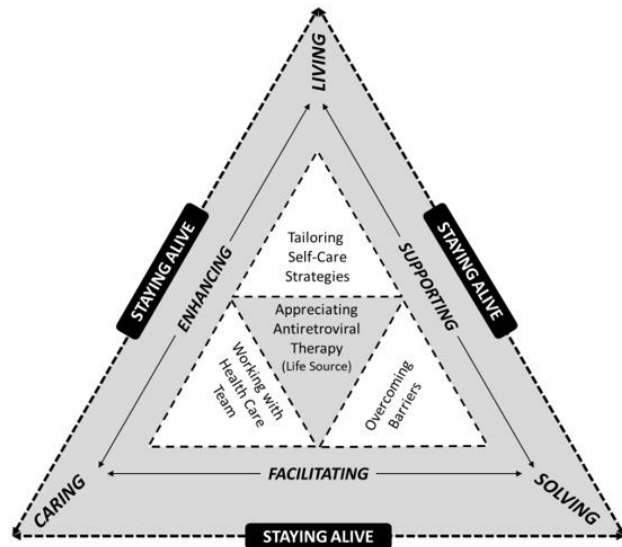


Figure 1 Theoretical representation for ‘Staying alive’ with antiretroviral adherence.

... practitioners [referring to students] listen too. I am ashamed because they [medical records] are private things and I do not know them, and they are going to meet other people and talk (Walter).

Working with the healthcare team

Life attributed to the ART emerges from the central role of healthcare teams, among which 'infectólogos' (infectious disease physicians in Spanish) and nurses are the central professionals interacting with PLHIV. In terms of physicians, PLHIV respect their scientific knowledge, as well as their remarkable human gifts. The nurses are appreciated for their personal proximity, protection and technical knowledge. Participants constantly reiterated ‘they treated me well’ to define courtesy, familiarity, availability, accessibility, decision making, awareness, resolvability and individualisation. PLHIV compare the physicians and nurses to ‘angels’ responsible for watching over their lives, a figure of special relevance in practicing Catholic countries.

If it weren't for them [health care professionals], I would no longer be here. So, I tell him that the staff of doctors, and more than all the nurses and technicians, for me coming to them is like I feel like a family, they are angels to me (Carlos).

Situations that could be considered inadequate care or poor professional conduct are perceived by PLHIV as rough but well intended. PLHIV focus on the comments from the healthcare team as strategies to motivate them to achieve health and wellness. What in other circumstances might result in a complaint, in the case of PLHIV is reason for reflection and sincere appreciation.

When I got pregnant, I stopped taking the treatment because I thought it would hurt my little boy; I didn't take it for a month and the doctor yelled at me angrily 'you have to take it because that won't hurt the baby!' and I kept

taking it, and I'll always be grateful to him because he made me open my eyes (Margarita).

[The nurse] told me in a bad mood ‘you are not invincible! I know patients who have done very well and the next day have been bad. So, you must take the medication properly!’. I did it and I'm still here (Ricardo).

In addition to physicians and nurses, PLHIV recognise good care is provided by all members of the healthcare team. PLHIV recognise their overall state of health is improved by everyone working together. Several participants noted the important collaborative role of pharmacists and psychologists in maximising the effectiveness of their care.

He [psychologist] is giving me very good recommendations that I am trying to put into practice in my daily life and yes, he is taking good care of me. I am still with the psychologist on that subject of anxiety and I am doing much better (Oscar).

The pharmacist is the one who has given me most information. She does not just give me my medicines, no, she explains everything to me. When the doctor changed my medicine because of the resistance I made it shocked me a lot because I was taking care of myself a lot, I did not have sex, I took the medicine on time...they explained and reassured me, especially the pharmacist giving me all that information and showing they cared for me. I will never forget that (Miguel).

Tailoring self-care strategies

Self-care is experientially learnt by PLHIV with acceptance of the diagnosis and increased familiarity with the treatment. As PLHIV engage in more self-care, they become aware of the relationship to living longer and better. Increased trust and better communication with the healthcare team results in PLHIV learning how to change a series of habits, including diet, exercise, alcohol consumption, drug intake, sex, and treatment adherence. Thus, PLHIV realise strengthening adherence results from their better self-care.

I have to be aware of what the treatment is, do things that do not affect me, deprive myself of some things. If not it [ART] will not work for me and I will get worse (Miguel).

On a personal level, self-care involves protecting themselves from situations that endangered them emotionally. This involves developing strategies for secretly taking medications to prevent exposures that can result in stigma and discrimination.

I prefer to take them [ART] away and so nobody finds out. Just like when I'm at home, when I'm with my partner, we wait for people to leave and how we know that we have the pills in our pockets, we take out the bottle, and that's it. You know, in case they react badly (Ricardo).

Establishing a routine for taking ART at the same time requires considerable effort, especially for PLHIV who travel, work long hours or maintain an active social life with alcohol consumption. Despite understanding

how to achieve medication efficacy, PLHIV struggle to manage the competing demands of living with staying alive. However, they are often willing to make unilateral decisions that put their adherence at risk. All participants acknowledge having missed doses, either by forgetfulness or consciously for a reason. As they realised there is not an immediate effect on the results of their lab tests, they were not too stressed and move on with their life.

Sometimes I have a meeting out there and I don't take it [ART]; I put it off the next day because I know I'm going to drink. One day only and the next day I will take it again, otherwise it would put my life in danger (Micky).

Engaging in self-care is managed concurrently with poor advice from family members, as well as their personal beliefs about physical changes and fears of side effects. PLHIV may suspect they would have problems, and some are convinced that ART will make them feel terrible, due to past experiences. However, fear of immune relapse or other complications continues to motivate PLHIV to keeping taking their medication. This necessity as well as the potential consequences for failure is reinforced through conversations with the healthcare team.

It [ART] makes me fat and I don't like to see myself like this. That is what bothers me and I have seen that since I have started taking the pill again, I was getting fat again and that bothers me, but I still take it, thanks to the nurse who told me that if I wanted to die or be in Intensive Care, so I would stop taking medication (Carlos).

Appreciating antiretrovirals

When initiating ART therapy, there are a series of side effects including gastric discomfort, dizziness, weight gain and nightmares. Although feelings emerging during the initial phase are often described as intense and difficult to manage, with time, reflective thinking, individualised care and tailored prescribing protocols, PLHIV report being able to adapt to the new reality, essential to stay alive.

At first, adverse reactions were difficult for me, but little by little they [health care professionals] have taught me that I live with that and I started to overcome it, I already got the idea of what I have. This is yes or yes; I have to take them (ART) (Ricardo).

However, memories about these side effects continue to be associated with beliefs constructed by social interactions with others in considering how to continue living with changes in therapy. For PLHIV, the medications produce changes in their bodies, which they must accept as the 'price to pay' to stay alive. Still, they feel grateful to the healthcare team and to science for allowing them the opportunity to continue living. PLHIV often describe medications as their life source and sometimes relief from their discomfort beyond the merely biological, transcending the social and the spiritual.

It [ART] is giving me more desire to live, so I feel better, I no longer have discomfort, I have more desire even to

work, to be with my friends. I also rest with peace of mind because I take it the moment I go to sleep, thinking and asking God that I will be better. Also, I think that it cleanses my blood more, that it kills the virus; in the talks I have had with the nurses they explained to us that if you are pending your medicine, the opportunity will come to kill all the viruses (Juan)

Finally, the recognition of ART as a life source is accompanied by a feeling of dependency and submission to medications. PLHIV understand their chronic disease does not allow many exceptions to the medical management plan. In other words, PLHIV realise their health and their ability to continue living depends on their adherence.

For a while my stomach hurts, it burns, but what am I going to do? I have to take it [ART]. It makes me want to vomit, but I have to take it by law. I have to drink water to make it happen, but despite everything it is a relief because I am alive (Margarita).

DISCUSSION

This study describes how ART is a life source for PLHIV. As evidenced by the participant voices, they focus on 'staying' alive' to continue living. Similarly, researchers in other areas of the world with different sociocultural contexts reported PLHIV are adherent to stay alive.^{23 70 71} In some low/middle-income countries, however, PLHIV call ART toxic due to the side effects or exposure as they become visible for discrimination.^{72 73} Appreciating ART as a life source requires experiential learning rather than obeying medical orders. PLHIV mature in understanding their infection as a chronic disease with the help of the healthcare team and significant people in their lives. Staying alive requires PLHIV to learn how to manage barriers to personal wellness such as stigma, prejudice and discrimination.⁷⁴⁻⁷⁷

The relationship between PLHIV and their healthcare team directly contributes to ART adherence. When PLHIV perceive better treatment, they are more adherent.⁷⁸ Good engagement with the healthcare team results in more effective information exchanges with PLHIV.⁷⁹ Some researchers address the 'good patients' (obedient, patient, courteous, attentive, intelligent, clean, honesty, gracious) as the most effective in adapting to the new lifestyle, adhering to ART and attending appointments.^{80 81} This study found caring relationships with the healthcare team, including the authentic presence of nurses, was similar to the other, but older, studies.^{82 83} However, this finding is not generalisable as many healthcare professionals continue to demonstrate a lack of knowledge,⁸⁴ maintain paternalistic attitudes⁸⁵ and avoid discussing sexual health.⁴¹ Despite 21% of PLHIV in Peru being denied health services during the last year,⁸⁶ they have more trust in their healthcare team than people with a HIV negative status.⁸² The effective information exchanges within the context of a trusting provider-patient relationship may explain the lack of

participant concern about ART medication knowledge in this study.

PLHIV try to adhere to ART because they recognise the medication keeps them alive. As a result, the definition of engagement proposed by Higgins *et al.*⁸⁷ needs to be reevaluated in the Peruvian context. Engagement, or 'the desire and capability to actively choose to participate in care in a way uniquely appropriate to the individual in cooperation with a healthcare provider or institution for the purposes of maximising outcomes or experiences of care' should also address survival. In this study, the participants choose to engage in self-care but always with the belief that non-adherence would result in their premature death. The submission to adherence has been described in other studies as the only way people infected with HIV can continue to live.^{23 88} In addition to adherence, this study describes the ways PLHIV engage in self-care activities, including health promotion. Similar to the findings reported by Iribarren *et al.*⁸⁹ PLHIV engage in diverse self-care activities, such as taking medications, modifying activities, altering diet, seeking help, waiting, managing thoughts, changing attitudes and altering the physical environment. These results are consistent in different groups and contexts such as people living in rural areas,⁹⁰ and older women living with HIV.⁹¹ In general, adherence appears as the social representation of staying alive.

In addition to staying alive, the social context of living, such as going to clubs to drink and dance, was important for PLHIV to connect with friends and meet acquaintances. In this regard, alcohol consumption is reported to impact ART effectiveness and to contribute to missing doses.⁹²⁻⁹⁴ However, participants in this study adapted ART management to plans to consume alcohol or to have a 'night out on the town' because they believed mixing alcohol with ART would produce severe side effects. This is especially a problem for PLHIV with strong alcohol-antiretroviral toxicity beliefs.^{95 96} PLHIV with a history of intentionally missing ART doses to engage in substance abuse (including alcohol) having lower ART adherence and poorer treatment outcomes.⁹³ The participants in this study, however, reported personalised but cohesive strategies for 'rescheduling' rather than missing or skipping doses to balance their desire to live with the reality of staying alive. They decided to implement these tailored strategies thanks to the support of their healthcare team.

Access to ARTs was a limited factor that interfered with adherence for participants in this study. Previous studies found long lines and difficulty getting appointments were barriers for adherence to treatment.^{97 98} Although the data were not consistently observed in this study, several participants complained about numerous procedures, as barriers, to schedule a new or reschedule an existing appointment. Previous research in this region of Peru found PLHIV were able to access medications despite the barriers with the assistance of their healthcare team.⁴⁰

Strengths and limitations

To the best of our knowledge, this is the first study to report ART adherence experiences of PLHIV in Latin America using a grounded theory approach. Furthermore, this is the first study to report such experiences from Peru. The research team has extensive experience in qualitative methods, including grounded theory, as well as previously published studies focused on improving the lives of Peruvians living with HIV. The research study design was rigorous as theoretical sampling facilitated a diverse sample; the constant comparative analysis resulted in understanding the participant experience rather than inductively positioning the experience in a preconceived context; and theoretical saturation was achieved.

Despite the strengths, there are three limitations for discussion. First, the sample represents a younger segment of the population principally in the second and third decades of life. However, this sample is similar to the age profile of an earlier study reported in the region.⁴⁰ Second, the results should not be generalised further than the Peruvian context without similar cultural and contextual characteristics. In Peru, as in other countries located in the Andean region of South America, the regional culture and developing economy context coupled with strong Catholic identity is dissimilar to other regions such as Africa and Asia. As such, the results could be informative for the similar sociocultural contexts of other countries in the Andean region of South America. Third, translating interviews can result in bias due to the adaptation of words and phrases from Spanish to English. As the research team was mostly bilingual and a previously reported strategy was used for the translation process, the risk for bias was minimised but not eliminated. The original quotes to support the categories in Spanish with translations in English are provided in online supplemental table 2 for transparency in reporting. The supplemental table also contains additional data for each category as a best practice to facilitate future metasynthesis in ART adherence.

Finally, as an important methodological notation, the incorporation of maximum variation sampling could have limited the findings to patterns observed across participants with significance derived from their heterogeneity.⁹⁹ The resulting theory may be broader in scope as a result of the sampling strategy. Future inquiries with more homogeneous samples resulting from different sampling strategies may provide additional depth to better inform the categories of the current theory.

CONCLUSION

Adherence emerges through experiential learning as PLHIV recognised ART as their life source. Adherence is not a spontaneous outcome, instead, the surprise of HIV diagnosis gradually transitions to living with HIV as a chronic disease. There are essential cognitive processes to assess ART in terms of recognising the benefits and implementing self-care strategies, including overcoming

personal, social and structural barriers related to adherence. Healthcare professionals need to understand the challenges encountered by PLHIV as they strive to be adherent with ART. Importantly, PLHIV trying to personalise strategies to continue living while staying alive. In order to maximise adherence, interventions may need to be tailored for individual situations with effective communication and mutual support. Community-based participatory research and other qualitative research designs may be helpful for future studies to further understand adherence dynamics as a survival strategy rather than compliance with a therapeutic plan.

Author affiliations

- ¹Grup de Recerca Infermera en Vulnerabilitat i Salut (GRIVIS), Departament d'Infermeria, Universitat Autònoma de Barcelona, Barcelona, Spain
- ²Qualitative Health Research, Evidence-Based Health Care South America: A JBI Affiliated Group, Lima, Peru
- ³South American Center for Qualitative Research, Universidad Privada Norbert Wiener, Lima, Peru
- ⁴College of Graduate Health Studies, A.T. Still University, Kirksville, Missouri, USA
- ⁵Facultad de Medicina Humana, Universidad San Martín de Porres, Chiclayo, Peru
- ⁶Department of Research, Saybrook University, Pasadena, California, USA
- ⁷Glaser Center for Grounded Theory, Institute for Research and Theory Methodologies, Poway, California, USA
- ⁸Escuela de Enfermería, Universidad Científica del Sur, Miraflores, Peru
- ⁹Estrategia Sanitaria de Prevención y Control de VIH-SIDA, Hospital Regional Lambayeque, Chiclayo, Peru
- ¹⁰Departamento del Desarrollo de Investigación Básica Clínica, Hospital Regional Lambayeque, Chiclayo, Peru
- ¹¹Servicio de Obstetricia, Hospital Regional Lambayeque, Chiclayo, Peru

Twitter Juan Manuel Leyva-Moral @juanleyvamoral, Patrick Albert Palmieri @tweetpalmieri, Blanca Katuzca Loayza-Enriquez @BlancaLoayzaEn1 and Kara Lynette Vander Linden @rtm_cgt

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ORCID iD

Patrick Albert Palmieri <http://orcid.org/0000-0002-0765-0239>

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