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Participants' representations of a psychosocial intervention to improve adherence to AIDS treatment

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This paper presents the qualitative investigation and analysis of representations constructed by 29 patients on the experience of their participation in a psychosocial intervention to improve adherence to antiretroviral treatment. The intervention was performed at a reference service in STD/AIDS of the State of São Paulo (Brazil). Long, semi-structured interviews were conducted with the patients in order to apprehend, understand and explain the relationship between the patients' everyday life and their adherence to treatment, investigating *if, how* and *why* the experience lived during the intervention transformed this relationship. The resulting qualitative analysis indicates that, by raising the patients' *awareness* of the importance of (self)care regarding the prescribed and continued use of medication, the intervention enabled the patients to *learn* their own ways of including adherence in their everyday life, and they may transform it through the improvement in this adherence.

Keywords: Aids/treatment. Patient adherence. Everyday life. Representations. Psychosocial intervention.

Introduction

Patient adherence to drug treatment is an important issue in the field of healthcare for people living with HIV (PLHIV)[1]. In addition to its crucial role in the achievement of the clinical result, adherence represents the way in which these people experience the relation to the disease and treatment in their everyday life[2].

To a set of patients, this relation expresses the fundamental contradiction of their lives, as the severity of the disease, which has become chronic, does not necessarily lead to the inclusion and maintenance of adherence as a daily and regulated activity in their everyday life – which means taking the medication regularly, following the recommended diet and changing their way of life.

Therefore, to understand and explain why and how their adherence difficulties occur and may be overcome, it is necessary to investigate the everyday life of this segment of PLHIV by means of their relations to the disease and treatment, in the multiple domains of their social practice – work, family and affective life, leisure, etc. At the same time, we should bear in mind that such relations are pervaded by the experience of stigma and discrimination, which, in turn, intensify the difficulties and make them become even more complex.

To analyze the possibilities that treatment adherence becomes fully included in the everyday life of PLHIV and, thus, transforms this everyday life and is simultaneously transformed by it, we need to know the situation and the living conditions of these people. This is only possible when we apprehend the representations they construct about their everyday living.

It is in the context of this proposition that this paper presents the qualitative analysis of representations constructed by a group of patients about their participation in a psychosocial intervention to improve adherence to antiretroviral treatment (ART), tested at a public reference service in STD/AIDS located in the city of São Paulo. The service offers outpatient assistance provided by a multidisciplinary team to approximately 4,500 patients from different age groups, levels of schooling, social conditions and places of origin.

The results of this intervention have been described in previous publications[3-4] and are now complemented by this paper, which analyzes it from the point of view of the patients themselves (self-designation). It apprehends the life histories of patients as subjects who are simultaneously individual and collective, to reveal them in their double determination: as life histories of physical, psychological and social suffering, but also of daily survival in relation to them; life histories that can be transformed by treatment adherence, provided that adherence is also transformed by them.

Methodology

The intervention

Among several intervention modalities to improve ART adherence, psychosocial interventions based on Care[5(c)] have consolidated as an important reference in the constitution of current health practices. Their application, as an alternative to the model of assistance that is exclusively based on the technical dimension, recommends that healthcare should involve an ethical-political dimension in the “dialogic relationship” between health professionals and PLHIV, based on the promotion of an individualized “listening” (Translation's Note: This is a free translation of the notion employed by the author), in which patients are viewed as subjects who have a “practical knowledge”[5] (p.63) that enables them to construct, in the singularity of their everyday life, the best way of living with their treatment, grounded on new understandings of their adherence difficulties and, consequently, new ways of facing and overcoming them[4,5].

Therefore, based on the presupposition that the patient is capable, in his/her context of life, of finding the best way of following his/her treatment, using autonomy as a stimulus to individual care, the psychosocial intervention performed in the health service mentioned above aimed to stimulate the participants to reflect on their everyday life of PLHIV, identifying factors that prevent treatment adherence and, simultaneously, interfere in their quality of life[4].

To achieve this, patients undergoing ART for more than six months at the service and with viral load detected in the last test were invited to participate in the

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[c] Concept written by Ayres[5] with the first letter in uppercase in order to differ it from the traditional meaning of assistance centered on clinical care.

research study. According to the design of the clinical trial, adherence measures were monitored by bottles of antiretroviral drugs (MEMS – Medication Event Monitoring System). The bottles have an electronic device that registers, for six months, the times when patients opened the bottle to take the medication: two months for randomization in the control and intervention groups; two months during the psychosocial intervention; and two months after it[3].

Three professionals from the service team were previously trained and conducted the intervention group. The professionals – two psychologists and one social worker – were divided across subgroups of patients and performed, individually, during the 3rd and 4th months of the research study, four *dialogic* encounters lasting approximately one hour, every fifteen days, about their (self)care difficulties[4,5]. With the representation of these difficulties in *scenes*[6](d), the encounters aimed to enable them to identify and understand what prevented them from following the treatment, so that they could recognize themselves as capable of constructing new ways of interacting with their (self)care[4,5].

Table 1 presents the methodology of the intervention.

Table 1. Methodology of the intervention

	Encounter 1	Encounters 2 and 3	Encounter 4
Objectives	Contract;	Increase knowledge about the treatment;	Deepen the understanding of feasible and desired changes in the context and in the patient's own conduct, aiming at self-care and at the improvement in the quality of care and of patient-professional communication;
	Identify situations and contexts of everyday life that are obstacles to the treatment;	Understand and decode real-life scenes;	Identify resources to pursue and sustain the paths chosen to face difficulties in ART treatment;
	Decide on priority issues and themes to be addressed in the subsequent encounters;	Amplify the scenes to a larger social and programmatic context;	Close the process.

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[d] In "conversations in scenes", patients act like characters who represent to the "scene director" (the health professionals) the treatment difficulties in their "sociocultural contexts", with the aim of discovering new ways of playing their own role.[6] (p. 165)

	Clarify technical doubts about the treatment.	Foster creative and active imagination about everyday life; Foster new personal repertoires to face the obstacles to the treatment that were identified.	
Themes	Mutual recognition of patients as experts on everyday life and professionals-researchers as technical experts;	Questions about the treatment;	Questions about the treatment;
	Review of patients’ social and inter-subjective context;	Real episodes in which the treatment is not followed;	Review of paths, solutions and repertoires;
	Questions about the treatment.	Paths to face obstacles and solutions “in scene”.	Conversation about how to face future obstacles and difficulties and sustain changes; Final clarifications and orientations on the research study.
Methodology	Discussion about the procedures, aims and contract;	Review of the contract and of the raised questions;	Review of the contract and of the raised questions;
	Free conversation and careful listening of the person’s life	Identification of typical non-adherence episodes;	Identification and exploration of scenes from real episodes;
	Focus on issues of the treatment and on situations and episodes in which following the treatment is difficult;	The participants choose their priorities from a list of problems;	Decoding and reinvention of scenes through active imagination and role-playing;
	Use of informative resources (folders, guidelines, adherence kits);	Identification and exploration of scenes from real episodes;	Information on social and programmatic resources, as well as on constitutional rights;
	Record of specific situations and episodes that seem to be important to cope with on recording sheets	Decoding and reinvention of scenes through active imagination and role-playing;	Record of decisions and plans for the future on recording sheets.
		Conversation about obstacles that are beyond individual action and are shared by other PLHIV; Discussion of individual and programmatic resources; Professional and patient record and organize hierarchically scenes and situations on recording sheets.	

* Table adapted from Basso et al.[3], by Santos et al.[4] (revised in March 2016).

The qualitative investigation

According to the intervention protocol, after the encounters, the concluding stage of the research study should investigate patients' representations about their experience of participation in the intervention. The aim was to explore and analyze *if, how* and *why* the experience of this process would have enabled an improvement in adherence that would be capable of changing their everyday life, while being simultaneously transformed by it.

Overall, 44 patients were present at the four individual encounters of the intervention. The main author of this article collected the oral reports of 29 patients who volunteered to participate in the qualitative stage of the research study and signed a consent document. These reports were obtained by means of the technique of interviews, which was considered more adequate to apprehend the life story of the research subjects, and were complemented by a field diary containing notes about their relations with the researcher and the context of the interviews, the service and its professionals. The reports followed an interview guide containing 40 semi-open-ended questions, lasted an average of two hours, were recorded and, subsequently, transcribed, and occurred between September 2008 and February 2009.

These interviews aimed to apprehend the research subjects' representations of their life trajectory since before they got sick, and focused on their current representations about the experience of the *scenes* enacted in each one of the intervention encounters[6].

The concepts of *representation* and *everyday life*

With the same theoretical perspective that grounded the intervention, based on the notion of Care[5] and on the constructionist psychosocial approach[6(e)], the qualitative investigation aimed to apprehend and analyze the relation between patients' conditions and way of life and their (self)care, by means of their representations[7].

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[e] Approach based on the dialogic communication between professional and patient, by means of constructed and shared meanings about the relation established to the treatment.

To analyze the *representations* constructed about/in/from the *everyday life* of the research subjects, the concepts of *representation* and *everyday life* formulated by Henri Lefebvre were employed as theoretical framework. Understood as the mediation between what was *lived* (simultaneously individual and collective) and what was *conceived* (concerning theoretical concepts and ideologies), representations constitute what is *perceived*, that is, the conscience that interprets (at the level of common sense) what was experienced and practiced, as it is not possible "to understand and live a situation without representing it"[7] (p. 63).

Therefore, it is by means of their representations that we aimed to apprehend and interpret the research subjects' *everyday life*, according to Lefebvre's conception, which considers the dialectical relation among the three elements that compose everyday life in the capitalist society: work, family and leisure (as activities performed in the individual's free time from work's and domestic life's obligations)[8].

Thus, the analysis was guided by the understanding that it is through representations that the research subjects can reflect on: the past time, when the disease did not determine their everyday relations and was not determined by them; the present time, in which everyday life is mediated by the illness and by lived relations like absence, caused by the loss of work, and/or the rupture in family or affective bonds, and/or the intermittence of leisure activities; and the future time, related to the possibilities of changing the everyday life and improving the conditions of health and quality of life.

Table 2 describes the interviewees.

Table 2. Patients' characteristics (self-reported in interviews)

Name	Age (in years)	Time elapsed since the diagnosis (in years)	Occupational situation	Sexual orientation	Affective relationships and sociability	Fragments of everyday life
Heitor	50	20	unemployed; sometimes works informally as a garbage collector	heterosexual	single; lives with his mother, siblings, nephews and nieces (a total of 20 people)	formerly homeless; alcohol and drug user; stigmatized by the family (mainly by his mother); feels guilty about the disease and for non-adherence, which is aggravated by the family relationship
Pedro	44	9	retired; his wife started working when he got ill, to help support the home	homosexual	married, 2 children; lives with the constituted family	revealed to his wife that he is HIV-positive and homosexual; the wife insists in maintaining their marriage; adherence hindered by depression caused by the marital situation
Saulo	46	22	retired	heterosexual	single; dates a patient from the same healthcare service; lives with his mother	former user of alcohol and drugs; social prejudice faced due to lipodystrophy; has been writing a diary about his trajectory of PLHIV for 6 years
Henrique	26	3	bank clerk and Math student/University of São Paulo	homosexual	single; has not lived with his family for 8 years; shares a home with a female friend	"imagined" the diagnosis "due to high-risk behavior"; adherence hindered by himself
Felix	43	25	autonomous hairdresser; worked in prostitution as a transvestite in Italy	homosexual	single; has been living with his partner for 5 years	former drug-addict; suffered prejudice from his ex-boss and neighbors; alleges not to have adherence problems
Cícero	46	8	bank clerk; on leave for 18 months due to hospitalizations and surgeries	homosexual	single; lives with his mother	prejudice from uncles, aunts and cousins (his mother revealed he is HIV-positive to the family); his brother died of AIDS. Intermittent and irregular adherence
Rogério	40	7	unemployed	homosexual	single; went back to his parents' home after his Social Security benefit was cut	uses crack (his brother also uses crack and is HIV-positive; his father is an alcoholic); depressive; adherence hindered by family life

Fausto	41	4	autonomous gardener	homosexual	heterosexual marriage for 3 years; 1 child; went back to live with his parents and sister after he separated from his wife	alleges that the fact that his family does not know he is HIV-positive and homosexual negatively affects his adherence; is afraid of getting ill and being obliged to reveal his double condition
Osvaldo	did not state his age (45-50 years)	8	unemployed; used to work as a driver in a company and was dismissed when he revealed he was HIV-positive; “helps” his wife in a catering business	heterosexual	married, 2 children; lives with his constituted family. His wife was infected by him and is assisted in the same service	episodes of domestic violence practiced by both. Suffered from depression; has already attempted suicide. On the day of the interview, he reported he had “forgotten” the medication at home
Raul	32	10	retired; used to be a clerk at CEAGESP; sometimes works informally as a real estate broker	homosexual	single; lives with his sister	does not have “empathy with the doctor” but is “afraid of” looking for another one; states he does not have adherence problems
Manoel	43	12	bank clerk	homosexual	lives with partner on weekends and with his mother during the week	apart from his partner, no one from his family and work knows he is HIV-positive. Had troubles to accept the use of the MEMS
Benedito	58	13	retired; has a temporary contract with the municipal government of Ermelino Matarazzo, in general services	heterosexual	3 heterosexual marriages (widowed 2 times, separated from the last wife, with whom he had 2 children); lives with an aunt and nephews	left his job (head waiter at a steak house), from which he retired because he suffered prejudice. He says he does not know how he was infected
Antenor	46	3	unemployed; receives donations from NGOs and sickness benefit (from the government)	heterosexual	heterosexual marriage for the 2nd time, 1 daughter. His daughter from the 1st marriage died. Lives with his wife, the 2nd daughter and the wife’s 2 children	alleges he started having HIV symptoms after a dental treatment; this would also be the cause for having spent “two years without having sex with my wife”
Alberto	44	12	unemployed; receives sickness benefit; used to work with his sister in a bread and cake factory	homosexual	brief heterosexual marriage; lives alone; ended a 1-year homosexual relationship without revealing he is HIV-positive to the partner	has not spoken to his mother for 4 years; the youngest sister revealed he is HIV-positive to the family. Receives treatment for depression; lives in isolation
Cláudio	60	20	has an office of “clinical philosophy for businessmen”;	homosexual	heterosexual marriage for 11 years, 1 adult son; lives alone	revealed he is HIV-positive only to the ex-wife and son; to the family of origin, he says: “I have

			is striving for a place in a Master's course in Psychology/University of São Paulo			leukemia"
Paulo	40	11 or 12	student inspector at an elementary school; attended a Foreign Trade course for 1 year	homosexual	single; 2 years ago went back to his parents' home after returning from Japan, where he lived for 10 years	is not sure if he has been HIV-positive for 11 or 12 years; waited a long time before looking for orientation and treatment, after the diagnosis
Firmino	50	13	used to be a machine operator and was dismissed; without the retirement benefit, lives on the severance pay and on the rent of 3 houses	homosexual	heterosexual marriage for 5 years; lives alone. He "suspected" he was homosexual and this was "confirmed" after the marriage	thinks his family knows but pretends not to know. Would like to change his medication to feel fewer side effects
Ernesto	51	2	used to be a cleaning assistant at a public hospital; receives sickness benefit	homosexual	single; lives alone	long relationship with the HIV-positive partner, who died; has been alone for 1 year and does not want new relationships
Juvenal	51	10	English teacher (private classes and language school); is in the 1st year of a language course at UNINOVE; private study of German and French	homosexual	had a heterosexual marriage; lives alone	only his ex-wife knows he is HIV-positive and homosexual. States he was not supported by the doctor to "be aware" of the treatment; intended to look for another doctor
Misael	42	7	unemployed	homosexual	single; lived alone	addicted to drugs and alcohol; at the time of the interview, was recovering from an "unexplainable" fall from the terrace of a building; died two years after the interview
João	72	20	has been retired for 6 years; works as the caregiver of the elderly woman to whom he worked as a butler for 43 years	homosexual	single, lives in the family house where he works; on his days off, he lives at his deceased mother's house	only dates young men: last relationship with a 26-year-old man. States: "I've never rebelled against taking medication"
Janaína	51	15	nursing assistant; retired	heterosexual	has been a widow for 13 years (her	suffered prejudice from her own family and

					husband contracted AIDS in a homosexual relationship and infected her); 3 children and 2 grandchildren; lives with the 2 youngest children	from her husband's family; fears that her children, who do not have a father, will also lose their mother; difficulties in the treatment due to worries about her drug-addicted son.
Guiomar	39	10	used to be a maid and was dismissed due to the seropositivity; it took her a long time to have a new job and then she left it	heterosexual	heterosexual marriage for the second time; 2 daughters and 3 grandchildren; lives with the second husband and the first grandson	ex-alcoholic; infected by the 1st husband, who receives treatment at the same service; prejudice from the family, mainly from her mother; left her job because "the work hindered the treatment"
Cleonice	45	12	formally employed at a cleaning company; was a cleaning lady at GAPA and Solidariedaids, where she attended courses and adherence groups	heterosexual	married for the 2nd time; her 1st husband, who infected her, died. 3 children (1 of each marriage and 1 of a relationship). Lives with husband and the 2 youngest children	alleges to forget the medication due to her "busy life" and that she lives well with HIV. Suffered prejudice from her first husband's family, and from aunts and cousins
Bianca	44	18	housewife; sometimes works informally as a garbage collector and receives donations from the Catholic church	heterosexual	single; 3 relationships, 3 children: 1 of each relationship; infected by the first partner; lives with her son from the last relationship, her sister and her nephew	suffered prejudice from her deceased mother and still faces her sister's prejudice, with whom she lives. Alleges she does not forget the medication, but "misses" the times in the morning
Rita	30	8	used to work at a store in a mall; is waiting for the sickness benefit; wants to work again	heterosexual	married and separated twice; lives with the 3 children of the first marriage. Infected by the first husband	her 1st husband tried to asphyxiate her when she said she wanted to separate from him; her 2nd husband (not HIV-positive) stole all her money when she was almost dying. Wanted to participate in the research study because she almost died.
Vilma	46	8	maid; wants to quit and find a lighter job	heterosexual	3 heterosexual relationships; infected by the 2nd partner, with whom she lived for 4 years. 3 daughters; lives with the single one and 2 grandchildren	the diagnosis resulted in self-perception as a "woman who didn't have a good character", fear of being stigmatized by her brothers, who already judged her non-marital relationships

Flávia	42	15	cleaning assistant in a hospital	heterosexual	married; 2 children; lives with the constituted family	her husband, who infected her and undergoes treatment at the same service, prevented her from leaving the MEMS within visitors' sight.
Marta	43	16	retirement benefit and husband's pension	heterosexual	widow with a son, was infected by her husband. Had one more son of a relationship that has already ended. Her 1st son was born HIV-positive and became HIV-negative. Lives with her parents and her two children	had experiences with drugs and alcohol. Said she understands the prejudice from her 2nd partner's family because they were serodiscordant. Fear of her 2nd son having HIV led her to think about having an abortion

Source: interviews collected by the main author between September 2008 and February 2009, at the above-mentioned service.

Results and analysis

"I am the one who hinders my treatment!" (Heitor)[f]

This statement, made by the interviewee with sharp objectivity while his eyes and voice were heavy with grief, was repeated in different ways in the reports of other men who participated in the research study. Heitor's statement reveals that social relations are interpreted as individual and personal issues when PLHIV self-evaluate their role and place in the daily struggle against the disease. It brings to the analysis two central and complementary set of problems, in the set of interviews: the double determination of the relation between everyday life and non/adherence to the ART; and the stigmatizations that are faced while living this everyday life.

a) Adherence and Everyday Life

Numerous parts of the interviewees'[g] reports show their recognition that difficulties experienced in work relations, family life, affective relationships and leisure interfere directly in their treatment and make them neglect adherence: "perhaps when I get a job this will motivate me to stick to the treatment" (Misael); "I was unemployed and had other things... so, time passed... Sometime later, I asked for information, to know if I had to undergo treatment" (Paulo); "I went through a very complicated period... [my son] was using crack, cocaine... and it's impossible to separate one thing from the other...! One day, I took [medication] at eight p.m., on the following day, at ten... midnight..." (Janaína).

The disease is one more of the severe and numerous problems that they face in their everyday living. However, it is not the only one and, at certain moments and in certain circumstances, it is not even the main one: "In fact, my adherence is not

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[f] The interviewees' names are fictitious to preserve their anonymity.

[g] The term "interviewees" refers to the set of research subjects, while "groups" concerns the specificities among/intra research subjects.

adherence to the medication; rather, it is adherence to life… because medication… I've never had problems to accept it" (Pedro).

Many complex factors prevent them from having a full relationship with life, taking care of the disease. When they discovered they were seropositive, they were constantly haunted by the representation of the imminent and inevitable brevity of life. Today, after the belief in this 'sentence' has been overcome – "I used to think it was really a death penalty!" (Antenor) – and as they need to search for ways of living with the disease, which has become chronic, treatment adherence would be the great issue of their everyday life. Nevertheless, many other issues are as important: lack of work, of an affective relationship, of life conditions, of (self)care; in short, lack of "adherence to life", as Pedro put it so well.

In the ruptures of their everyday life of PLHIV, adherence to ART is a fundamentally determinant element to the performance of daily activities, which, however, place a constant challenge to the inclusion of treatment in their life: "I used to work a lot; sometimes I forgot [the medication]… when I remembered it, I was on the train, at the workplace… I arrived home so tired… I forgot it…!" (Rita).

The possibility of learning new ways of facing the challenge is the factor that most motivated them to accept to participate in the research study: "it's not easy to take these drugs correctly… our daily life is difficult… it's so full of things to do!" (Marta).

The research subjects 'forget' to take the medication because of breaks in the daily routine: "I won't say that I don't forget it; it's impossible! Sometimes, I'm not at home… I forget to take it with me…" (Firmino). Inversely, sometimes they do not take the medication because part of the routine was already complied with: "it's much easier something that makes me wake up than something that prevents me from sleeping" (Manoel). On weekends, leisure activities make them 'forget' the medication to avoid discrimination by third parties: "when you go to someone's place, you have to hide yourself to take the medicine" (Cleonice). On the other hand, on weekdays, the unemployed men and the women overloaded by domestic routine 'forget' to take the medication mostly in the morning: "at night, I used to take it correctly, because you don't have so many chores; but, during the day, you turn it off, because you tune in to your children, to the things you have to do..." (Marta)

Being occupied with everyday activities was the most common justification for 'forgetting' to take the medication. Therefore, the intervention professionals suggested to them, during the *scenes*, small arrangements in the daily routine: fixing reminders to visible places (fridge, mirrors); programming the cell phone to ring at the time the patient should take the medication: "I told her [the professional] that I bought the cell phone because of the research study. I didn't have the habit of taking my medicines on time; I didn't know about this difference. And, during the encounters, we discovered a way of doing it" (Pedro).

But why had they not thought of such simple arrangements before? Their life histories show an oppressive everyday life, fragmented[8] and (self)isolated, which hinders the re/cognition of forms of care. However, these forms of care can only be formulated and practiced within their everyday life: "we always have a solution, but sometimes, we don't want to search for it" (Pedro).

In the intervention, this re/cognition is enabled by the experience of the scenes[6]. When they examine their life as if they were out of it but were able to act upon it, they unveil, thanks to the dialog with the professional, some strategies hidden in/by their everyday life.

Intermittently absent from the *reality* of their everyday life, medication is always present in their *representations*: "[the medicine] means that I must take it for the rest of my life" (Bianca); "without it, it's practically a death certificate" (Marta). Nevertheless, sometimes the conscience of the importance of medication does not find time and space to be included in the everyday life. This results in the 'routine' of non-adherence, mentioned by Juvenal: "the loss of the first day...one hour more, one hour less... ends up leading you to a custom, a frequency, because the thing is so naïve... [...] that you end up believing that once, twice, three times, nothing is going to happen. But then you end up getting into a routine: one day, you have a class; on the other day, you'll go out... you go to bed earlier... you were not feeling well... and so on...".

The non-adherence ‘routine’ translates the impossibility of living their everyday life in its full configuration[8]. This happens for several reasons, such as the loss of working relations and/or the intermittence of leisure activities, the deterioration of family bonds, the instability of affective relationships: “today, I say that if it weren’t for my wife, I’d be living on the streets..., because we totally lose the reference of everything” (Antenor).

Thus, the life of the great majority is characterized by (self)isolation and by the concealment that they live with HIV, which results from situations of prejudice and discrimination that they face in the multiple spheres of their social practice. With the rupture of their former way of life, they start living according to what the new circumstances allow or impose. Some reports are particularly painful – reports from single men who, due to financial difficulties associated with the worsening of their health conditions, had to go back living with relatives who barely know or do not accept their condition of PLHIV: “I used to live alone...when my benefit was cut, I was evicted, I had to sell my stuff. Unfortunately, I went back to my parents’ home... I became depressed: I don’t want to think about taking medicines anymore!” (Rogério).

In addition to changes in their family and working lives, there is the difficulty in maintaining former leisure activities (“I don’t have the energy to go out anymore” (Firmino)) and in establishing affective relationships[9] – “every time I think about it, I think it’s not worth beginning a relationship” (Janaína). This is represented in the dilemma between the desire to build a relationship and the fear of new losses: “[lack of] getting someone who likes me, who wants to stay with me... but I don’t see myself living with anyone anymore” (Vilma).

The representation of this ambivalence is strengthened by health conditions that justify (self)rejection (“lipodystrophy has destroyed me; it’s impossible to maintain my self-esteem with a body like this!” (Janaína)) and aggravate their affective loneliness: “it’s been seven years since I last had a relationship with a man” (Bianca); “to me, it has to be a person... it’s only fickle relationships... for sexual satisfaction rather than emotional interaction” (Pedro).

Experiencing (self)rejection in the spaces of personal and social relations explains their (self)isolation: “my family lives near me, but I don’t exist for them. This hurts me a lot! I’m isolated. I just come for the consultations; otherwise, I don’t go out” (Alberto); “suddenly, I isolated myself inside my home; depression affected me in such a way...I lost control… I started drinking a lot, I started using drugs… I was almost losing my wife, because she couldn’t bear it anymore” (Osvaldo).

Although reaching moments of lower or higher intensity, depression[9] constitutes an important element of their everyday life, since the discovery of seropositivity, due to reasons that are generally combined: fights with relatives caused by prejudice and discrimination; non-acceptance of changes in their former way of life and unfamiliarity concerning the new one; terror of depending on relatives’ help and/or care; dread of dying and not raising their children; tiredness, discouragement, revolt due to the treatment “for the rest of their lives”; but also, fear of death which, although represented as always lurking, does not make them take care of themselves.

In light of this scenario, the idea of suicide[9] has already been around and still torments many of them, like Osvaldo, who, in fact, attempted to kill himself. Depression has also caused or aggravated alcohol and/or drug use[9], represented as a way out to escape from the oppression of the everyday life of PLHIV: “After I discovered [seropositivity], some days I didn’t even go home; when I finished work, I went to the bar to drink. I did this during six months. I’m going to die anyway… I have nothing to lose!” (Guiomar); “We want to reduce our suffering through drugs, alcohol... I myself couldn’t undergo the treatment. I knew I was ill, but I was the only one who knew it. So, I drank, I smoked, I used drugs… but I stayed alone, always alone!” (Heitor).

(Self)isolation is the most frequent response to prejudice. Only two single men allege that they do not suffer it in their family of origin: “my family knows about it; I try not to hide anything to make things easier; this has helped me a lot” (Cícero). While the other single men and the married ones (self)isolate themselves **from** the family (either living with it or not), the women (self)isolate themselves **in** the family they have constituted, but they generally estrange themselves from their family of origin or are maintained estranged by it: “I have two brothers here in São Paulo; it’s been two years since I last visited them. They don't even call me to know how I've been, if I'm alive or dead…" (Vilma).

Difficulties in family relationship are constant in the life of those who have revealed their seropositivity and, with few exceptions, have faced prejudice: "I come from a very macho and ignorant family. My sister… I've heard that her grandson can't get near me, otherwise I may destroy his life. My father was very prejudiced…!" (Juvenal); "my sister loathed me…she didn't let me wash my clothes in the tub… Until today, she doesn't eat the things I cook" (Bianca).

The episodes of worsening of the health conditions generally prevent them from continuing to hide the everyday life of PLHIV: "I told them because lipodystrophy started to become visible" (Saulo); "mainly when I was debilitated, I had the impression that what I had was written on my face" (Pedro). The revelation is usually made to some relative who is closer and who, contradictorily, disseminates the news, causing experiences of prejudice and discrimination: "because of my family, the whole neighborhood knows that I have it [HIV]. […] I rebel because of this. Not because of the illness, but because of society… and my family" (Alberto).

When health difficulties become visible through changes in the appearance, bringing stigmatizations through *body abominations*[10] (p.14), many of them try to omit the real purpose of the medication, alleging that they suffer from another disease that is socially and morally accepted, like cancer. In fact, some of them have already had cancer (as a result of AIDS), "because people think that those who have AIDS are thin…and me, fat, obese, with lipodystrophy, will never have AIDS! [laughs]" (Janaína).

Trying to avoid stigmatization for *blames of an individual character*[10] (p.14), they constantly try to hide, mainly from their relatives, experiences of vulnerability situations (either previous to seropositivity or current experiences: sexual relations without protection, different occasional partners), now represented by themselves as *deviant behaviors* (p. 151): MSM (men who have sex with men) relations, among the majority of the single men, and five formerly married and one married man, also considered adulterous; infection, by heterosexual relations, of three married men – equally adulterous – and two single men, already stigmatized as drug-addicts by their relatives; the refusal of a married man and a single woman to admit the cause of their infection; and the attribute doubly betrayed, self-granted by the other women, who ascribe their infection to their husbands or partners infected in MSM relations (Table 2).

In these contexts of double concealment of seropositivity, the interviewees' stigmatization would be preceded by stigmas attributed as a *social identity* to *discredited* segments[10] in life in society (homosexuals, adulterers, drug-addicts, betrayed women), bringing them prejudices and discriminations referring to these *attributes*[10], which they start to *accept* as constituting their individual identity.

Therefore, they face a dilemma that is as cruel as seropositivity: revealing or hiding these *attributes,* as well as the everyday life of PLHIV, although this concealment almost seems to be a game, in which some relatives pretend not to know what they already know: "perhaps they deduce what it is. They know that I've been undergoing treatment, but I don't know if they know exactly which treatment; they haven't asked; they don't care. If they had asked me, I would have told them" (Paulo).

The group of women, in turn, did not have the option of 'telling it or not' to the partner's family, either because their partners contracted AIDS and died (five cases), or because the relationship ended (two cases), revealing the women's infection. Although they self-represented themselves as doubly betrayed, as victims of adultery and of the infection transmitted by the partners, they are represented as adulterers by their partners' mothers and/or sisters, who think they are responsible for the partners' illness: "until today, I believe that his mother and his family think that the one who transmitted AIDS to him was me" (Rita, separated from her husband, who infected her); "he says that I was the one who infected him" (Flávia, the only woman who remains married, whose husband receives treatment at the same healthcare service). Also in the relationship with their family of origin, the representation of the possibility of stigmatization or their real experience make these women isolate themselves in an exclusive relationship with their children and/or grandchildren: "I'd like to go to my mother's house and receive some attention: 'how are you, my child? How is your treatment going?' She has never done this!" (Guiomar).

To the MSM, either single or formerly married, stigmatization due to HIV is represented as doubly problematic because it implicitly contains the stigma of homosexuality, represented as even worse than the illness by the family of origin: “my mother died two years ago; I never told her that I was HIV-positive… I was the biggest target of her prejudice” (Cláudio, formerly married). Due to this, to the majority of them, (self)isolation has occurred as a way of avoiding a double revelation that would make them leave their father’s house: “I almost never go there and they’ve never come to my house. We don’t even speak on the phone. They are very prejudiced against everything: they don’t know I’m gay, but they have much prejudice against homosexuals” (Henrique, single).

(Self)isolation is represented by all of them as, perhaps, the only possible way of facing (self)stigmatization in their everyday life of PLHIV: “I think that the greatest prejudice is that of ourselves in relation to ourselves” (Pedro); “because what’s in our head is not so much the illness; it’s the prejudice” (Flávia).

Only the groups of men blame themselves[10] (Translation's Note: This is a free translation of the notion employed by the author) for the disease and the everyday life that determined it - “it wasn’t so much a surprise… because I’d had a high-risk relationship, without a condom” (Pedro); “if you contracted the virus it’s because your life was more irregular than what is considered normal” (Manoel). Due to this, (self)isolation becomes the possible alternative to the remission of the past. Therefore, they view the infection almost as a second chance in life; an opportunity to exercise the self-care that can redeem them from their former *deviant behavior*, no matter if they will have to live in an everyday life that is normalized and regulated by the virus: “the virus has a bad side, which is prejudice, and a good one: I was addicted to drugs and if it weren’t for the virus, how was I going to stop? So, the virus helped me!” (Saulo); “HIV, to me, came right on time. I think that if I hadn’t been infected yet, I would’ve died of an overdose, which I think would be worse… spiritually speaking” (Felix)

b) The Intervention and its Representations

However, although the virus warns them of the need of self-care, it is with the intervention that the majority of them starts to understand the importance of their own role in the plot of the treatment: “the research study led me to adhere to responsibility towards myself; it helped me to live better with the disease” (Pedro).

Participation in the research study enables them to recognize difficulties in taking full control of the treatment because they think they are unable or unauthorized to give opinions about their self-care. Reproducing the recurrent asymmetric doctor-patient relationship[2], they add to the well-known sentence “my doctor knows what’s best for me” the representation that the doctor “isn’t there to listen to problems”: “the consultation is like this: ‘is everything all right with you’? ‘Have you been taking the medication correctly’? But in the encounter [of the research study], I talked more about me, about my problems…The doctor has a full schedule, I can’t stay there and tell her everything!” (Raul).

Many participants reported that the intervention enabled them to understand the importance of the dialog between doctor and patient as an instrument to construct and/or improve adherence, as “the doctor-patient relationship must be revised… the doctor should try to discover who that patient is. I didn’t have much freedom to communicate with him. To me, the research study itself was what helped” (Juvenal).

The intervention encounters also brought changes in their relation to the service, enabling the provision of assistance by other professionals of the team, concerning problems related to the ART: nutrition, depression, anxiety, alcohol and drug addiction, low self-esteem, etc.: “it was because of the research study that I started treatment with the psychiatrist… it has helped me a lot!” (Cícero).

Although they accepted to participate in a research study targeted at improving adherence, some of the men tried to dissimulate their role of research subjects and change it to mere collaborators in the discovery of new treatments: “to contribute with the research study… not me as a person… not that I needed it; rather, I was helping” (Cícero); “because some people forget to take the medication” (Paulo); or they stated that their adherence difficulties do not happen constantly: “as my viral load started to be detectable, I thought that participating in the research study might be related to it" (Rogério).

However, it is important to highlight that almost all the interviewees firmly believed in and fully assumed their role of subject in a study that enabled them to learn the correct use of medication: "in the research study... I think the researchers become more and more interested in knowing, and I, too, become more and more interested in knowing better" (João); "I learned many things: what to do and not to do, how to take and not to take the medication" (Benedito). Moreover, the research study allowed them to "talk about things that we don't want to accept; and if there's someone instructing you, afterwards you reason: 'what she told me is really true' " (Rita).

What they learned through the research study enabled them to identify that their greatest difficulty is taking the medication at regular times in their disorderly everyday life, in order to guarantee the level of adherence that was achieved when this was monitored and encouraged in the encounters with the professionals: "the research study meant adherence to the treatment; it opened my mind to it. In the first month, I was 100% 'British' when I took the medication, in the second, I relaxed a bit, and in the third, I relaxed even more; now, I'm 60% 'British', but I always take the medication..." (Manoel).

It is through the scenes[6] enacted in the intervention that they 'become aware' of the factors of their everyday life that hinder or prevent their adherence, and start to understand the importance of viewing the awareness-raising regarding self-care as an instrument to transform their way of life: "There was one moment in the research study that marked me most. We enacted a kind of experience... about the time I left home to go to work and got my medicines. When I was doing this... I stopped and stood paralyzed! Precisely when I was going to get the medicines! Until now, I don't know why this happened, what this means... but... if I could pick one moment of the research study, this would be the moment at which I started taking the medication" (Henrique).

Other interviewees also emphasized the importance of this third session (enactment of *scenes*), which they used to relate to the fourth session (totality of the experience), representing both as moments that particularly fostered the awakening of the *conscience* towards adherence: “I thought they made you think more. It was a kind of reflection… analyzing everything you yourself said” (Saulo).

Their life histories and the relationship constructed with the professional determined the identification of the encounters (Table 1) that were most significant to raise their awareness regarding the importance of adherence. For example, to Fausto, it was “more the first one… in which I told my entire story, since my first memories of me as a person until the moment I was with her [the professional]”; and to Cleonice, the second encounter: “when she pulled my leg” [about] “my problem of forgetting” [the medication]. On the other hand, the totality of the intervention is unanimously valued by all the interviewees, thanks to the acquired learning: “I liked all the encounters because each one was a… victory…a difference in victory. It was like a school, where I was learning…and learning more and more…” (Saulo).

However, this does not prevent some research subjects from opposing the positivity of the encounters, which legitimate their participation in the research study, to the obligatoriness of using the MEMS[3], which made them state that they “would not like” to participate again in a similar clinical study: “I thought that little lid sucked! I don’t get the medicines at the time I have to take them. I get everything earlier. But, if I got them earlier, I’d have to note it down… can you imagine it?! I hardly even took the medication…!” (Henrique).

Some men also reject the MEMS because they refuse to admit their non-adherence (“I’m a mature man; I know I have to take the medicine at that time” (Cláudio)); or they try to justify that opening the bottles might hinder their adherence, exposing them to new discrimination experiences, in the domestic and/or work environment.

Nevertheless, all the interviewees understand the pertinence of the use of the MEMS in association with the encounters, because learning that daily and regular doses are obligatory shows, to them, the relationship, approached in the encounters, between adherence and their everyday life. This enables them to understand that, without transforming their way of living life and of taking care of themselves, it will not be possible to achieve the adherence that will make their everyday life viable: “[the research study] exposes you to everything and doesn’t hide anything: both the effects [of the medication] and the patient’s personal…normal, daily life, here [health service] and at home” (Alberto); “the research study? It’s like… the true conscience… like ‘they’ve already taught me how to walk; now they’ll let go of me’ ” (Juvenal).

With the intervention, they learn, therefore, to re/interpret and re/invent their relationship with the treatment and they may, opportunely, make the legacy of this learning become their guide to find the best *possible* way of changing life in order to live life: “The research study was a new beginning of everything. It doesn’t mean that I’d been sleeping… but I’d been in a state that was, perhaps, similar: doing things fairly right most of the time, but without that true conscience: ‘I NEED TO’!” (Juvenal); “I was my own accomplice” (Rita).

Conclusions

A secret life represents the everyday life of the interviewees. In an attempt to avoid the social stigmatization related to HIV, these men’s and women’s daily living is grounded on concealment strategies, whose most frequent and serious consequence is the hindering of their treatment adherence.

There are many reports on prejudice and discrimination suffered at different spaces of social relations; however, undoubtedly, it is in the family context that the experiences are most recurrent and dramatic, as they are added to stigmatizations that already exist or that are virtually possible. The vulnerability to the disease has caused, to all of them, the permanent vulnerability to prejudice and stigmatization. This explains, for example, the dramatic attempt to hide homosexuality from the families of origin, reported by ten out of twelve research subjects in the group of single men, and by six out of nine research subjects in the group of formerly married men, who had dissimulated it in heterosexual marriages.

Concealing the *socially attributed identity*[10] is represented as the possible way of living the individual identity; even to Pedro, who confined to his home the homosexuality that he revealed only to his wife who, however, insists in not releasing him. Pedro, like the group of women, hides himself from the family of origin to secretly live the condition of PLHIV inside the domestic space of the constituted family. The single and formerly married men, in turn, had to get out of the domestic space to be able to assume their homosexuality and/or face seropositivity: Saulo took refuge in the itinerancy and anonymity of work in a circus; Felix spent a long time in Italy to be able to live anonymously as a transvestite; Paulo lived in Japan for ten years; Henrique spent one year in Argentina; Heitor lived on the streets for a long time; Cláudio, Alberto, Firmino, Juvenal and Fausto got married to hide their MSM relationships from their families; Raul, Ernesto and Rogério abandoned their fathers' house; Benedito took advantage of work opportunities to be distant from his family for years; Manoel lives with his mother during the week and with his male partner on weekends, hiding his homosexuality from neighbors and relatives respectively; João lived for 43 years in the family house where he worked as a butler; Osvaldo got away from everything by means of alcohol and drugs; Antenor 'locked himself' in depression and isolated himself from his wife and children; Misael hid himself from the treatment and died two years after the interview.

The immediate consequence of the rupture of family relationships is the experience of a fragmented routine in whose disorganization and wanderings (self)care usually finds neither time nor place. How can one take the medication regularly, perform clinical tests, attend consultations, eat and sleep well, avoid alcohol and drugs, keep a good self-esteem, be away from depression, have/keep affective relationships while, at the same, he/she must hide his/her real identity in order to live a secret life?

The intervention, by means of long conversations with the professionals and dramatization of scenes experienced in the interviewees' everyday life, enabled them to have space and time to search for new possible ways of organizing their life and living. It awakened their *conscience* – which was hidden, so that they could hide their everyday life of PLHIV – of their capacity to, with their own resources and conditions, attempt to include the treatment in their way of life. In short, it showed them the possibility of protagonism and autonomy to find the possible path of (self)care, removing the veils that conceal their living: “the encounters…? It’s the same thing that… a person who is alive carrying a dead person on his back; when that corpse is removed, you feel it, right? So, I was able to say many things and I felt good! I removed that weight from my back!” (Saulo).

Collaborators

The first author, Ana Cristina Arantes Nasser, was responsible for the conception and development of the qualitative study, for the collection and analysis of the empirical material and for the writing and revision of the manuscript. The second author, Maria Ines Battistella Nemes, coordinator of the Qualiaids line of research, was responsible for the supervision of the first author’s postdoctoral stage, and contributed to the revision of the manuscript.

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