

Affective relations and treatment adherence for HIV and problematic drug use (Argentina, 2014-2016)

Los vínculos afectivos en la adherencia a tratamientos por VIH y por consumos problemáticos de drogas (Argentina, 2014-2016)

Vínculos afetivos na aderência a tratamentos contra o HIV e por uso problemático de drogas (Argentina, 2014-2016)

Daniel Jones ^{1,2}
Santiago Luján Cunial ^{2,3}

doi: 10.1590/0102-311X00035919

Abstract

The article analyzes interactions between therapeutic experiences and affective relations in the history of patients with chronic health conditions: persons with problematic drug use receiving therapeutic care in religious devices and persons with HIV under clinical care and antiretroviral therapy. The article uses a qualitative methodology based on in-depth interviews. The hypothesis is that the treatments (pharmacological or psychological) usually prove insufficient to provide adequate therapeutic responses to these two chronic conditions. Both groups acknowledged the central importance of affective dimensions for adherence to the proposed treatment regimens and a comprehensive (and thus more effective) approach to HIV and drug addictions. The article concludes by presenting a notion of adherence that extrapolates individual behavior involving mere compliance with prescribed treatments. Adherence is less a personal than a collective experience, in which family, peer networks, and professionals and other therapeutic reference persons play a central role.

Incurable Patients; Treatments; Patient Compliance; Drugs; HIV

Correspondence

S. L. Cunial
University of Pennsylvania.
133 S. 36th Street room 4448, Philadelphia, PA
19104-6215, U.S.A.
scunial@sas.upenn.edu

¹ Consejo Nacional de Investigaciones Científicas y Técnicas, Buenos Aires, Argentina.

² Universidad de Buenos Aires, Buenos Aires, Argentina.

³ University of Pennsylvania, Philadelphia, U.S.A.



Introduction

When individuals are diagnosed with a chronic health condition, they undergo experiences, emotional states, and clinical challenges resulting individually and socially from living with an illness for life (the incurable nature of chronic diseases applies to the conditions analyzed in this article, such as HIV, while for other diseases like hepatitis C, due to clinical progress, cure is not only feasible but highly probable). Unlike acute diseases (short-lasting, and with a clearly defined beginning and end), chronic illnesses tend to require lifelong treatment. Individuals make daily decisions and take measures to live with “their illness” and the circumstances resulting from it, marked by a web of relations with significant others that can facilitate (or hinder) their treatment.

What place does affect occupy in the treatment of chronic health problems? What roles are assigned to family and friends, therapeutic reference persons, and peers with whom they share their illness or treatment? What affective expectations and experiences permeate such relations and prove significant for initiating and sustaining treatment? This article seeks to answer these questions based on a comparative analysis of HIV and problematic drug use. HIV has changed from a clinically fatal disease to a chronic illness. At the start of the epidemic in the 1980s, the infection evolved rapidly to AIDS disease and imminent risk of death. The development of increasingly effective antiretroviral treatments since the mid-1990s led to prolonged life expectancy and good quality of life for persons with HIV. The clinical challenge is now how to sustain treatment ¹, where success depends on survival and quality of present and future life. There have been few cases of AIDS cure based on the CRISPR technique ², and since advances in this area are still controversial, the disease is still defined as chronic and incurable.

Although there are different ways of relating to drugs, we will focus here on problematic use and addiction, defined as a “chronic illness” by therapeutic reference persons and people in treatment that we interviewed. This definition comes from Alcoholics Anonymous and was extended to other approaches that share the 12-Steps methodology and its abstentionist approach (i.e., the person does not go back to using alcohol). The premise is that addiction is a disease with no cure and which thus follows the person for life, latent during periods of abstention, and thus always requiring strong self-surveillance and some form of therapeutic follow-up in order not to “relapse”. While the current article draws on original notions from the people interviewed, the definition of addiction as a chronic illness is also based on medicine and psychology. Professionals and devices from these fields emphasize that treatment of problematic drug use and addiction (given their chronic nature) should be maintained over time (in some cases for life) in order to be effective and avoid drug use ³.

Such situations of chronicity raise the challenge of treatment adherence: how to comply with the prescribed treatment over time. In treatments provided for both conditions, one predominantly pharmacological (for HIV) and the other psychological (for addiction), these clinical dimensions alone prove insufficient for individuals to comply with them continuously over time and achieve good health results, to achieve an undetectable viral load in HIV and to avoid relapsing with drug use, respectively.

This means that therapeutic responses oriented exclusively by clinical rationale are insufficient for dealing with these chronic conditions, according to all parties involved. According to Michel Foucault (*The Birth of the Clinic*) ⁴, the point of departure for medical rationale is that illness always presents as a set of visible symptoms and signs that can be observed by a medical professional. Focusing on these visible and individual dimensions of the illness ⁴ assumes a limited interest in the relational networks in which individuals experience their illness. Thus, in the therapeutic experiences explored here, we are interested in examining various affective dimensions permeating interpersonal relations for people with chronic illnesses in treatment: those with problematic drug use receiving care in religious devices and those with HIV under clinical and antiretroviral therapy in health institutions. Both groups require long-term treatments that pose challenges for adherence and share socially stigmatized health conditions.

The article aims to analyze the roles of affect in the therapeutic experiences of the above-mentioned populations, both for the people in treatment themselves and those treating them. We thus explore the meanings assigned to their affective relations with families, partners, friends, other persons with the same condition and/or in similar treatment, and therapeutic reference persons in dynamics of motivation, follow-up, containment, isolation, and/or rejection that vary over time.

The article's main finding is that pharmacological or psychological care alone is insufficient to produce adequate treatment responses to these two chronic conditions, according to the persons that undergo these treatments and those providing them. Emerging in these groups is the central nature of affect for adherence to proposed treatment plans and a comprehensive approach to HIV and drug addiction that would allow such plans (from patients' and providers' perspective) to achieve greater treatment success and personal wellbeing than when affect is not included. This central nature of affect in treatment does not mean that it is the only approach: the devices analyzed here mainly adopt clinical approaches. Nevertheless, despite the improvements that those providing these services seek (and sometimes achieve), affective support is viewed as complementary to strictly clinical care. In this sense, the selection of the religious devices analyzed here is not the consequence of the authors' preference for them or an assumption that they function better than non-religious devices; rather, it results from selection from a collective project in which the authors participate, as elaborated in the methodology.

The article begins by presenting the conceptual framework and methodological strategy. We then analyze the dynamics of three groups with relevant treatment roles, connoting affective dimensions: (a) family and friends; (b) peers (with the same health condition and sometimes with similar treatments); and (c) therapeutic reference persons (physicians, psychologists, socio-therapeutic operators, and others). The conclusions systematize the contribution by this analysis to a definition of adherence beyond individual behavior (involving mere compliance with treatment prescriptions).

Conceptual framework

Considering treatments for problematic drug use, the literature largely concentrates on therapeutic communities, outpatient treatments, in-hospital detox programs, and day hospitals and community-based approaches. One such approach follows a prohibitionist-abstentionist paradigm⁵ that proposes the "addict's" institutionalization and reclusion as a sick individual, while another views drug use as an issue of social inclusion and prioritizes approaches located in vulnerable territories⁶. Most of these approaches are based on a psychological model, focusing on the individual and family histories of drug use as causal factors in the problem⁷. However, the relational affective issue is frequently ignored while prioritizing individual responsibility as the problem's principal trigger and thus the determinant of the treatment's effectiveness³, even though discrimination, stigma, and lack of support pose obstacles to therapeutic success^{8,9,10}.

In the case of HIV/AIDS, the development and application of highly active antiretroviral therapies (HAART) since the 1990s changed the prognosis of HIV infection favorably, making it a chronic transmissible disease¹¹. Numerous studies have focused on treatment adherence since the advent of HAART. We are interested in retrieving studies on the influence of factors like social and family networks that people in treatment rely on and the existence (or lack) of partners and children¹², as well as the physician-patient relationship, which includes patients' perspectives on the trust developed through this bond and form of communication.

The current article draws theoretically on socio-anthropological studies on chronic illnesses, complemented by research on affect. The former have questioned the biomedical views centered primarily on the temporal dimension of chronic conditions, highlighting the need to relate chronicity to the social contexts of individuals experiencing chronic illness¹³. Traditionally, the chronic illness/acute illness dichotomy has been based on a strict timeline criterion, with the former marked by long duration and the latter by a shorter time frame¹⁴. The distinction overlooks the fact that new technologies allow reducing the symptoms of some chronic illnesses such as HIV, besides not addressing other consequences that transcend biology, such as social discrimination¹⁴. Thus, the socio-anthropological current reconceptualizes chronic disease in terms of chronicity, maintaining the idea of a disease without a cure¹⁴, while including the process of internalization of the disease and the ways by which the diagnosis becomes part of the person's identity¹⁵.

This notion of chronicity responds to each person's characteristics¹³ and recommends looking beyond the individual and analyzing his or her family dynamics, as well as dominant ideologies on the disease, etc.¹⁶. Individuals with chronic illnesses must adjust their lifestyles and life projects as a func-

tion of their diagnosis¹⁷. Such changes in their routine can generate stress and depression, hindering their adoption of a treatment regimen. This literature thus features the role of family members and health professionals in the internalization and treatment of chronic illness¹⁷.

Along this line, a study of a population with motor disability states: *“A person with a chronic health condition needs continuing and prolonged care from the family, which is distinguished from the specific care provided by health professionals”*¹⁸ (p. 1066). This family role is underlined by a systematic review of studies on chronic diseases¹⁹. In the references identified in the region, the theme of affect in health professionals is analyzed by examining their quality of life and mental health²⁰, rather than the affective dimension of the treatments they provide. A review of the literature on antiretroviral adherence highlights: *“In relation to perceived social and family support, defined as the patient’s subjective perception of support (emotional, instrumental, and informational) and trust and intimacy in family and social networks, studies have reported such support as an important cofactor in the progression of HIV infection”*²¹ (p. 55). This same review signals a gap we have identified in our own research: *“In relation to the variable of affect and emotion, the review found interesting studies that show their influence on perceived health status; nevertheless, there were no studies that dealt with this topic specifically in relation to HIV infection”*²¹ (p. 58). The article thus also resumes the social sciences’ interest in affect, with growing but still incipient intellectual development in Latin America^{22,23,24}.

Expanding the studies’ focus beyond chronic diseases, we identified some studies on therapeutic practices that emphasize that their efficacy depends dealing with affect, often at a pre-conscious and pre-discursive level. For example, Jeanne Favret-Saada, in an ethnographic study of witchcraft in a rural area of France, raises *“the hypothesis that therapeutic efficacy, when it occurs, results from a certain work performed on non-represented affect”*²⁵ (p. 155). A study by Ariel Ducey²⁶ on training for nursing assistants in the United States develops the concept of affective technologies. These *“seek to achieve a level that is not one of ideology or consciousness, but prior to them, precognitive, less explicit and predictable, conditioning which attitudes and emotions can be expressed, and managed, modified”*²⁷ (p. 146), modeling the affective capacities of the workforce in charge of therapeutic processes. In both experiences examined here, despite the huge distance between them, affects play a central role in the therapeutic processes, including opaque forms for the subjects involved, often at a pre-conscious and pre-discursive level, thus requiring additional investigative effort to screen for clues in the interviews.

In line with Ariel Ducey, the work by Ania Tizziani on a training program for domestic workers in Greater Buenos Aires, Argentina, offers another clue for reflecting on the affective commitment required of therapeutic reference persons in the treatment of chronic conditions: *“The demand to mobilize affects (...) can be viewed as an intervention that seeks to generate a commitment in participants (...), defined at the affective level and not at the strictly work-related level”*²⁷ (p. 146-7). Tizziani also reclaims the notion of emotional work.

Following the pioneering work by Arlie Hochschild, studies on emotional work have demonstrated the leading role played by the management of emotions in certain services jobs. The notion of emotional work refers to different work practices involving the establishment of personal relations and requiring workers to manage their own emotions to induce specific feelings in the clients (or patients)²⁷.

The affective mobilization expected of health professionals and therapeutic reference persons, translated as emotional work, assumes greater involvement in healthcare (“listening”, “empathy”), not inconsistent with the required technical expertise.

Methodology

Based on research in chronic health conditions in which we participated, we proposed to analyze the affective dimension’s roles in therapeutic experiences, assigned to both those receiving treatment and those providing it. The first study addressed processes of adherence to antiretrovirals in persons with HIV²⁸. In 2016, we conducted interviews and discussion groups with seropositive persons over 18 years of age under medical follow-up in the city of Buenos Aires, Greater Buenos Aires, and the city of Mar del Plata. We selected a heterogenous intentional sample by place of residence, gender, and age. We conducted 60 individual interviews with persons with HIV (15 in Buenos Aires, 15 in Mar del

Plata, and 30 in Buenos Aires): 31 men, 27 women, and 2 trans women. We held three group discussions with the same population profile). We also conducted 15 interviews with health team members (five per cluster) from public and/or private institutions. The second study analyzed religious devices providing care to persons with problematic drug use in Buenos Aires and Gran Buenos Aires ²⁹. In 2014 and 2015, we interviewed 31 people in treatment for drug use (heterogenous intentional sample by place of residence, gender, and treatment stage) and 25 therapeutic reference persons from 25 institutions that incorporate some religious dimension in their treatment proposal.

In Argentina, there are no regulatory agencies or specific ethical regulations for research projects in the field of human and social sciences applied to health. Nevertheless, according to the ethical standards in any scientific research, we work on the basis of voluntary participation through informed consent. Before beginning the interviews or group discussions, each participant received an individual consent notice in accessible language, specifying the themes and the way they would be approached, the approximate duration of the meeting, and the destination of the resulting information. We insisted on voluntary participation, anonymity, and confidentiality. We have thus followed and complied with international ethical principles and the contents of the *Declaration of Helsinki*, insisting on the interviews' privacy and respect for the rights of the people interviewed. The results are presented in such a way that the neither the participants nor their surroundings can be identified individually. The quotes are thus identified with pseudonyms.

The individual interviews and discussion groups were recorded, and the transcriptions provided the material for analysis. The analysis prioritized the perspective of the people that were studied, acknowledging that their testimonies themselves are first-order interpretations ³⁰. The link between an interpretative focus and a qualitative methodology involves an inductive emphasis in the development of knowledge, since the patterns stem from an analysis of specific experiences and opinions of actual actors ³¹. Based on this classified and pre-analyzed material, we conducted an in-depth interpretation.

Comparative analysis

What is the role of affect in the treatment of chronic health problems? What roles are played by family and friends, therapeutic reference persons, and peers with whom the patients share their illness or treatment? What affective expectations and experiences permeate these bonds and prove significant for initiating and sustaining treatment? We contend that it is essential to explore this affective context because HIV, drug addictions, and their therapeutic responses are not experienced in isolation. Trajectories of chronicity are framed by a web of ties that are transformed directly or indirectly by living with (and being treated for) these health conditions.

People with HIV and drug users, as well as those who treat them, refer spontaneously to the importance of love, affection, and empathy from those shaping the daily life surroundings of those in treatment, explaining the success or failure of treatment adherence. Such interpersonal ties can function as obstacles or facilitators to follow-up in treatment regimens. Affect can be expressed as emotional support in the face of crises or as practical helps such as reminding someone to take their antiretrovirals. On the other hand, disinterest, misunderstanding, and rejection in significant interpersonal relations often hinder the effective treatment of chronic conditions.

We now analyze three relevant groups in treatment: (a) family and friends; (b) peers with the same health condition or similar treatment; and (c) therapeutic reference persons.

The role of family and/or friends: support and relapse

- **Unreceptive surroundings and their relations to relapse and/or treatment dropout**

Families and friends can cause emotional stress for someone experiencing a chronic condition. When such interpersonal settings are unsympathetic or rejection is expected (for example, due to the habitual stigma of seropositive status or drug addiction), the individual may decide not to share the information or avoid family and friends.

For some people with HIV, an alternative to breaking ties with family members or friends is to keep their seropositive status a secret. Using defensive reasoning, some decide not to disclose the information to significant members of their settings. Maintaining secrecy not only impacts the ways of relating and socially and affectively connecting (including with partners or spouses), but also forces the person to deal with additional stressful factors such as taking medication at moments and in places that do not compromise the undisclosed diagnosis.

Situations of discrimination that produce interpersonal alienation can also lead to treatment dropout. *“When I told them about the illness, of course I had problems in my family. My wife and I separated, and my children started avoiding me”* (male, 57 years, HIV+).

P: What would you emphasize in the HIV issue today?

R: Discrimination against persons with the virus in the process of accessing work. And relations with family members, which also involves discrimination, and this can work against adherence” (infectious disease physician, public hospital).

The influence of these affective relations in treatment experiences appears frequently in the interviews. The inability to count on friends or family members (who, after learning of the health condition, fail to accept it or accompany the person in treatment) can discourage treatment follow-up and affect quality of life, both for HIV and addictions: *“Emotions are important, because if you don’t have support and someone to talk to, (...) you get depressed and feel like throwing the pills into the trash to end it all”* (male, 28 years, HIV+). *“If the family isn’t there for you, it’s harder for you to follow the treatment, because you’re in bad shape emotionally”* (reference person, therapeutic community).

Whether through fear of discrimination or rejection by families and/or friends (especially in the case of HIV) or through misunderstanding and lack of follow-up in both conditions, many of the people interviewed in this study stopped frequenting these settings. The radical way they break off some highly significant and long-lasting ties is explained by the high expectations of support and the pain resulting from lack of empathy in the face of a life-long condition.

In short, the first point is the importance of the affective relational framework of family and friends. This setting can spawn either feelings of support that lead to better treatment adherence, as we discuss in the next section, or feelings of abandonment and rejection that work against treatment continuity. In such trajectories, not adhering to treatment results from a dynamic that transcends each individual’s autonomous decisions, where lack of support in this affective setting plays a central role.

As a second point, follow-up by family and friends (i.e., who accompanies the person, and how they do so) is neither a fixed scenario nor a linear process. Over time, the web of relations is transformed:

“My mom was sort of afraid of me. She would always clean the bathroom with bleach after I left. But she changed, and now we’re on good terms. One day she went to my bed, on a day when I was in bad shape and didn’t get up. (...) She was totally in the dark about the treatment, so I let her take her own time, and she eventually understood what the illness was about” (woman, 40 years, HIV+).

Family members’ and friends’ understanding of the health condition and knowledge of the available treatments are preconditions for support for people to deal with them.

- **Empathetic surroundings as motivation and logistic support**

Just as an unsympathetic or hostile relational framework can hinder adherence to a treatment regimen, persons with both health conditions (HIV and addiction) and their therapeutic reference persons emphasized that follow-up by family members or friends results in better adherence. Various studies have underscored the central role of families in sustaining care for individuals with chronic health conditions^{18,19}.

First, affective relations can generate psychological incentives for undergoing treatment. This includes daily encouragement to persist, such as: *“The family’s backing, with someone always telling you, ‘Come on, it’s nothing, you know [the medication] is going to help you’”* (male, 44 years, HIV+). And there is the common remark that the treatment is important not only for the individual’s own well-being, but also for that of some family member, almost always a son or daughter. This affective motivation to sustain a treatment regimen appears as “being well for them” (*“my children don’t deserve to see me like this”*, referring to a serious immune state or addiction), whether to be able to reconnect affectively or

to be able to perform a parental role of care and support, which would be impossible if the individual were under the effect of drugs or with low immune defenses due to HIV.

“It was really hard for me to start this treatment. I was drinking a lot, when I knew that I had this disease, HIV, and that alcohol and drugs were not the solution. So, I did it for myself and my kids, because I have two teenage kids” (woman, 51 years, HIV+).

Second, affective relations also play a relevant role when persons that disclose their serological status or addiction to family members receive practical support to begin and/or sustain treatment. For people with HIV, the father, mother, partner/spouse, and/or children can remind them to take their meds to avoid skipping doses (besides exercising some control over their compliance with the treatment regimens), as well as to help follow other prescriptions such as diet:

“I always have the pill bottle ready with ten doses, in case I’m out on the street and I know that I have to take my medicine at two or three in the afternoon. And I always take it. My family helps too, even my grandson. He doesn’t know what it’s about, but he tells me, ‘You have to take the San Lorenzo pill [referring to the colors of a local soccer team], the pink and white one” (woman, 46 years, HIV+).

A family member that provides emotional support and helps the person with routine management of the treatment (accompanying them to appointments, picking up prescriptions, or helping them take their meds) is viewed by the attending professionals as an essential ally for adherence.

“It really helps us a lot when there’s a supportive family. This patient is also a former inmate. And she’s great. She was on the verge of death, but we had the sister-in-law’s help, helping give her the medication. Having family support is essential. I don’t mean necessarily the whole family, but at least one member. (...) It’s much easier to approach them on this subject, because we have someone to help us. Otherwise they may not even come to their appointment sometimes” (infectious disease physician, public hospital).

The previously mentioned systematic review of chronicity¹⁹ mentioned this therapeutic task-sharing for people with chronic conditions in which the family and health services interact in complementary and virtuous ways. Practical help from the family also plays a relevant role in problematic drug use, where the treatment is often driven (and sometimes sustained over time) at a family member’s initiative, to seek a treatment response for the person’s health, as happens with family members of people with motor disability, facilitating the search for rehabilitation¹⁸, either because they are fed up with the consequences of consumption (physical decay, breakdown of interpersonal relations, trouble with the law), or a combination of both. Thus, some people are taken to treatment by family members when their own determination to start therapy is insufficient:

“I couldn’t go two minutes without smoking freebase. (...) When you make the decision not to do drugs anymore, your family has to do whatever is necessary. (...) My mom has also been very overprotective and doesn’t understand much about the illness. She has always wanted to keep me in a little crystal box, so my aunt and uncle went with me and gave the okay for me to be admitted to this institution, because these thoughts kept racing through my head. (...) I was chained to a cot, hand and foot” (male, 28 years, therapeutic community).

Once treatment has started, regular follow-up by the family is essential, especially visits to individuals admitted to therapeutic communities or participation in the service’s treatment dynamics. On the other hand, if some family member or friend of the person in treatment continues to consume drugs, the therapeutic institutions emphatically recommend that they distance themselves from these settings in order to achieve recovery.

Peer groups: support based on shared experiences

Support for persons with these chronic conditions is a crucial factor for their treatment adherence, since such health conditions tend to be associated with loss of social ties³². However, analyses of the positive effects of more receptive social settings tend to focus on the relations with people that do not experience the same condition³³. In our research, the interviews highlight the role of peer groups in the treatment adherence process, a theme that has received relatively little attention³³. Our interviews with people revealed inspiring examples, accumulated knowledge, and emotional support from those who share the same health condition in dealing with chronic suffering.

Some approaches to addictions promote peer interest in sustaining retention in treatment, a therapeutic dynamic in which affect is considered nodal.

“Here, affect circulates. If the person doesn’t show up within 10 days, it doesn’t go unnoticed. A peer calls you and says, ‘What’s wrong, why didn’t you come?’ This call alone means a lot, ‘because they care about me...’ (...) Because they’ve been through the same as you, because we’ve been in your place and we know what it means” (reference person, outpatient service).

“The program has everything. First, it’s been proven that group therapy is the only kind that works, because you can see yourself in a mirror. When an addict speaks, the others automatically begin to identify with what they feel and think. (...) It’s the unity in the group, in the events, in the workshops. When a group session ends, you all go to eat at the home of one of the friends. You get to know people with the same illness, who have the same madness in their head but who aren’t doing drugs now. So, you think to yourself, ‘How do these crazy people manage?’ And that’s basically what attracts you. (...) Meanwhile, there’s the containment, (...) the group containment. We’ve seen people that wanted to consume, and the whole group in the house met that night to keep them clean. Patients that have gone to parties at Narcotics Anonymous (...) see other people without alcohol that are doing fine” (reference person, therapeutic community).

Given the urge to fall back into doing drugs, in abstentionist treatments like those discussed, peers offer emotional support and inspiration. Sharing therapeutic or relaxing spaces with people that are clean helps limit oneself to the immediate present and serves as a stimulus for the future, seeing peers that have quit consuming, a desirable goal for their own recovery.

For people with HIV, contact with others who have undergone treatment experiences with good clinical results also acts as an incentive to continue treatment, seeing their state of health and life attitudes, confirming that HIV is not synonymous with death. These peers can also provide emotional backing to deal with the psychological burden and practical challenges of taking daily medication for life, by sympathizing for having gone through a similar experience: *“It’s really good to have a person that also has the disease and has coped with its difficulties. To have the support of someone who also has HIV, who knows what they went through or are going through themselves” (male, 19 years, HIV+).*

People with HIV with longer treatment time tend to play a pedagogical role for patients who have more recent experience with the virus, allaying their feared association with death and other stigmas (such as physical deterioration). Formal and informal HIV peer networks interact with seropositive people, helping them rationally and psychologically process their realignments vis-à-vis the meanings of the disease and their own fears, for example immediately after the diagnosis:

“What helped me was the people meeting here. There was this group of patients, and there was this patient who realized my despair. And he calmed me down. He said, ‘Look, I’m a dad, my kids are healthy, and nothing’s wrong with me.’ He was about my age. I even remember that he hugged me. Whenever I remember it, I cry. Because when somebody tells you that [the diagnosis from the infectious disease physician], you’re standing right there, and they tell you ‘I’m sorry, you’re going to die. And I’m fine and healthy.’ That’s how I took it” (woman, 47 years, HIV+).

Peer networks foster dialogues that redefine HIV as a condition of vitality, not of death, combining expert knowledge with the person’s own experience of living with the virus, in a discourse that does not renounce biomedical specificities, but is modulated in an affective dialogue that is highly valued by its participants. Peers build empathy in very immediate ways, because they offer a sympathetic ear based on similar sufferings and accumulated learning that enables the emotional “catharsis”. The kind of understanding that can only be offered by someone who has been through similar moments with their own seropositive status (the diagnosis, managing and disclosing the information, the start of therapy, side effects, and accumulated toxicity in the body) involves a presumption of empathy (often confirmed in the interaction) that is highly appreciated by those in treatment and that seeks to ensure their adherence by appealing to peers.

“I needed a way to take a weight off. Everything that was happening in my life had been piling up inside, and the group [of people with HIV] was like a place to vent my emotions, where I could let it all out. All the shit I was experiencing, if you’ll pardon the expression. And it really did me good. It does me good. It’s a beautiful group. Sometimes I don’t get along with everyone all the time. But it’s a beautiful place just the same. All young people, you need to be there, to talk with somebody who feels and knows what you’re going through. It’s about feeling comfortable. Because you know that the other person has the same problem that you do and knows what you’re going through” (male, 22 years, HIV+).

Thus, the bond with people experiencing the same suffering tends to facilitate treatment adherence, based on the positive effects as the person redefines the disease³³. Interacting with peers that

have undergone similar experiences favors acceptance of the suffering through approaching new strategies and tools to deal with the present and glimpse future horizons.

Therapeutic reference persons and health professionals: beyond surveillance and information

The demand for follow-up and affective support also relates to a wide range of therapeutic reference persons that perform occupations of care:

*“Such occupations require performing activities that contribute to health and physical safety, as well as developing cognitive, physical, and emotional skills in the people that interact directly with the recipients of such services. These occupations are typically concentrated in the health sector, (...) and the most frequent ones are therapists, physicians, and nurses”*³⁴ (p. 151).

Investigating the affective dimension in interventions means conceiving of treatment beyond the traditional clinical focus. Mobilizing an affective commitment in healthcare is not viewed by the parties involved as inconsistent with the expected therapeutic expertise. The physicians, psychologists, and social therapists we interviewed perform emotional work, that is, the deliberate act by professionals to attempt to modify a feeling or emotion³⁵, in this case in patients with chronic health conditions. They work on the emotions of people with HIV or drug users in order to motivate them to continue their treatments, based on empathetic understanding of their experiences and the hopeful suggestion of a more promising future. That is, they seek *“to establish an emotional connection with the people they care for”*¹⁵ (p. 143) in order to foster treatment continuity.

Affect has a central place in treatment proposals for addiction. The need to complement expert professional knowledge with an affective dimension appears in psychologists, through building a bond that allows them to understand emotions by empathizing with the people they care for and even expressing such emotions physically.

“You may know a lot, but the emotional part is also important, (...) the fact of generating empathy, of understanding all the emotions the kid is going through” (psychologist, therapeutic community).

“If you know a lot about addiction but don’t approach a youngster and give them a hug and a kiss, are you an expert?” (psychologist, therapeutic community).

The interviews question whether expert professional knowledge suffices for a therapeutic approach to addiction. They thus propose to begin by hugging the person that appears before them, broken down by drug use, allowing them to express their pain, listening to and supporting them:

“It’s really hard to get the kid to even reflect on his situation. That’s why lending a sympathetic ear is so important. That’s where we make our mark: take life as it is, not judge it, and listen. (...) You can help the kid to beat addiction without having to professionalize everything. Because sometimes when you professionalize everything it produces a kind of split in the bond. (...) One of the most important kinds of poverty (which is not measurable, the way you measure per capita income) is the issue of orphanhood or loneliness. So, we offer a space for listening and familiarity” (coordinator, neighborhood community).

An extended perception is when a professional promotes a bond with a patient that transcends conventional clinical interaction, generating additional incentives to continue treatment, by displaying a personal interest in the patient’s improvement. This interest is manifested in the willingness to meet the patient’s requirements beyond the office or clinical and stipulated hours.

“Dalila showed me that she cared, and that made the change. I mean, whenever I needed to I’d send her a WhatsApp and she’d send one back and ask me how I was doing. (...) At first, she was constantly asking me how I was, what I was doing, saying that if I needed anything to call, to call her if I thought of anything. In other words, I have this relationship with Dalila, if I call her on the phone I can speak easily, and if she’s not seeing a patient right then, she gives me room to talk. It’s not the professional position of such-and-such an appointment time, you know? And that’s what I cherish from her, that in all the years of therapy I’ll ever have, I’ll never find another psychologist like Dalila” (woman, 27 years, outpatient clinic).

People with HIV identify affective professional follow-up as a facilitator for adherence. While “cold” and depersonalized treatment by an infectious disease physician who is unreceptive to the needs and concerns of a person in treatment is difficult to sustain, cordial care, attentive to the patient’s emotions, facilitates adherence:

“The physician-patient relationship is essential for me. I’ve experienced the kind of treatment where you’re not just a record, a name, or a number, but where there’s – maybe not exactly a friendship – but cordial treatment, where they listen to you. I went recently, not scared but concerned, because I had this ugly cough (and I’m still hoarse two weeks later). And [the physician] tells me, ‘It’s nothing, but let me take a listen.’ And he listened to my lungs and said, ‘You’re going to take this medicine, but do this and don’t come to the hospital. You may have a cough for a month, don’t worry.’ One way or another, they give you the meds and you come away with your mind at ease. (...) That helps me a lot. A relationship that’s cordial, the real thing. Not where you sit in front of a doctor, who pesters you, who’s like an iceberg. At least that he pretends that you matter” (woman, 47 years, HIV+).

This expectation and appreciation of medical care is identified by studies on other chronic conditions. Treatment adherence improves when professionals create room in the appointment that transcends the mere transmission of information in order to promote a relationship based on interest in the patient’s personal experience, ranging from occasional symptoms to the side effects from medication.

Conclusions

Box 1 provides our synthesis of the analyses.

The article’s main finding is that clinical or psychological treatments prove insufficient to produce adequate treatment responses to these chronic conditions, both in the eyes of those receiving and those providing the care.

Our analysis provides elements for conceiving of treatment adherence beyond an individual logic, that is, complying with treatment prescriptions solely on the basis of individual will and discipline. In this sense, the article did not attempt to elaborate generalizable results, but to analyze in depth the role of affect in treatments for chronic conditions exclusively in the target institutions. In both conditions explored here, HIV and problematic drug use, the treatment regimens take on a collective dimension:

Box 1

Roles of significant groups in treatment of chronic conditions.

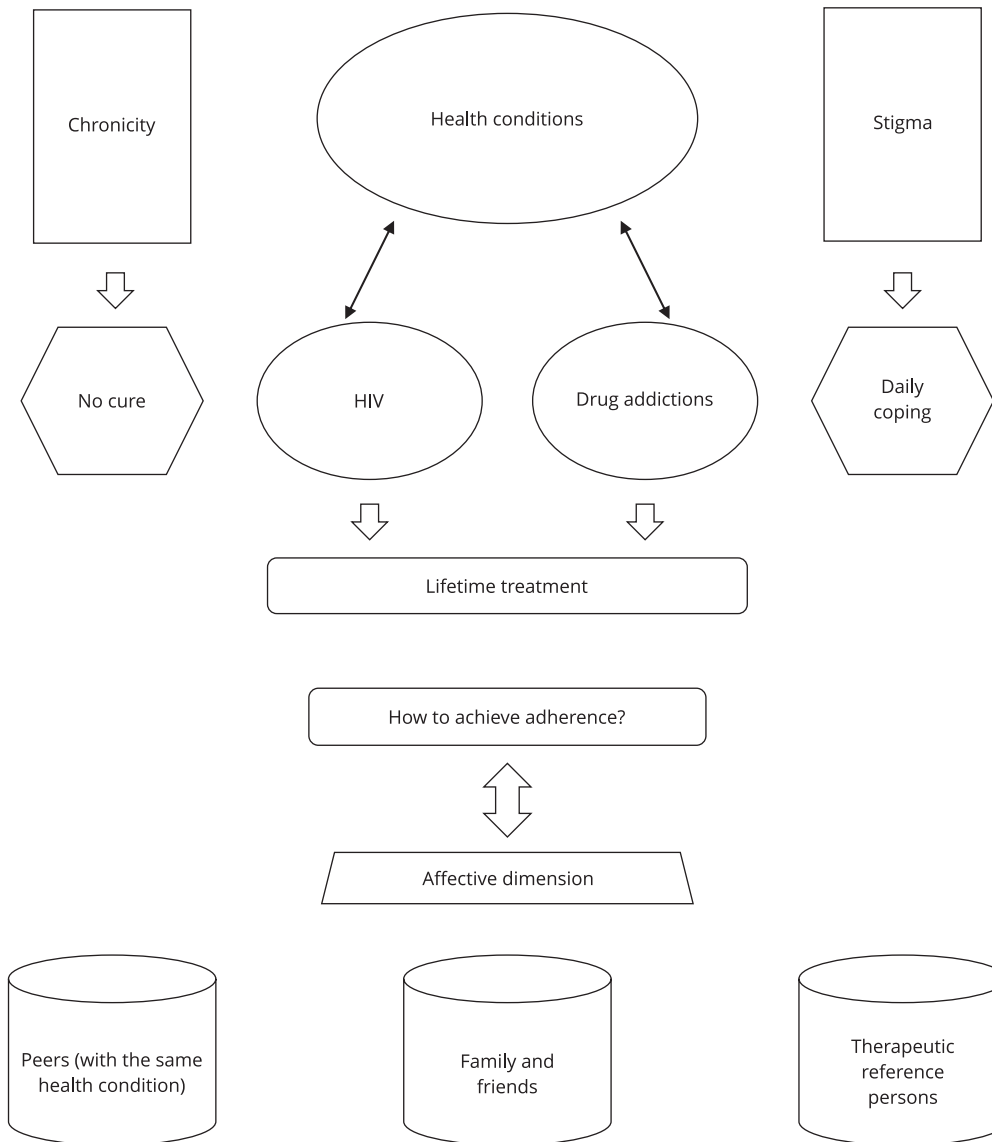
Significant group		Injection drug users	Persons living with HIV
Family and friends	Negative influence	In occasional relapses in drug use and treatment dropout.	In treatment dropout.
	Positive influence 1: as motivator	To be able to be there for the family and set an example for life.	To not die and to be there for the family.
	Positive influence 2: as material and logistic support	To begin treatment (including taking the person for therapy against their will).	To take the person to medical appointments and to remind him or her to take their meds.
Peers (with the same health condition or in similar treatment)		Offer emotional containment through understanding of common experiences (to be able to quit drug use) and showing the example of successful treatments.	Offer emotional containment through understanding of common experiences (of living with HIV and having to follow lifetime treatment). Act as examples of successful treatments, good quality of life, and vital attitudes.
Professionals		Generate a bond of trust and allow expressing feelings and experiences of persons in treatment.	Generate a bond of trust and allow expressing feelings and experiences of persons in treatment (beyond merely transmitting information).

the people who begin them and manage to continue them are traversed by a network of affective relations that functions as fundamental motivation and support.

Having addressed adherence through the experiences of those undergoing treatments allowed us to understand such adherence as a process involving a set of perspectives in dialogue and dispute between professionals, patients, and family, friends, and peers (Figure 1). Adherence assumes a complex and dynamic trajectory in which knowledge is accumulated and one appeals to bonds permeated by affect, helping one remain in treatment and above ensuring good quality of life. This is not the result of individual voluntary acts alone, but depends on a dynamic, contingent, and heterogeneous relational web that may or may not favor adherence.

Figure 1

Relational key for treatment adherence in chronic diseases.



For people with HIV, family members' reminders and presence, constantly reminding the person to take their meds and do their tests, as well as other forms of care, besides the possibility of sharing experiences and feelings with peers with the same health problem and empathetic professionals, all favor adherence over time, by generating dynamics of follow-up and shared responsibility. Something similar happens with treatments for addictions, often initiated at a family member's initiative or requiring their active participation in the treatment dynamics. When conceived as a chronic disease, lifetime follow-up by the family (as long as the other members are not involved in drug use themselves) tends to help the individual follow the prescribed treatments (such as maintaining abstinence).

The importance of these roles of affective relations help us to conceive of treatment adherence for chronic conditions from a collective and relational logic, as suggested (by contrast) by the negative effects of lack of follow-up or emotional containment, as happens by an "inadequate" reaction by the people around individuals with HIV or drug addiction. In many cases, adherence is less a personal than a collective experience in which the web of family members, peers, and professionals plays a central role. People's bonds may sometimes appear to explain treatment dropout or avoidance, but in many other cases they function as incentive or support.

Contributors

D. Jones and S. L. Cunial contributed to the study design, conduct and analysis of the interviews, data interpretation, writing and critical review; they also approved the final version.

Additional informations

ORCID: Daniel Jones (0000-0002-8823-8587); Santiago Luján Cunial (0000-0002-4657-7388).

Acknowledgments

We wish to thank the people interviewed here, who remain anonymous, for having shared their experiences. We also thank the National Division of AIDS and STDs of the Argentine Ministry of Health and the Argentine National Council for Scientific and Technical Research (CONICET) for financing the research that gave rise to this article. Finally, we thank the two anonymous reviewers for providing comments that significantly enriched the article's final version.

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Resumen

El presente artículo analiza los cruces entre experiencias terapéuticas y vínculos afectivos en las trayectorias de dos grupos de pacientes con padecimientos crónicos: personas con consumos problemáticos de drogas en tratamiento en dispositivos religiosos de atención terapéutica; y personas con VIH bajo atención clínica y tratamiento antirretroviral. El artículo parte de una estrategia metodológica cualitativa, basada en entrevistas en profundidad. La hipótesis es que los tratamientos (farmacológicos o psicológicos) usualmente resultan insuficientes para brindar respuestas terapéuticas adecuadas a estos dos padecimientos crónicos. Los grupos entrevistados reconocen la centralidad de las dimensiones afectivas para la adherencia a las pautas de tratamiento propuestas y para un abordaje integral, y consecuentemente más efectivo, del VIH y de las adicciones a las drogas. El artículo concluye presentando una noción de adherencia que excede el comportamiento individual de mero cumplimiento de las prescripciones de los tratamientos. La adherencia es menos una experiencia personal que colectiva, en la que el entorno cercano de familiares, redes de pares y profesionales y otros referentes terapéuticos juegan un papel central.

Pacientes Incurables; Tratamientos; Cooperación del Paciente; Drogas; VIH

Resumo

O presente artigo analisa as intersecções entre experiências terapêuticas e vínculos afetivos nas trajetórias de dois grupos de pacientes com padecimentos crônicos: pessoas com consumos problemáticos de drogas em tratamento dentro de locais religiosos de atenção terapêutica; e pessoas com HIV sob os cuidados clínicos e tratamento antirretroviral. O artigo parte de uma estratégia metodológica qualitativa, baseada em entrevistas em profundidade. A hipótese é que os tratamentos (farmacológicos ou psicológicos) comumente resultam insuficientes para proporcionar respostas terapêuticas adequadas para estas duas doenças crônicas. Os grupos entrevistados reconhecem a centralidade das dimensões afetivas para a aderência nas pautas dos tratamentos propostos e para uma abordagem integral, e consecuentemente mais efetiva, do HIV e da dependência as drogas. O artigo conclui apresentando uma noção de aderência que excede o comportamento individual de mero cumprimento das prescrições dos tratamentos. A aderência é menos uma experiência pessoal do que coletiva, em que o ambiente familiar, as redes de pares e profissionais junto com outros referentes terapêuticos jogam um papel central.

Pacientes Incuráveis; Tratamentos; Cooperação do Paciente; Drogas; HIV

Submitted on 25/Feb/2019

Final version resubmitted on 08/Oct/2019

Approved on 31/Oct/2019