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Re-signifying HIV through exercise: from death sentence stigma to healthy self-perception

Yeimmy Rodríguez-Moreno^a, Omar Antonio Calderón-Cardona^a, Jaime Alberto Gallo-Villegas^b and Carlos Enrique Yepes-Delgado^c

^aIntern/Resident Medicine Applied to Physical Activity and Sports, Universidad de Antioquia (UdeA), Medellín, Colombia; ^bSchool of Medicine, Universidad de Antioquia, Clinic and Research Center SICOR, Medellín, Colombia; ^cSchool of Medicine, Universidad de Antioquia, Hospital Pablo Tobón Uribe, Medellín, Colombia

ABSTRACT

Despite HIV being considered a chronic disease and the benefits that exercise interventions can bring to HIV-infected patients, the application of physical activity is currently low. Some qualitative studies have been conducted; however, it is currently little known about the meaning of the experience of exercising in people with HIV. This hermeneutic research used 21 in-depth, semi-structured interviews with patients with this condition. The analysis was based on a grounded Theory methodology, which is theoretically supported by symbolic interactionism. It was possible to advance in re-signifying HIV from a social stigma context. This process, through exercise and social, family and medical support, comes from the breaking of individual and collective perception paradigms. Particularly, exercise changes the perspective from a HIV-infected person on the verge of death to a healthy, active and functional individual with personal goals. Thus, by contributing to functionality and health recovery, exercise re-signifies life. Moreover, commitment to physical activity goals is influenced by inner tensions that can hinder or encourage this habit and demand further research. HIV infection shifts from being a death sentence to a healthy self-perception beyond the diagnosis.

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Exercise; chronic disease; HIV; life-change events; social stigma; health; grounded theory

Introduction

Human immunodeficiency virus (HIV) is a condition with a high disease burden. In 2021, 38.4 million people were diagnosed with HIV and 650,000 died of it (Joint United Nations Programme on HIV/AIDS 2022a). Additionally, 1.5 million of new infections were reported by the Health World Organization, which was a significant rise, even higher than expected by the World Health Organization (WHO) (Joint United Nations Programme on HIV/AIDS 2022b). Moreover, this infection is considered a chronic disease due to the increase in life expectancy after the use of antiretroviral therapy (Karpiak, Shippy, and Cantor 2006; Smit et al. 2015). This generates specific needs in this population because of exposure to cardiovascular (Currier et al. 2003; Friis-Møller et al. 2003) and metabolic risk factors (Grinspoon and Carr 2005).

Regarding medical treatment of HIV infection, literature includes evidence of the effects of exercise as complementary therapy; effects such as improvement of the physical condition, body composition and psychological aspects (Jaggers 2018; Ozemek, Erlandson, and Jankowski 2020).

CONTACT Yeimmy Rodríguez-Moreno  yeimmy.rodriguez@udea.edu.co  School of Medicine, Universidad de Antioquia, Carrera 51D número 62-29, La Candelaria, Medellín, Colombia

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Nonetheless, despite benefits, the global application of current physical activity (PA) recommendations is low; 28% of the world population do not meet the goals set by the WHO (WHO 2022) and, more specifically, compliance figures with these guidelines in people living with HIV (PLWH) have been observed with a wide heterogeneity due to multiple factors. This implies a limitation for comparing the level of PA in the HIV population versus global adherence or other specific population groups (Vancampfort et al. 2018); Hence, developing the need of understanding the nuances regarding inclusion and variability in adherence to PA in PLWH.

To do so, besides the biomedical aspect, stigma and discrimination implications for PLWH must be considered (Rodkjaer et al. 2011; Schuft et al. 2018). Of people with HIV, 2.5% are sex workers, 7.7% are men who have sex with men (MSM), 5% are injecting drug users, 10.3% are transgender people, 1.4% are in prison (UNAIDS DATA 2023). For this reason, HIV infection is associated with individuals from marginalised and socially 'reprehensible' groups (Catalan et al. 2020; Chapman 1998; Sontag 2003). More than 50% of people aged 15–49 with HIV have experienced discriminatory attitudes (UNAIDS DATA 2021), which has important implications for this population, such as criminalisation, gender, and intra-family violence experiences (Lyons et al. 2022; UNAIDS DATA 2021), decreased adherence to treatment (Katz et al. 2013), denial of job offers and health services, among others (Lyons et al. 2022; UNAIDS DATA 2021). This results in unique experiences for this population when internalising their disease (Baumgartner and David 2009; Catalan et al. 2020), which, according to some studies, occurs in three stages: (1) diagnosis with emotional reaction, (2) postdiagnosis turning point and (3) integration (Baumgartner and David 2009). Within the coping process, it has been recommended the inclusion of a healthy lifestyle (Siegel and Schrimshaw 2000); however, there are few conducted qualitative studies that enquire about the use of exercise as a contributing tool to cope with the disease. The research, mainly conducted in developed countries, has included patients over 50 years old with a motivators and barriers approach (Chetty, Cobbing, and Chetty 2022; Johs et al. 2019; Neff et al. 2019; Simonik et al. 2016).

In Latin America, there has been a poor advancement in reduction of new HIV infections and access to comprehensive treatment (in which the use of exercise is quite limited), developing limitations for the disease treatment in comparison to developed countries (Joint United Nations Programme on HIV/AIDS 2022a). Specifically, in Colombia, by 2022, 12919 new cases of HIV were diagnosed and 34.79% of the incident cases were in the AIDS stage. Of the newly diagnosed cases, 58.6% belonged to vulnerable populations (MSM 3.94% and users of psychoactive substances 7.31%) (Cuenta de Alto Costo 2023). These figures support the narrative of perceptions of the diagnosis being exclusively for socially marginalised people. This results in painful experiences due to discrimination from the policy, health-care system, society and church, affecting the person's life project (Erazo and Canaval 2018; Flores and Yolanda 2015; Lafaurie and Zúñiga 2011; Núñez-Curto 2019). Nonetheless, and despite similarities in stigma and discrimination linked to HIV, there is a study that evidences the resignification process of the disease. The study shows a shift from an existential crisis to the acknowledgement of the disease that makes it possible to see HIV infection as a driving force for life change (Erazo and Canaval 2018). This results in the exploration of experiences of PLWH, their evolution in acknowledging the disease and how this determines the use of PA.

Finally, the experience of coping with HIV disease acquires unique nuances to be understood as it is a highly stigmatising disease and coping with it varies with the social support particular context of each individual, including multiple individual experiences. Moreover, exercising is a behaviour that contributes to post-traumatic growth (Chen et al. 2020; Erazo and Canaval 2018; Kitilya et al. 2023; Siegel and Schrimshaw 2000), yet there is high variability in its application. This can result from cultural factors (Tudor-Locke et al. 2003) or motivational ones (Teixeira et al. 2012), which are influenced by the meaning given to PA. However, after a thorough literature search, there are few studies exploring this approach, much less in an explicit way. Therefore, this study's objective was to understand the meaning of doing PA in people with HIV. Understanding this phenomenon will permit establishing guidelines in favour of exercise inclusion in comprehensive programs for HIV.

Materials and methods

Design of the study

A hermeneutic study that aims at understanding the phenomenon from an intersubjective and intimate perspective of the participants through the interpretation of their interaction with the research team in an integrative and holistic manner. The methodology of this research is grounded theory, which is composed of procedures that seek to explain the phenomena through a mainly inductive analysis that starts from the participants' data and continues to the formation of a theory that emerges from the stories. This theory constitutes a set of logically organised and interrelated categories that form an explanatory framework for the study phenomenon. This methodology, rigorously used, is expected to result in an explanatory framework that transcends the variables of person, time and place (Glaser 2002).

The grounded theoretical methodology has symbolic interactionism (SI) as its theoretical support, which focuses on the study of humans' behaviour through their actions. These are the result of a complex web of interactions between the individual himself, his experiences and his social environment, creating relationships of action – interactions that modify the meaning given to people, situations or things. The transformation of the initial meaning contributes to change the acting and behaviour of the person (Blumer 1969; Yepes-Delgado 2023). It is for this reason that three pillars of SI are considered: (1) people direct their actions toward things or people in their environment according to the meaning they give them; (2) meaning is a consequence of social interaction; (3) meanings are modified depending on the interpretation of life experiences (Blumer 1969).

Participants

Twenty-one semi-structured interviews were conducted between 2022 and 2023. The interviews contained questions on three main topics: social, cultural and health context, in which the social context and support and the experience with the disease were inquired; Treatment and secondary effects; PA, in which general questions were asked about the reasons, experience, myths, perceived benefits and side effects regarding exercise. Criteria of inclusion were: (1) having a HIV/AIDS infection diagnosis; (2) being 18 or older; (3) filling out the informed consent form; (4) being part of a comprehensive care program for patients with HIV/AIDS. Interviews lasted about 90 minutes and were conducted by the researchers with authorisation from the interviewees; notes were also taken during these sessions.

The interviewees agreed on meeting with the researchers in a comfortable place and signed the informed consent form. This document mentioned the objectives of the study, the volunteer nature of their participation, and the possibility of refusing to answer any questions or stopping the recording.

Initially, participants were chosen based on convenience as some of them had previously had contact with the researchers and the Postgraduate Program in Medicine Applied to Physical Activity and Sports through prior research work. Subsequently, with the emergence of the categories and initial partial results, some aspects to explore in greater depth were identified, and the interview script was modified to explore new scenarios and experiences. Then, after modifying the script, the theoretical sampling was carried out by interviewing key participants that would allow advancements in the construction of the final theory that would explain the current phenomenon (Charmaz 2006; Yepes-Delgado 2023). During collection of data, some patients with an appointment did not arrive, therefore, they were replaced. Characteristics of the interviewees can be seen in [Table 1](#).

Table 1. Sociodemographic and clinical profile description.

Interview	Age	Sex	Marital Status	Education Level	Years After Diagnosis	Social Support	HIV Classification	Comorbidities	Does PA	Type of PA	Volume (min/w)
1	30	M	Single	Highschool	10	Partner	A3	High blood pressure, psychiatric unknown	Yes	Mixed	600 Intermittent 60–120
2	56	M	Unión libre	Technician	4	Family and partner	A3	No	Yes	Aerobic	
3	53	F	Single	Professional	9	Family	AIDS	Breast cancer	Yes	Aerobic	360
4	42	M	Single	Highschool	18	Family	Unknown	High blood pressure	No	N/A	N/A
5	51	F	Unión libre	Elementary School	5	Family	Unknown	Hypothyroidism, cerebral toxoplasmosis	Yes	Mobility, physical rehabilitation	360
6	56	M	Single	Highschool	10	No	AIDS	Toxoplasmosis, high blood pressure	Yes	Mixed	360
7	32	M	Unión libre	Technician	6	Partner	Unknown	Advanced chronic insomnia	Yes	Aerobic	30
8	40	M	Unión Libre	Technician	23	Family and partner	Unknown	Dyslipidemia	Yes	Mixed	105
9	49	M	Married	PhD	26	Family	AIDS	Bipolar disorder	No	N/A	N/A
10	43	M	Single	Professional	14	Family	AIDS	Hepatitis C, neurosyphilis	Yes	Strength	600
11	37	M	Unión Libre	Specialist	6	Family and partner	Unknown	High blood pressure, anxiety and depression, chronic ulcerative colitis, obesity	Yes	Mixed	150
12	52	M	Single	Highschool	3	Family	Unknown	No	Yes	Aerobic	30
13	57	F	Single	Highschool	14	Family	AIDS	High blood pressure	Yes	Aerobic and yoga	360
14	56	M	Single	Technician	21	Family	Unknown	Diabetes	Yes	Aerobic	1200
15	29	M	Single	Postgraduate	7	Friends, partner and foundation	B1	Depression and anxiety	Yes	Mixed	150
16	35	F	Unión Libre	Technician	15	Foundation and partner	AIDS	No	Yes	Yoga	120
17	24	F	Single	Professional	1	Foundation	Unknown	No	No	N/A	N/A
18	35	M	Single	Technologist	4	Family, friends and foundation	A2	No	Yes	Mixed	180
19	44	M	Single	Professional	8	Family and foundation	AIDS	No	No	N/A	N/A
20	31	M	Single	Professional	1	Family, partner and foundation	Unknown	No	Yes	Aerobic	300
21	48	F	Single	Professional	25	Family, friends and foundation	A1	No	Yes	Mixed	360

F: Female; M: Male; min/w: minutes/week; Unión Libre: marital status that implies more than two years of living together.

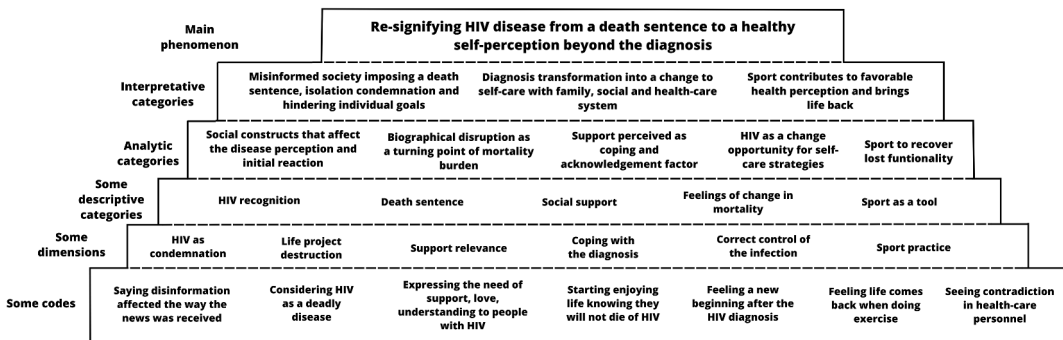


Figure 1. Abstraction levels of open, axial and selective coding.

Analysis

Both collection and analysis of data processes occurred simultaneously. We started with 10 interviews and, after script adjustments, 11 more were conducted. Collection and analysis of data were developed through the constant comparative method (Morse et al. 2009) with an interactive, iterative and systematic process involving codes, theory and researchers. It is considered interactive as it confronts and compares the perspectives of participants, researchers and scientific literature (Corbin and Strauss 2015; Yepes-Delgado 2023).

It is also an iterative process since an inductive analysis is carried out from the participants' narratives to the theory. But there is also a deductive analysis, which starts from the theory and the scientific literature to the participants' narratives in order to find details and provide theoretical sensitivity (Corbin and Strauss 2015; Yepes-Delgado 2023).

Finally, it is systemic in following orderly and rigorous procedures that allow analysis and theoretical construction advances (Corbin and Strauss 2015; Yepes-Delgado 2023). This method permitted reflection on the data, which led us to identify emergent categories and patterns to be thoroughly analysed in order to throw meaningful conclusions.

Reliability between the audios and transcripts was verified, and then we conducted the analysis of data in three stages: (1) descriptive; (2) analytic; and (3) interpretative (Corbin and Strauss 2015). Initially, at the descriptive stage, open coding was carried out by means of a detailed line-by-line analysis of the interview transcripts, maintaining fidelity with the participants' narratives. Second, an agreement was reached between researchers on developed codes to create descriptive categories. Within these, properties and dimensions were identified, allowing the formation of subgroups that explain the variations and characteristics within the descriptive categories. Afterwards, the analytic stage, through axial coding, we used the properties and dimensions to create analytic categories that would give greater theoretical relationship and explanation. At this stage, some phenomena were identified, along with their conditions, action and interaction relationships, and consequences, organised in a matrix of the paradigm (Corbin and Strauss 2015) (Figure 1).

Finally, at the interpretative stage, the analytic categories were grouped in a more abstract way through selective coding. This allowed the identification of a core category at micro (personal), meso (social support) and macro (surroundings) levels, using a conditional/consequential matrix, which exposed a basic social process to meet the proposed objective (Figure 2). During the process, researchers consistently agreed on emerging categories. Field notes were taken in journals, and experiences and transformations of the research team were frequently examined. The results were sent to the 21 participants of whom 7 provided feedback identifying themselves with the research findings.

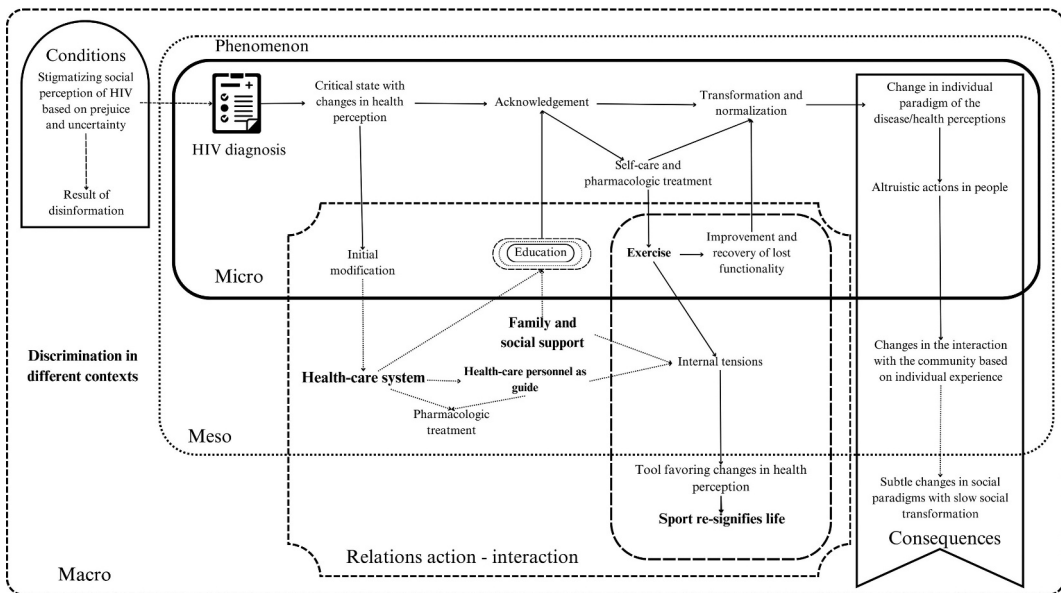


Figure 2. Social basic process of re-signifying HIV and its relation with exercise.

Ethical aspects

To validate our work, the researchers were introduced as academics aiming to understand the experience of participants without promising anything in return. We offered respectful treatment and showed interest in their experiences. As a result, they agreed on participation and told us their experiences openly and in detail. This study was categorised as research of minimum risk in accordance with Resolution 8430, 1993 (Ministerio de salud de Colombia 1993) and considered the basic ethical principles from the Belmont report (United States 1978). Moreover, considering possible psychological affectation for participants during the interviews, we had available psychology personnel in all the interviews, being a requirement for follow-up to individuals without later affectations. Before its execution, the study was approved by the institutional review board (IRB) of the School of Medicine of the Universidad de Antioquia, record No. 021 of 2021 and Virrey Solis IPS E-DEST-FO07.

Results

As a result of data analysis, some descriptive categories were found, including: HIV recognition, death sentence, social and family support, sport signifies life, medical assistance, evolution, and physical activity, among others. After analysing these categories, we moved forward to analytic categories such as: (1) social constructs that affect the disease perception and initial reaction; (2) biographical disruption as a turning point of mortality burden; (3) support perceived as coping and acknowledgement factor; (4) HIV as a change opportunity for self-care strategies; (5) sport to recover lost functionality. Finally, we moved to the following interpretative categories; (1) misinformed society imposing a death sentence, isolation condemnation and hindering individual goals; (2) diagnosis transformation into a chance to self-care with family, social and health-care system support; (3) sport contributes to favorable health perception and brings life back (Figure 1). These categories permitted exposing a basic social process organised with the conditional/consequential matrix, having as condition: social stigma at a macro level, which results in a HIV re-signifying phenomenon at an individual level and is influenced by supporting or limiting factors in the disease coping: social, family, health-care system

support. Re-signifying the disease has as a consequence elimination of health stigmas at individual and social levels. Exercise emerged as a coping method with multiple internal nuances (Figure 2).

A society that imposes a death sentence

Current social representations of disease by HIV constitute macro conditions, which are the beginning of coping with the infection. Society perceives PLWH as individuals from specific marginal groups who are seriously ill and near a cruel and early death. These precepts are based on a misinformed context that converges with judging eyes and moral supremacy, degrading patients to 'second-class people', which results in discriminatory attitudes in different contexts. This is why, at the diagnosis moment, the participants faced heart-breaking news associated with a previously suspected death sentence. This perception was favoured by physical, emotional and social critical conditions that, in some cases, were externally pointed out by the patient's close social circle.

They were shown skinny, almost dead, with lots of brown cloths, so you'd think: when will I be there? When?.
(Male, 56 years, seller)

This is how the re-signifying process of the disease begins, which constitutes a complex phenomenon. It starts with the biographical disruption of diagnosis, the socially imposed meaning of stigma and morbid and deadly perception, and will develop with coping with the disease.

From biographical disruption to re-signifying the disease

After the HIV diagnosis, individuals experience a sudden and significant change in their life project and immediate family due to social stigma and guilt perception. This change causes a biographical disruption that interrupts the life projection of the participants, their social relationships, threatens their identity and radically transforms their daily lives. This event triggers an individual process influenced by diverse factors that hinder or enhance coping with the disease and which will be explained below.

Support perception, which begins in the health-care system, modifies the catastrophic perception of the disease through different experiences in each health-care centre. These were different for each individual. Additionally, medical guidelines regarding pharmacological treatment and lifestyle changes started the patients' learning about their disease. However, due to fear of rejection and isolation, patients had an emotional dilemma as to whether to share the diagnosis with those close to them. This inner struggle made individuals look for social and family support to have company to face the disease, but it also meant to worry for the wellbeing of the loved ones. At this stage, the interviewees identified as fundamental the family, friends, and foundation's support. The participants' interaction with these support networks fostered the learning process meet acknowledgment of the disease:

We sometimes have things in our hearts that simply heal when telling someone else. (Male, 40 years, independent)

My brother's reaction was a hug, and I think that's better than any medicine; feeling a close person's support (. . .)
It was a release, understanding I wasn't going to be on my own in this process (Male, 43 years, business manager)

Following the basic social process, after acknowledging their disease, they, after acknowledging the diagnosis as a treatable condition, adopted pharmacological treatment and lifestyle changes (including higher levels of PA) as conscious self-care strategies. These changes triggered a positive evolution in the health of PLWH, transforming and normalising the disease. Thus, HIV went from being a deadly infection to a chronic disease a person can live with, to the point that some participants ended up worrying more about other comorbidities. This is how HIV gave them a change opportunity in order to resume their personal life project by facing an invisible death:

Something that really surprised me was burying my dad and mom as I thought they would bury me. (Male, 49 years, teacher)

Diabetes can mean other more serious issues (. . .) sugar makes me finish HIV, makes HIV different from HIV, like a different disease, so I don't think it's more dangerous than sugar. (Male, 56 years, seller)

When you see you're recovering, overcoming it all, trust comes back, faith comes back, hopes come back, you believe in things again, in life, I don't know, you maybe live more intensely (Female, 53 years, architect)

Health perception as breaking point of stigma

The phenomenon of re-signifying HIV disease, developed in previous sections, results in breaking paradigms. At a micro level, in the individual, acknowledging the disease favoured prospecting in the medium and long term, especially when reaching the undetectable status. This allowed the participants to resume their life project, which they considered unrealisable or uncertain at the time of the biographical disruption due to the fragile physical and emotional state in which they were. By coping with the disease, improving their PA and functionality and emotional peace of mind, the interviewees were able to accomplish those goals important to them that were cut short by the diagnosis. In addition, living for several years with HIV and resuming the important aspects of life (social, family, economic, among others), including their perception of being physically active (even more than other people without the diagnosis), favours the perception of surviving a disease that was considered fatal and with little time to live and transforms it into a diagnosis that does not condition the health or potential of a person. This is how PLWHs shift their perception of HIV from a death-sentenced individual to a healthy person with life quality and able to meet goals regardless of a diagnosis.

It's nonsense, I won't die from this; I may die, but not from this. (Male, 49 years, teacher)

Through this individual process, the participants developed a more active social role through altruistic actions to encourage HIV education. This allows the community to be more aware of the infection, prognosis and real meaning of the disease based on individual experiences that affect the meso level.

Community interaction with HIV-positive people and an active social role create subtle changes in social paradigms and slowly transform the health perception of the patient with HIV. Moreover, the change in health self-perception of PLWH breaks pre-existing social stigma, moving forward in the education of the disease at a macro level. This slowly transforms the meaning of the disease through the individual experience and social interaction of people with HIV, changing the misinformed social perspective and resignifying the disease on a personal and social level. Nonetheless, in spite of scientific advancement, there is still prejudice, even among the youth with recent diagnosis. These stigmas must be modified through education and acknowledgement of the disease.

There is unjustified stigma of the disease and, although it is necessary to have specific care, one no longer lives according to the diagnosis but to be healthy, regardless of being HIV positive. (Male, 29 years, postgraduate student)

People always think that someone with AIDS is terminally ill, but they see I'm absolutely healthy (. . .), everyone sees it as the worst and the sickest patient in the world, and I'm not the sickest patient in the world, I'm the most recovered one. (female, 53 years, architect)

It is fundamental to highlight the vital role of education and social participation in re-signifying and overcoming previously evidenced stigma. An active role before the disease allows fostering information dissemination and support of scientific and social advances, which favour coping with the disease for both individuals and society. This permits people

to think 'HIV does not rule me' and that there is a chance to be healthy beyond the diagnosis.

Somehow, this knowledge allows us to have an active role in what's going on. When I don't have knowledge, I'm in the other's hands. I think an active role when being diagnosed is important. It changes your perspective. You're no longer 'the poor one, the victim, the one about to die'. (female, 48 years, psychologist)

Exercise as a tool that brings life back

In the studied phenomenon, PA is a strategy with multiple influences and nuances at the micro, meso and macro levels.

Exercise is part of lifestyle changes adopted by patients to deal with their disease and improves their health. At the micro level, exercising complements the recovery process of intrinsic capacity that was lost due to the diagnosis, which results in a positive evolution of the disease. This is evidenced by the passage from the prostrate individual in critical stages of the disease, dependent on others for daily activities, to an independent person, physically active and able to perform demanding activities at a higher level than even people without HIV. These activities are important for the participants and allow them to fully develop and contribute to their health perception. Additionally, the participants highlight a positive emotional impact, developing peace of mind that contributes to the transformation and normalisation of the disease. Regarding compliance with recommendations of PA, this depends on factors such as previous experience, interests and individual motivations (health, appearance, among others). In some cases, these motivations encourage exercise as an obligation to be healthy. Even for those people who do not follow the recommendations, exercise is an important self-care tool, and once they begin, they feel guilty of not starting before:

You feel better. You can go up a hill without getting tired. You can put on your sneakers without getting tired. (Male, 37 years, project coordinator)

The day I see myself in the mirror of the gym exercising (...) I'll feel like a complete fool, not for doing it, but for not doing it for 30 years. (Male, 44 years, AV producer)

A relevant factor is the availability of support contexts through family and social support networks that promote exercise as a self-care tool. Additionally, health-care personnel play a vital role in education, as some participants have received contradictory information and scarce guidelines. Despite knowing the benefits of exercising for diverse diseases, patients lack clarity about its concrete benefits for HIV, much less of the way to deal with secondary effects of antiretrovirals and their effects on exercise practices.

Considering the aspects mentioned above, PA means a tool that can help challenge stereotypes and prejudice related to this disease in general by showing that PLWH can lead an active and healthy life, opposite to established death-related suppositions, allowing the change from a living dead person to a functional and independent individual, with the possibility of living many years with the disease and capable of achieving their goals. Somehow, exercise, when contributing to functionality and health recovery, re-signifies life.

As I was recovering my life, especially in sports, my health was strengthening (...). This gave place to a beautiful feeling of well-being, and I've felt it every time I work out; life comes back to me. (Male, 43 years, business manager)

Discussion

In these findings, participants narrated their re-signifying experiences of HIV. This process begins with the existence of social stigma that results in a biographical disruption in

individuals. Subsequently, with health-care personnel's guidelines, and family and social support, the patients added healthy habits, PA and pharmacologic treatment to their life. Thus, PLWH changed their perception of HIV from a fast-paced deadly disease to a chronic condition that does not preclude the possibility of being healthy and having quality of life beyond the diagnosis. This breaks health paradigms both in individuals and society, resulting in the normalisation of HIV through a socially active role that favours education about this disease.

First, it is indispensable to understand the infection experience in order to also understand the significance of PA in this population. The participants talk about an established social image of HIV that encourages stigmatisation of a 'ruined identity', morally despicable and related to social groups with high 'contagious' risks (Chapman 1998; Sontag 2003). In this study, even in young people with recent diagnosis, death sentence sensation of the disease remains. Even individuals with information about the disease are afraid of social condemnation, which still exists and generates a 'long-term "shadow" cast by HIV infection' (Catalan et al. 2020). This will eventually result in an inner struggle about whether to share or not the diagnosis: discredited versus discreditable, as a way to face social stigmatisation (Goffman 1963; Judgeo and Moalusi 2014; Schuft et al. 2018).

Following this social representation of HIV, participants experienced a biographical disruption with the diagnosis that sets the beginning of living with a chronic disease (Alexias, Savvakis, and Stratopoulou 2016; Bury 1982). This interruption of their life project is commonly related to a death sentence that transcends geographical and time boundaries, which is widely mentioned in literature (Catalan et al. 2020; Erazo and Canaval 2018; Lafaurie and Zúñiga 2011).

After biographical disruption, with the impression of being between life and death, post-traumatic growth begins (Catalan et al. 2020; Erazo and Canaval 2018; Siegel and Schrimshaw 2000). Through this process, a positive meaning is given to the disease, seeing it as a chance of change by adopting healthy lifestyles that include PA (Chen et al. 2020; Erazo and Canaval 2018). Based on Siegel's article, in our study, transformational coping continues many years after the diagnosis, even to the participants' present days (Siegel and Schrimshaw 2000). This suggests that stress-related growth is not limited to the initial stage of the disease, but it is internalised as a way of living that contributes to breaking health paradigms with regard to HIV (Solomon et al. 2018). The adoption of healthy habits as a coping strategy was also seen in the study conducted by Alexias (Alexias, Savvakis, and Stratopoulou 2016). Nevertheless, beyond the vision of the disease as an integral part of patients' identity, our research perceives the disease as another diagnosis that, after its normalisation, will not determine a person, their health or their life project.

Furthermore, social, family and health-care personnel support means a fundamental factor in re-signifying HIV. The health-care system enhances pharmacologic and nonpharmacologic treatments to preserve individuals' health; however, self-care, family, friends, and foundations' support permit the creation of safe environments for PLWH (Ventura-Elías, González-Ortega, and Chaparro-Díaz 2021). These conditions improve the quality of life and health perception of patients as PLWH, those close to HIV-positive individuals, and the general community who learn about the disease (Arias and Gutiérrez 2011). Support in different contexts implies turning points post diagnosis, which allows coping with and assimilation of HIV infection as a chronic disease when: (1) learning about HIV; (2) having external support and (3) in medical intervention (Baumgartner and David 2009). Nonetheless, contrary to Baumgartner's findings, participants in our study with one-year diagnosis managed to internalise HIV disease as part of their being, and after stress-related growth, interviewees developed an identity that was not determined by HIV (Baumgartner and David 2009).

In Bastidas' study (Erazo and Canaval 2018), the process aforementioned can also be seen, starting with symptomatology until HIV becomes an incentive for life change. In our research, causes of the phenomenon are not limited to the presence of symptomatology, but they begin with imaginary social ideas coming from disinformation. Moreover, results of life change continue with normalisation of the disease, which is related to tensions of health perception in PLWH. This is due to favourable evolution of the disease perceived by the interviewees, which opposes the death

sentence perspective at the diagnosis moment. The concept changes with individual experience and their relation with HIV infection, re-signifying health beyond the absence of the disease (Licchelli, King, and Smith 2023).

This perception of being healthy, despite testing HIV positive, was seen in our participants regardless of their age, different from participants in Licchelli's study (older than 50) (Licchelli, King, and Smith 2023). Additionally, health is seen as a resource to do what people care most for, which is a relevant factor in the concept of health (Licchelli, King, and Smith 2023; Solomon et al. 2018). This is in relation to defining functional ability as 'capabilities that enable all people to be and do what they have reason to value' (WHO 2015). This consideration, despite appearing in relation to healthy ageing (WHO 2015), applies to all people. However, it is important to consider the growing relevance in medical areas of ageing of the general population and PLWH (Rudnicka et al. 2020; Smit et al. 2015).

Changes in health perception of PLWH are related to conducting PA. In our study, participants had the perception of being healthy at the time of the interview. This, different from the profile in 'no sport due to fatigue' of Schuft et al. (Schuft et al. 2022) enabled our participants to include PA as a habit. Nevertheless, it is worth noting that some interviewees expressed a reduction in their intrinsic capacity (WHO 2015) at the initial stages of the disease, which limited their functionality even in common daily activities, developing negative self-perceptions (Gray et al. 2021). However, with the control of the disease, functionality was improved in order to 'reactivate' (Araya et al. 2022) and have a greater exercise level and health perception.

At the stage of coping, participants included exercise as a strategy of disease and symptoms management, which is similar to the profile 'sporty to manage fatigue' of Schuft (Schuft et al. 2022). Our interviewees reached the profile 'healthy because sporty' at the normalisation stage, in which participants include exercise as part of a healthy life regardless of a diagnosis. This finding agrees with studies in which the rise of auto efficiency enhances ways to feel better and seem healthier (Araya et al. 2022; Kitilya et al. 2023). For the profile 'no sport, no fatigue, no problem', some individuals in our study perceived exercise as foreign to them; however, they acknowledged the importance and benefits of an active lifestyle, showing guilt for not leading one (Schuft et al. 2022).

These variations regarding PA have different internal tensions, which have been explored in studies in developing countries (Araya et al. 2022). At the individual level, previous experience with sports or exercise and interests of every person influenced the choice of which activity to conduct and predisposition to whether to start or continue with this habit after HIV diagnosis. Social and gender stereotypes can be relevant aspects in the application of PA; however, this must be studied more deeply in further research as this is a topic that did not emerge strongly in our study (Kitilya et al. 2023). One of the drivers found in this article is the improvement of physical (auto efficiency) and mental health (Araya et al. 2022; Gray et al. 2021; Johs et al. 2019; Kitilya et al. 2023). It is precisely the improvement in self-efficacy that contributes to a greater perception of functionality and health, which in turn allows for an increase in the level and adherence to exercise as the individual's physical capabilities strengthen. On the other hand, laziness and lack of habit regarding exercise are the main barriers at the individual level.

From a different point of view, according to previous research, social support is also a crucial factor to fulfill the recommendations of PA (Araya et al. 2022; Gray et al. 2021; Kitilya et al. 2023). Motivation coming from community and family contexts either encourages or hinders exercising and is perceived as a fundamental factor during the initial stages of implementation (Araya et al. 2022; Gray et al. 2021; Kitilya et al. 2023). Thus, the interaction with environments that accompany the individual in exercising and encourage them to include and maintain this habit favour the propensity to be physically active and improve the health perception of PLWH. However, in some cases, this support is dispensable when the habit has been acquired and interiorised as part of a daily routine.

Furthermore, health-care personnel play an important role in choosing a healthy lifestyle: their guidelines and advice are vital to begin and continue with it. However, PLWH finds multiple contradictions in these professionals, which hinders proper guidance and support

from the health-care system, creating a barrier for people and communities (Kitilya et al. 2023). This results in exercising based on individual and close experiences without proper assistance of trained personnel. This contributes to individuals believing in myths about types of exercise (for example, that strength exercise is contraindicated in this population) and about the use or not of supplements that increase physical capacities or optimise composition, which can also increase deleterious health effects such as musculoskeletal injuries.

It is fundamental to consider multiple aspects that allow defining the degree of readiness of participants to begin and continue exercising. This includes the progress in the process of resignification in which the patients find themselves with social support, basal functional condition of the person, perceptions and attitude towards PA, exercise experience, and accessibility (Simonik et al. 2016). It is through understanding the role of exercise in the process of the disease resignification and acknowledging the importance of accompaniment as health professionals that we can favour the inclusion of exercise as a coping and functionality recovery strategy for PLWH.

Limitations

There were some limitations in this study due to the authors' training as physicians and not in social sciences or medical anthropology. This may have limited the conceptualisation and theoretical development of some categories. Further training in social studies might have led to a deeper understanding of the studied phenomenon.

Conclusion and implications

A transformational process of HIV from the death sentence to a healthy self-perception beyond the diagnosis was evidenced. Exercise was seen as a means that enables changes towards favourable health, both individually and collectively.

This re-signification of the disease is a way to internalise HIV as a chronic condition. Nowadays, with ageing of the world's population and new health challenges, there is a new stage of the internalising process: normalisation with perception changes of individual and social health. This is why research efforts, and medical assistance must include strategies that comprise exercise as part of self-care, enabling healthy ageing for PLWH and preserving their functionality.

In order to implement exercise as a healthy habit, it is necessary to include trained professionals in the program of assistance of patients with HIV that can provide accurate guidelines. This, along with health-care personnel training, enables communication among different professionals to give comprehensive support to people. It is also worth noting the need for further research to continue making efforts in the comprehension and conceptualisation of internal tension regarding exercising so as to provide professionals with accurate guidelines to share with their patients and establish focused objectives for them. Within these aspects, we consider taking into account factors related to gender roles, economic factors and access to exercise programs that may influence adherence to exercise. In addition, we consider it essential to study the role of stigma and discrimination and their direct impact in sport and exercise contexts.

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Notes on contributors

Yeimmy Rodríguez-Moreno Physician, Resident of the Postgraduate Program in Medicine Applied to Physical Activity and Sports, Universidad de Antioquia, Medellín (Colombia).

Omar Antonio Calderón-Cardona Physician, Resident of the Postgraduate Program in Medicine Applied to Physical Activity and Sports, Universidad de Antioquia, Medellín (Colombia).

Jaime Alberto Gallo-Villegas Physician, Specialist in Medicine Applied to Physical Activity and Sports, Master and PhD in Epidemiology. Professor at the School of Medicine, Universidad de Antioquia. Coordinator of the Knowledge Management Unit, Clinic and Research Center SICOR, Medellín (Colombia).

Carlos Enrique Yepes-Delgado Physician, Specialist in Health Services Management, Master in Public Health, PhD in Epidemiology. Professor at the School of Medicine, Universidad de Antioquia. Medical Epidemiologist, Hospital Pablo Tobón Uribe, Medellín (Colombia).

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