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RESEARCH

EXPERIENCES OF CHRONIC TRANSMISSIBLE ILLNESS: DISCURSIVITIES OF PEOPLE LIVING WITH HIV

EXPERIÊNCIAS DO ADOECIMENTO CRÔNICO TRANSMISSÍVEL: DISCURSIVIDADES DE PESSOAS VIVENDO COM HIV

LA EXPERIENCIA DE VIVIR CON UNA ENFERMEDAD CRÓNICA TRANSMISIBLE: DISCURSOS DE PERSONAS CON VIH

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ABSTRACT

Objective: to analyze the discursive meanings produced by people living with HIV about the experience of chronic illness. ***Method:*** qualitative study, anchored in the theoretical-methodological framework of discourse analysis of French matrix. Based on a semi-structured script, 11 individuals assisted in the Specialized Care Service for infectious diseases in a municipality in the interior of São Paulo state were interviewed. We also considered the description of the sociodemographic, behavioral and clinical profiles of the participants, based on a closed questionnaire. ***Results:*** sociodemographic and behavioral profiles were similar to epidemiological data of infection at national and international level. Regarding the clinical profile, the predominance of individuals with detectable viral load is detectable. The (re)knowledge of the epidemiological profile of the participants allowed the apprehension and understanding of the production conditions in restricted and broad senses that are the basis of the discourses. The interpretative gestures allowed the elaboration of two discursive blocks: meanings of incorporation and (re)production of biomedical discourse; and normalization to resistance: processes of experiencing HIV in chronicity. Discursive analyses indicated the incorporation and reproduction of biomedical discourse with meanings built in pathology. It was also observed the attempt to align with the thought of HIV normalization. However, weakening aspects (prejudice, discrimination and stigma) were the basis of the subjects' discourses. ***Conclusion:*** the results can contribute to the qualification of care, especially in the approach by the multidisciplinary team, favoring dialogical spaces about chronic experience with HIV.

Keywords: Chronic Disease; Acquired Immunodeficiency Syndrome; Public Health; Qualitative Research.

RESUMO

Objetivo: *analisar os sentidos discursivos produzidos por pessoas vivendo com HIV acerca da experiência do adoecimento crônico.* ***Método:*** *estudo qualitativo, ancorado no referencial teórico-metodológico da Análise de Discurso de matriz francesa. A partir de roteiro semiestruturado, foram entrevistados 11 indivíduos assistidos no Serviço de Atendimento Especializado em doenças infectocontagiosas de um município do interior paulista. Considerou-se, ainda, a descrição dos perfis sociodemográfico, comportamental e clínico dos participantes, a partir de questionário fechado.* ***Resultados:*** *os perfis sociodemográfico e comportamental assemelharam-se aos dados epidemiológicos da infecção em âmbitos nacional e internacional. Quanto ao perfil clínico, chama atenção a predominância de indivíduos com carga viral detectável. O (re)conhecimento do perfil epidemiológico dos participantes possibilitou a apreensão e a compreensão das condições de produção em sentidos restrito e amplo que estão na base dos discursos. Os gestos interpretativos possibilitaram a elaboração de dois blocos discursivos: sentidos de incorporação e (re)produção do discurso biomédico; e da normalização à resistência: processos de experienciar o HIV em cronicidade. As análises discursivas indicaram a incorporação e a reprodução do discurso biomédico com sentidos edificados na patologia. Observou-se, ainda, a tentativa de alinhamento ao pensamento de normalização do HIV.*

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Contudo, aspectos fragilizadores (preconceito, discriminação e estigma) estiveram na base dos discursos dos sujeitos. ***Conclusão:*** *os resultados podem contribuir para a qualificação da assistência, especialmente na abordagem pela equipe multiprofissional, favorecendo espaços dialógicos sobre a experiência crônica com o HIV.*

Palavras-chave: *Doença Crônica; Síndrome da Imunodeficiência Adquirida; Saúde Pública; Pesquisa Qualitativa.*

RESUMEN

Objetivo: *analizar el significado de los discursos que producen las personas con VIH/ SIDA sobre la experiencia de vivir con una enfermedad crónica.* ***Método:*** *estudio cualitativo, en base al marco teórico-metodológico del Análisis del Discurso de matriz francesa. A partir de un guión semiestructurado, se entrevistó a 11 personas en el Servicio de Atención Especializada de Enfermedades Infecciosas de una ciudad del interior de São Paulo. También se consideró la descripción del perfil sociodemográfico, conductual y clínico de los participantes, en base a un cuestionario cerrado.* ***Resultados:*** *el perfil sociodemográfico y conductual fue similar a los datos epidemiológicos de la infección a nivel nacional e internacional. En cuanto al perfil clínico, se destaca el predominio de individuos con carga viral detectable. El (re) conocimiento del perfil epidemiológico de los participantes permitió captar y comprender las condiciones de producción en un sentido amplio y restringido que yacen en la base de los discursos. Los gestos interpretativos permitieron elaborar dos bloques discursivos: significados de incorporación y (re) producción del discurso biomédico; y de la normalización a la resistencia: procesos de la experiencia con el VIH crónico. Los análisis discursivos indicaron la incorporación y reproducción del discurso biomédico con significados construidos sobre la patología. También hubo un intento de alinearse con la idea de normalizar el VIH. Sin embargo, la base de los discursos de los sujetos fueron los aspectos debilitantes de la enfermedad (prejuicios, discriminación y estigma).* ***Conclusión:*** *los resultados pueden contribuir a la calificación de la asistencia, especialmente por parte del equipo multidisciplinario, favoreciendo espacios de diálogo sobre la experiencia crónica con el VIH.*

Palabras clave: *Enfermedad Crónica; Síndrome de Inmunodeficiencia Adquirida; Salud Pública; Investigación Cualitativa.*

INTRODUCTION

The health situation in Brazil is established, among other aspects, by a demographic transition with accelerated population aging and an incomplete epidemiological transition. This scenario has demanded a complex profile of diseases to the Unified Health System (*Sistema Único de Saúde* - SUS), with the rise of chronic non-communicable (circulatory diseases, diabetes mellitus, cancer) and transmissible conditions (acquired immunodeficiency virus [HIV]), leprosy, tuberculosis [TB], some viral hepatitis).[1]

Chronic conditions are understood as disease situations that can be of long – longer than three months – or indefinite duration, and that give rise to reactive or proactive social responses, episodic or continuous and fragmented and integrated by all those involved in the process (health care system, health professionals, users).[1]

With regard to HIV and AIDS, from the emergence of the first cases – in the 1970s – to the present day, the disease has taken on chronic degenerative aspects that have raised its reinterpretation as an experience of illness. Some actions contributed to this new scenario, including the worldwide expansion of access to antiretroviral (ARV) drugs, which, among other aspects, favored the decline in mortality from AIDS-related causes from 1.9 million deaths in 2005 to 1 million in 2016.[2]

This important advance cooperated for the prolongation of life expectancy after the diagnosis of the disease, but it should be considered that the dispensation of medications does not necessarily guarantee success in treatment. Aspects such as schooling level, age group, complexity of the therapeutic regimen, side effects of medications, difficulties in adapting to the daily routine of treatment, and mental disorders (depression, anxiety) – for example – very much interfere in the risk of treatment abandonment[3]and, consequently, in living with the disease.

Other aspects are also added to the potential weakening of (co)living with HIV, among these the integration with the health service. A study[4]revealed that the formation of a link with the health service can be improved from the change of the strictly biomedical paradigm, present in the current care model. In this sense, an expanded view of care that considers cultural, social and emotional aspects can favor care more in tune with the needs of individuals, in addition to the pathophysiological aspects.

It becomes pressing, therefore, to understand the effects of the meaning produced by the sick about the experience of (co) living with HIV, given the possibility of developing processes of subjectivity that can influence/characterize the way people living with HIV (PLHIV) (re)act to this condition of chronic disease.

In the face of the above, the study has the following as guiding question: "What meanings are attributed by PLHIV in relation to the experience of illness?" The objective of this study was to analyze the discursive meanings produced by PLHIV about the experience of chronic disease.

METHOD

This is a qualitative study, anchored in the theoretical-methodological framework of discourse analysis (D.A.) of French or Pechêuxtian matrix, whose epistemological framework is based on the intersection of three major areas of knowledge: Linguistics, admitting the non-transparency of the language; Historical Materialism, stating that man makes history, being affected by ideology; and Psychoanalysis, recognizing the influence of the unconscious on the subject.[5]

D.A. recognizes discourse as a practice of language that transcends the deep description of the language and constituent elements of an utterance. It works in the interpretative boundary between language and ideology, considering the effects of the meaning produced between interlocutors, as ideologically captured, incomplete, split and constantly moving subjects.[5]

From this, this theoretical-methodological framework is an important ally in public and collective health studies (as fields of knowledge), since it can raise the reflection about the conditions of production of discourses, as well as guide the understanding of the meanings that determine and that are determined by individual, collective and socio-historicalprocesses[6] about health care practices, especially with regard to HIV and AIDS.

The definition of the study participants proceeded intentionally, including individuals of both genders, who had reached the civil age of majority, started treatment for AIDS with ARV in 2000, were in outpatient follow-up for the treatment of the disease in 2015, and were physically able to participate in the study. It should be noted that the year 2000 was considered a milestone of this investigation, given that, in this period, the scenario studied was in second place in the ranking of the 100 Brazilian municipalities with the highest incidence of AIDS (per 100,000 inhabitants) in the country.[7]As criteria for exclusion, people in situations of deprivation of liberty were considered.

Thus, 29 individuals became eligible to participate in the study, of which five refused to participate and 10 were not contacted after three attempts to schedule the interview. Therefore, 11 individuals became eligible to participate in this research, which are represented in the text by the capital "P" (in reference to the word "participant"), by Arabic numerals – in view of the temporal ordering in which the interviews were conducted – and by gender.

Data was produced between May and August 2015 in the facilities of the specialized infectious diseases (SAE) services in a municipality in the inland of state of São Paulo, Brazil. The main objective of this health service is the integrality of health actions and services directed to the transmissible diseases and infections of the citizens. To this end, it has a multidisciplinary team that integrates actions – among other services – of Medicine, Nursing, Nutrition, Social Work and Pharmacy.[8]

Through the semi-directed interview technique – in which there is fluidity in the command of the dialog (sometimes the interviewer, sometimes the interviewee) – the statements were generated on the days of medical consultation scheduled in the health service, thus optimizing the mobility of the participant to the place. From this, the individuals in the waiting room were approached, explaining to them the reasons that made them eligible to participate in the study, as well as the objectives of the research, and thus continued with the invitation to participate in this research.

After reading, acceptance and signing of the Free and Informed Consent Form, the interviews were carried out. These were performed after the end of the medical consultation, exclusively by the first author, individually, in a private room of the health service, with the help of digital media for recording the statements. The interviews lasted from six to 18 minutes. It is worth noting that the interviewer had no relationship with the research participants. An interview script was used that included four semi-directed questions, led by the following aspects: meanings of the HIV illness and the disease as a chronic condition.

The empirical material was transcribed in its entirety and – already conformed in an analytical *corpus*– it was inserted in the Atlas ti software, version 7.0, which was used exclusively to organize the volume of material generated in the interviews, as well as to facilitate the visualization of the fragments that would be later analyzed. The interviews were individualized and, by reading and rereading the material in detail, it was possible to compose the units of meaning (codes) that allowed for the emergence of the discursive formations (memos). Sequentially, it was possible to group in networks of meanings (family) and, therefore, to carry out the in-depth analyses, in view of the objectives adopted in this study. It is noteworthy that there were no interferences of the Atlas ti software in the selection of the analyzed fragments, nor in the analyses undertaken on the analytical corpus.

Considering the methodological procedures of D.A., the empirical material was analyzed through the following stages: 1) passage from the linguistic surface to the discursive object. At this stage the illusion was undone that what was said by the subject could only have been done in this way and not in another, through those words and not others. It was sought to understand how the symbolic object produced meanings by/for the subjects; 2) passage from the discursive object to discursive formation. At this stage, the processes of affiliation to certain networks of meaning were observed, which, in turn, are anchored in ideology; and 3) passage from the discursive process to ideological formation. In view of the thinning to the networks of meaning, the affiliations of the participants to the dominant ideology were observed and how it materialized in their sayings. Traces, clues and textual marks were considered for this.[5]

D.A. – as a theoretical-methodological device – considers the saying and also the non-saying that it is constitutive of the discursive process and that, therefore, it has meaning. In other words, what has already been said and forgotten makes sense (echoes) in the updated saying, through interdiscourse, of discursive memory.[5] Thus, the present study led the analyses of the unsaid taking them by the notion of the implicit,[5] revealed in the discursive formations to which the participants' discourses were affiliated.

Additionally, this research took into account the aspects related to the sociodemographic, behavioral and clinical characterizations of the interviewees, with a view to the production of data from the direct report, as well as information contained in the individual health records filed in the SAE. For this purpose, a specific form composed of 20 closed questions was used, considering the results of laboratory tests up to six months prior to the performance of this research.

Descriptive statistical techniques were used to analyze these data by means of absolute and relative frequency distribution. It is emphasized that such analyses were important in that they allowed understanding the conditions of production in a restricted (immediate context) and broad (social, historical and ideological contexts) sense that build the participants' discourses. Thus, these data offered the possibility of analytical complementation of qualitative findings.

In view of the ethical commitment to scientific research involving human beings, this study was submitted to and approved by the Research Ethics Committee of the responsible institution, under CAAE protocol 34170214.1.0000.5393 and Institutional Edict No. 191/2014.

RESULTS

Most of the participants (63.3%) were female, with a mean age of 48.6 (±8.5) years old. Predominance of white and brown skin color (45.5% each), incomplete elementary school (36.4%) and married/stable union marital status (45.5%) was observed. Among the interviewees, the majority (81.8%) reported heterosexual practices and all reported non-use of illicit drugs during the research period. Regarding T-CD4+ lymphocyte count tests, there was predominance (45.5%) of results higher than 500 cells/mm^3 and, in viral load tests, the majority (54.5%) was detectable, being below 1,000 copies.

In accordance with the proposed objective, as well as the methodological procedures of D.A., two discursive blocks were elaborated: meanings of incorporation and (re)production of biomedical discourse; and normalization to resistance: processes of experiencing HIV in chronicity.

In the first discursive block, interpretive gestures were mobilized that comprise the production of meanings about incorporation, as well as the (re)production of a legitimate discourse on HIV, in view of anchoring in biomedical/scientific knowledge (dominant and hegemonic) about the disease.

In fact, the participants joined the discursive formations of ordering and austere compliance with protocol therapies. To this end, the interviewees positioned themselves on the margins of their own experience of the disease, using implicit and explicit expressions, in third person, as a way to legitimize their sayings based on the authority of biomedical knowledge about HIV.

> *You need to have control! Take the medicine right!* (P4, female).

> *If you don't take the medication, you die! It's fatal! It's no use, because you're going to die! One thing or another, you're going to die!* (P9, female).

Affiliations were also observed to the discursive formations in tune with the meanings of holders of knowledge about the disease, with words centered on pathology and health practices, from the appropriation of medical/technical terms.

> *HIV by itself doesn't kill anyone! What kills, are opportunistic diseases, right?!* (P3, male).

> *Oh, I think it's a disease* [referring to HIV] *that it mainly attacks the person's immune system, right?! So if the person bombards their body, first with inadequate nutrition, with drug addictions, alcohol, smoking, wrong practices... all this lowers our immunity. That's where the disease evolves!* (P7, male, annotations are ours).

In the second discursive block, interpretive gestures were mobilized that presume the attempt to echo meanings consonant with normalization, the naturalization of (co)living with HIV, from the affiliation to discursive formations in tune with the senses of daily tasks.

> *I lead a normal life! I take the medication, I drink beer. I go out, I drink beer. I lead a normal life!* (P1, female).

> *Normal! So I wake up early, do my job, drink my coffee. If I have to go out, I go out! I take my granddaughters to school, I bring them. It's normal for me!* (P5, female).

> *It's a life, like, normal! I work, do my things. I'll follow up!* (P6, female).

> *I have a normal life. I don't have to separate anything!* [referring to the household items used by the other residents of the house] *I do things super well!* (P8, male, annotations are ours).

> *Normal! There's nothing for me. I'm normal! I'm fine, super fine! Always was!* (P10, male).

Nevertheless, we observed consonant sayings to the discursive formations that presuppose the existence of weakening of the normalization of (con)living with HIV, in view of the difficulties with the management of the effects of the disease, drug therapy, as well as the personal wear generated by social prejudice and abandonment.

> *I tried to kill myself, you know?! My life was complicated! I just cried! But really do what, right?! Now the consequences of life come. My eyes are swollen, I have an allergy. I have to take care of myself!* (P2, female).

> *Oh, there's still a lot of prejudice! For as long as it does, right, it's there* [referring to HIV]. *But there is! There are prejudiced people! It's bad! Because sometimes you have no friendship because of the person being prejudiced. Sometimes the person stops talking to you, away from you. Then, it's difficult! I used to work, they fired me! Because of that! There's a lot of prejudice!* (P4, sex female, annotations are ours).

> *A normal, normal life, isn't it! Normal, if I didn't take any medication. But it's difficult! The medicine gives a lot of effect. It makes you sick, it gives dysentery, it gives depression!* [...] *The medicine also does a harm to us that is not a joke!* (P9, female).

> *Even, I switched, right, the medicine! With the other* [medicine] *I was getting sick, very nauseous* [...] *I couldn't take it, it gave mea craving for vomit... I lost weight!* (P11, female, annotations are ours).

DISCUSSION

The sociodemographic and behavioral profiles observed in this research are in agreement with epidemiological data of infection at national and internationallevels[9,10] regarding low schooling, heterosexual practices, low illicit drug use and good adherence to antiretroviral therapy (ART). However, it differs from the results at the national level in relation to the predominance of the disease in women and the self-declared race/skin color variable. There was also similarity with the findings of astudy[11] conducted in the state of São Paulo, especially regarding the time of living with the disease (>12 years).

Regarding the clinical profile, the predominance of individuals with detectable viral load draws the attention. This finding is similar to the data presented by a world report,[10] in which it was observed that more than half of the PLHIV (52.6%) did not reach viral suppression. Aspects such as the incipient annual testing of viral load, stigma, discrimination, failures in the integration among the health services dealing with TB and HIV, as well as resistance to existing drugs, are some of the barriers to achieving viral suppression globally.[10]

D.A. goes beyond the understanding of the text by its extension and also by its literality. It therefore treats it as a discursive fact, considering the way in which the text organizes the relationship between language and history in the meaning of the subjects, considering memory, interdiscourse, ideology.[5] Therefore, D.A. works with the historical materiality of language, given textual heterogeneity, among other aspects, regarding the nature of the languages (oral, written, scientific, literary, etc.).[5]

Thus, the findings herein presented allowed for a reflection on the conditions of production in restricted (immediate context of the production of the sayings) and broad (social, historical and ideological contexts involved in the discursive process) directions, from the observation of the sociodemographic, behavioral and clinical profiles of the participants who build the analyzed discourses.

The increase in life expectancy of PLHIV is a reflection of the new conformation of the disease, which has assumed aspects of chronicity over the years. Thus, (co)living with HIV in this perspective will lead the sick to the articulation of multiple confrontations, which will give rise from/in the subject an interpretative work that – for D.A. – will occur by transience and also by the sedimentation of the senses, depending on how affected the subjects are by the language (naturally fails) and history (susceptible to disruptions).[5]

For D.A., discourse is configured as an effect of meaning between interlocutors, considering the social places that they occupy as subjects and not as individuals.[5] Thus, the discursive process from which every discourse is born in another and determines another,[12] in view of the affiliations to discursive formations. The concept of discursive formation comprises the production of meanings directly related to ideology, instituting what should and can be said in a given conjuncture.[5]

Thus, some discourses become legitimized and assume status of truth, as seen in the positivist scientific discourse that understands the world from objectivity, regularity[13] and in which the Medical Sciences are incorporated.

With this reflexive understanding, it was verified that the incorporation and (re)production of the biomedical discourse established sayings in the margins of the experience of illness from HIV infection from the perspective of individual/own subjectivity, so that the participants referred to an experience of others, from implicit and explicit sayings in the third person ("you"). This use of indirect forms in the discourse is characterized as an attempt to obscure the subject of enunciation. However, subjectivity is inherent to language, so its constitution will take place even if there is no exposure of the self.[14]

Similar results were also observed in astudy[15] with PLHIV in which it was possible to perceive representations of AIDS as a disease of the other. Such attitudes generated feelings of invulnerability to the disease, favoring inertial environments in the face of preventive practices and the delay in the search for health services.[15]

The appropriation of medical/technical terms was also observed, as well as the persistence of meanings of ordering, austerity on the use of drug therapy. These aspects denote an attempt by the subjects to legitimize their statements obscured by the biomedical discourse, whose model is in line with the strict observation of organic and pathophysiological damage.

A study[16] conducted with patients affected by chronic diseases revealed that there was appropriation and reproduction of the medical discourse as a way to turn the saying considered layman into a scientific saying. It should be considered that the time of exposure, as well as coliving, of the individuals with the chronic condition of illness becomes proportional to the apprehension of medical/technical terms[16] and, therefore, to the reproduction of the dominant discourse. In this parallel, there was similarity with the findings of the present study, since the time of coliving with chronic illness of the participants was 15 years and the mean age was 48.6 years old.

It is understood that the incorporation and (re)production of the biomedical discourse can favor the establishment of a hierarchical care process, in which health professionals (anchored in the dominant discourse) assume the leading role in conducting the state of illness to the detriment of the individuals themselves. This scenario can generate postures of passivity in relation to the regular follow-up of treatments, for example, and favor the plastering of the patient-health professional relationship.

The participants' role in the management of the disease is a way to experience the process of chronic illness based on their choices, on the maintenance of their treatment. Therefore, it is necessary that there is a proximal and co-responsibility relationship, so that the sick have governability over their care, feeling supported by the health professionals (physicians, nurses) involved in the process.[17]

If the production of discourses aims to conjure powers by interspersing individuals in subjects so that their sayings make sense;[5] therefore, the reverberation of (other) senses will not occur randomly, innocently. Regarding HIV, the institution of a discourse of normalization, of naturalization of (co)living with the disease, was observed.[18] These meanings are reflected in the interviewees' statements from the affiliation to discursive formations in tune with the perspective of daily tasks, inherent to the routine of practical life.

Similar results were obtained in a study[19] on the experience of adolescents living with HIV about drug adherence. Among other aspects, the participants mentioned feeling "normal" as the other healthy adolescents, given the performance of activities of everyday life such as games, playing ball, or going to school.

In view of this, (co)living with HIV in chronicity seems to be configured as a problem, either from the individual point of view, as well as socially. We observed sayings in tune with discursive formations that presume the existence of weakening of the discourse of normalization of (co)living with HIV, among which the difficulties with the uninterrupted use of drug therapy were mentioned.

Over the years, advances in HIV drug therapies have greatly contributed to the increase in the survival of patients. However, it should be considered that the success of the treatment should be thought beyond the ingestion of the tablets, with a view to overcoming the reductionist and crystallized thinking about the biomedical understanding of the disease.[20]

Treatment adherence from the perspective of a chronic condition is closely related to the experiences that have occurred throughout the process, being at the mercy of the problems and variability faced by the individuals in their environment, thus determining episodes of greater or lesser adherence to the therapy. Therefore, the individuals should be evaluated/understood according to their adherence condition at a given moment and conjuncture.[17,18,20-22]

In agreement with this understanding, astudy[23] conducted with PLHIV showed that some clinical characteristics, such as undetectable viral load and asymptomatic manifestation of the disease, directly influenced on the advent of ART and, consequently, on the quality of life of the participants. In view of this analytical alignment, the present study observed a predominance of laboratory results with detectable viral loads that may suggest – among other aspects – difficulties of the individuals in the treatment management recommended by the health service and, also, periods of lower therapy adherence.

The meanings of social prejudice and abandonment identified in the participants' sayings were also configured as weakening of the discourse of normalization of (co)living with HIV. Another study[24] with PLHIV observed, among other aspects, that intrafamily and social prejudices negatively impacted on the process of living with the disease, so that the absence of social and/or emotional support to the participants turned into isolated reactions and harmful psychological conditions.

In fact, there has been a rise in movements that deny the existence of HIV and AIDS on websites and Internet forums. A study[25] developed in Russia's largest denialist HIV community analyzed 4,821 posts and comments, and the explanation of the meanings of disease denial occurred from three main aspects: denial of the diagnosis, reluctance to follow the therapy instituted and the advice considered unsatisfactory by the health professionals who assist the sick. The results of the study suggest, among other aspects, that the practices of the health professionals can contribute to the generation of meanings of HIV denial. Thus, health counseling is expected to consider an approach more aligned with the particularities of each patient.[25]

From the above, it is understood that the HIV vicissitudes throughout its history have required from the actors involved (sick individuals, managers, health professionals, community) the commitment to foster reflections and health actions aligned with the real needs of this constantly becoming illness condition. Therefore, it is pressing that there are dialogical spaces between the sick and the health professionals, especially at the local level, in order to consider the identity particularities of each subject in their environment, thus surpassing the strictly pragmatic and biomedical understanding of HIV.

FINAL CONSIDERATIONS

The interpretive gestures established in this study provided the observation of the incorporation, as well as the reproduction of a pragmatic, pathologicist discourse about (co)living with HIV. As a consequence, the interviewees seemed to position themselves on the margins of their own experience of illness. Moreover, the appropriation of medical/technical terms aroused meanings of austerity, of ordering in relation to protocol therapeutic follow-up, thus denoting an attempt to transvestite the lay saying into a scientific saying about the disease.

Such a scenario can favor in the sick postures of passivity in relation to the maintenance of their care (drug treatment, for example); this is because a hierarchical care process is established, in which health professionals – based on the scientific discourse – assume the leading role in conducting a therapy that they ignore and, often, disregard the particularities of the subjects in their environment.

From this, there may be an establishment of demotivating, destimulating and sometimes distrustful environments, which can be reflected – for example – in the way the sick deal, react to and resist the experience of (co)living with HIV as a chronic condition, sometimes translating into situations of helplessness, discouragement and even distrust in the therapeutic and established care.

Statements related to normalization, naturalization, (co)living with HIV were also observed, from the perspective of a practical, everyday life. Despite this, weakening aspects of the ideals of HIV normalization were also discursivized, given the difficulties with the uninterrupted use of medications, as well as the conflicting feelings caused by situations of prejudice, stigma and discrimination to which the subjects are exposed throughout the chronic process of the disease.

As a limitation, it is admitted that the objectives proposed in this study did not allow for the insertion of sayings of health professionals working in the SAE. Nevertheless, it is believed that the results may enable less crystallized dialogs – especially regarding the perspective of the approach by the multidisciplinary team – on the maintenance of HIV, favoring co-responsibility for health care.

Moreover, the subjective conjuncture in which the theoretical-analytical framework adopted in this study is constructed, as well as the incompleteness constitutive of the saying, could provoke other interpretative gestures that, consequently, would reverberate other effects of meanings from the context presented in this investigation.

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REFERENCES

1. Mendes EV. Interview: The chronic conditions approach by the Unified Health System. Cien Saúde Coletiva. 2018[cited 2019 Apr 9];23(2):431-5. Available from: http://dx.doi.org/10.1590/1413-81232018232.16152017
2. Joint United Nations Programme on HIV/AIDS (SWZ). Ending AIDS: progress towards the 90-90-90 targets. Genebra: UNAIDS; 2017[cited 2019 Apr 9]. Available from: http://www.unaids.org/sites/default/files/media_asset/Global_AIDS_update_2017_en.pdf
3. Ministério da Saúde (BR). Secretaria de Vigilância em Saúde. Departamento de Vigilância, Prevenção e Controle das Infecções Sexualmente Transmissíveis, do HIV/Aids e das Hepatites Virais. Protocolo Clínico e Diretrizes Terapêuticas para o manejo da infecção pelo HIV em adultos. Brasília: Ministério da Saúde; 2018[cited 2019 Feb 15]. Available from: http://www.aids.gov.br/pt-br/pub/2013/protocolo-clinico-e-diretrizes-terapeuticas-para-manejo-da-infeccao-pelo-hiv-em-adultos
4. Surniche CA. A continuidade da assistência na visão do doente de tuberculose: uma análise discursiva [dissertação]. Ribeirão Preto: Universidade de São Paulo, Escola de Enfermagem de Ribeirão Preto, Departamento Materno-Infantil e Saúde Pública; 2015.
5. Orlandi EP. Análise de Discurso: princípios & procedimentos. 8ª ed. Campinas (SP): Pontes Editores; 2009.
6. Macedo LC, Larocca LM, Chaves MMN, Mazza VA. Análise do Discurso: uma reflexão para pesquisar em saúde. Interface – Comunic Saude Educ. 2008[cited 2019 Apr 9];12(26):649-57. Available from: http://www.scielo.br/pdf/icse/v12n26/a15.pdf
7. Ministério da Saúde (BR). Secretaria de Vigilância em Saúde. Departamento de Vigilância, Prevenção e Controle das Infecções Sexualmente Transmissíveis, do HIV/Aids e das Hepatites Virais. Bol Epidemiol AIDS. 2002[cited 2019 Feb 9];16(1):1-2. Available from: http://www.aids.gov.br/pt-br/pub/2003/boletim-epidemiologico-aids-2002-abrdez-2002
8. São José do Rio Preto (SP). Secretaria Municipal de Saúde. Atenção Especializada. Complexo de Doenças Transmissíveis. São José do Rio Preto: SMS; 2019[cited 2019 Mar 18]. Available from: http://gestao.saude.riopreto.sp.gov.br/transparencia/modules/mastop_publish/?tac= USDSI_Comp_Doen_Tran1
9. Ministério da Saúde (BR). Secretaria de Vigilância em Saúde. Departamento de Vigilância, Prevenção e Controle das Infecções Sexualmente Transmissíveis, do HIV/Aids e das Hepatites Virais. Boletim Epidemiológico HIV/AIDS. Brasília: Ministério da Saúde; 2018[cited 2019 Feb 15];49(53). Available from: http://www.aids.gov.br/pt-br/pub/2018/boletim-epidemiologico-hivaids-2018
10. Joint United Nations Programme on HIV/AIDS (SWZ). Knowledge is power: know your status, know your viral load. Genebra: UNAIDS; 2018[cited 2019 Apr 9]. Available from: http://www.unaids.org/sites/default/files/media_asset/jc2940_knowledge-is-power-report_en.pdf
11. Fundação Sistema Estadual de Análise de Dados. A vida com aids no estado de São Paulo: informações e desafios para a política pública de saúde. São Paulo: SEADE; 2015[cited 2019 Feb 20];24(1). Available from: https://www.seade.gov.br/wp-content/uploads/2015/05/ Primeira_Analise_n24.pdf
12. Orlandi EP. Discurso em análise: sujeitos, sentidos e ideologia. 2ª ed. Campinas (SP): Pontes Editores; 2012.
13. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 12ª ed. São Paulo (SP): HUCITEC; 2010.
14. Brandão HNN. Introdução à análise de discurso. 3ª ed. Campinas (SP): Editora da Unicamp; 2012.
15. Ribeiro LCS, Giami A, Freitas MIF. Representations of people living with HIV: influences on the late diagnosis of infection. Rev Esc Enferm USP. 2019[cited 2019 Feb 20];53:e03439. Available from: http://dx.doi.org/10.1590/S1980-220X2018009703439
16. Hilário EAP, Reinaldo AMS. A apropriação e a reprodução do discurso médico por paciente com insuficiência renal crônica. Rev Enferm UERJ. 2007[cited 2019 Feb 20];15(4):544-8. Available from: http://www.facenf.uerj.br/v15n4/v15n4a11.pdf
17. Ferreira DC, Favoreto CAO. Analisys of the narrative oh HIV patients: the building of therapeutical adhesion. Physis. 2011[cited 2019 Feb 20];21(3):917-36. Available from: http://dx.doi.org/10.1590/S0103-73312011000300009
18. Mazanderani F, Paparini S. The stories we tell: qualitative research interviews, talking technologies and the 'normalisation' of life with HIV. Soc Sci Med. 2015[cited 2019 Feb19];131:66-73. Available from: http://dx.doi.org/10.1016/j.socscimed.2015.02.041

19. Korrouski MFC, Lima RAG. Treatment adherence: the experience of adolescents with HIV/AIDS. Rev Latino-Am Enferm. 2009[cited 2019 Feb 20];17(6):947-52. Available from: http://dx.doi.org/10.1590/S0104-11692009000600004.

20. Seffner F, Parker R. A neoliberalização da prevenção do HIV e a resposta brasileira à aids. In: Associação Brasileira Interdisciplinar de Aids. Mito vs Realidade: sobre a resposta brasileira à epidemia de HIV e aids em 2016. 2016[cited 2019 Feb 20];p.24-32. Available from: http://abiaids.org.br/wp-content/uploads/2016/07/Mito-vs-Realidade_HIV-e-AIDS_BRASIL2016.pdf

21. Bonolo PF, Gomes RRFM, Guimarães MDC. Adesão à terapia anti-retroviral (HIV/aids): fatores associados e medidas da adesão. Epidemiol Serv Saúde. 2007[cited 2019 Feb 19];16(4):261-78. Available from: http://dx.doi.org/10.5123/S1679-49742007000400005

22. Silva JAG, Dourado I, Brito AM, Silva CAL. Factors associated with non-adherence to antirretroviral therapy in adults with AIDS in the first six months of treatment in Salvador, Bahia State, Brazil. Cad Saúde Pública. 2015[cited 2019 Feb 19];31(6):1188-98. Available from: http://dx.doi.org/10.1590/0102-311X00106914

23. Silva ACO, Reis RK, Nogueira JA, Gir E. Quality of life, clinical characteristics and treatment adherence of people living with HIV/AIDS. Rev Latino-Am Enferm. 2014[cited 2019 Feb 19];22(6):994-1000. Available from: http://dx.doi.org/10.1590/0104-1169.3534.2508

24. Jesus GJ, Oliveira LB, Caliari JS, Queiroz AAFL, Gir E, Reis RK. Difficulties of living with HIV/Aids: Obstacles to quality of life. Acta Paul Enferm. 2017[cited 2019 Apr 9];30(3):301-7. Available from: http://dx.doi.org/10.1590/1982-0194201700046

25. Meylakhs P, Rykov Y, Koltsova O, Koltsov S. An AIDS-Denislist online community on a Russian Social Networking Service: patterns of interactions with newcomers and rhetorical strategies of persuasion. J Med Internet Res. 2014[cited 2019 Feb 20];16(11):e261. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4260080/