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ADHERENCE TO TREATMENT OF YOUNG ADULTS LIVING WITH HIV/AIDS FROM THE PERSPECTIVE OF COMPLEX THINKING

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ABSTRACT

Objetive: to understand the adherence to treatment of young adults with HIV/AIDS treated in a specialized care service from the perspective of complex thinking.
Method: a qualitative study, with the data grounded theory approach. Twelve young adults aged from 15 to 24 years old living with HIV/AIDS, nine health professionals and four mothers participated in the study. Data was obtained from interviews conducted between April and September 2016 and analyzed using the constant comparative method.
Results: the adherence to treatment of young adults with HIV/AIDS has been understood as a dynamic, multifactorial and constantly changing phenomenon. This process involves multiple aspects, including fear of becoming ill, physical and social death, discrimination and stigma. It was found that even in the face of these difficulties, young adults decide to continue their treatment in search of normalization of health, a long and common life like other young people who do not live with HIV/AIDS.
Conclusion: it was considered that in view of the complex and changing phenomenon, adherence to treatment of young adults with HIV/AIDS should be understood and managed by health professionals.

DECRIPTORS: HIV. Medication adherence. Young adult. Grounded theory. Nursing care.

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ADESÃO AO TRATAMENTO DOS ADULTOS JOVENS VIVENDO COM HIV/AIDS SOB A ÓTICA DO PENSAMENTO COMPLEXO

RESUMO

Objetivo: compreender a adesão ao tratamento dos adultos jovens com HIV/aids atendidos em um serviço de assistência especializada sob a ótica do pensamento complexo.
Método: estudo qualitativo, com a abordagem da teoria fundamentada nos dados. Participaram do estudo 12 adultos jovens com idade entre 15 e 24 anos, vivendo com HIV/aids, nove profissionais de saúde e quatro mães. Os dados foram obtidos a partir de entrevistas, realizados entre abril e setembro de 2016 e analisados mediante o método comparativo constante.
Resultados: a adesão ao tratamento de adultos jovens com HIV/aids foi compreendida como um fenômeno complexo dinâmico, multifatorial e que está em constante mudança. Tal processo envolve múltiplos aspectos, dentre eles, o medo de adoecer, da morte física e social, da discriminação e do estigma. Foi constatado que mesmo diante dessas dificuldades, os adultos jovens decidem seguir com seu tratamento em busca da normalização da saúde, de uma vida longa e comum como os demais jovens que não vivem com HIV/aids.
Conclusão: foi considerado que diante do complexo e mutável fenômeno, a adesão ao tratamento dos adultos jovens com HIV/aids deve ser compreendida e gerenciada pelos profissionais de saúde como um todo complexo.

DESCRITORES: HIV. Adesão à medicação. Adulto Jovem. Teoria Fundamentada. Cuidados de enfermagem.

ADHESIÓN AL TRATAMIENTO DE LOS ADULTOS JÓVENES QUE VIVEN CON VIH/SIDA, SEGÚN LA ÓPTICA DEL PENSAMIENTO COMPLEJO

RESUMEN

Objetivo: comprender la adhesión al tratamiento de los adultos jóvenes con VIS/SIDA atendidos en un servicio de asistencia especializada, según la óptica del pensamiento complejo.
Método: estudio cualitativo, con el enfoque de la teoría fundamentada en los datos. Del estudio participaron 12 adultos jóvenes con edades de 15 a 24 años, con VIH/SIDA, nueve profesionales de la salud y cuatro madres. Los datos se obtuvieron a partir de entrevistas realizadas entre abril y septiembre de 2016 y se los analizó mediante el método comparativo constante.
Resultados: la adhesión al tratamiento de adultos jóvenes con VIH/SIDA se comprendió como un fenómeno complejo, dinámico, multifactorial y en constante cambio. Tal proceso implica varios aspectos, entre ellos el miedo a sufrir, a la muerte física y social, a la discriminación y al estigma. Se constató que pese a estas dificultades, los adultos jóvenes deciden seguir son sus tratamientos en búsqueda de normalizar su salud, de una vida prolongada y común como los demás jóvenes que no viven con VIH/SIDA.
Conclusión: se consideró que, en vista del fenómeno complejo y cambiante, la adhesión al tratamiento de los adultos jóvenes con VIH/SIDA debe ser comprendida y manejada por los profesionales de la salud como un todo complejo.

DESCRIPTORES: VIH. Adhesión a la medicación. Adulto joven. Teoría Fundamentada. Cuidados de enfermería.

INTRODUCTION

Infection with HIV/AIDS is considered a complex problem.[1] This infection, in addition to its chronicity, has the characteristic of transmissibility. A chronic transmissible disease is also considered a complex condition that needs to be understood by patients, families and health professionals.[2] Given the recognition of the multiple facets surrounding the disease process and treatment of this infection, it is clear that when this situation becomes part of the lives of young adults, the issues become even more complex.[3]

Complex thinking is based on some principles, among them, the dialogical, retroactive, recursive, holographic, systemic or organizational ones, autonomy/dependence and the principle of the reintroduction of knowledge into knowledge.[4] Complex thinking is based on the need to distinguish and analyze; it should replace simplification and thus allow programming and clarification. And from the perspective of the construction of this thought, complexity takes into consideration the context, the history of the interrelationship and interdependence of the structure with its environment.[4–5]

The young adult living with HIV/AIDS encompasses multiple aspects, forming a complex whole, that is, we are facing a multidimensional phenomenon, a dynamic, multifactorial, comprehensive and constantly changing process over time. It is considered one of the most important challenges regarding the care of people with chronic diseases.[6–7] In addition, it is seen as a significant problem, mainly because of the fact that people with chronic diseases are poorly adherent to treatment, causing difficulties that may further weaken this process.[6] This is repeated in the context of adherence to treatment of young adults with HIV and AIDS and can be ratified in national and international settings.[8–10]

The treatment of people living with HIV/AIDS has been thought of as a complex phenomenon in the literature.[11–12] Some studies have brought Edgar Morin's concept of complexity closer to Nursing/Health and issues related to HIV/AIDS, including adolescence/youth and treatment adherence.[12–13] However, these issues need to be further explored.[14]

Adherence to treatment for people living with HIV/AIDS is not restricted to taking antiretrovirals and following the prescriptions of health professionals.[11,15] We are facing a behavior of adherence which encompasses multiple dimensions, among them, those that contemplate the aspects related to patient, treatment, socioeconomic, health systems and disease.[7,15] Therefore, we are facing a multifaceted and therefore complex phenomenon.[7,11]

Thus, it is important that there is an interdisciplinary monitoring of young adults living with HIV/AIDS in health services and the development of practices focused on the care of this population and their families.[16–17] Thus, adherence to treatment is a matter of complexity,[1] once complex thinking reconnects knowledge allowing the reform of thought and the development of new knowledge, enabling a new look at the phenomenon studied.[18–19]

In this perspective, the objective of the present study was to understand the adherence to treatment of young adults with HIV and AIDS treated in a specialized care service from the perspective of complex thinking.

METHOD

A qualitative study was carried out, having the Data Grounded Theory (DGT) as research design.

The research scenario was a specialized assistance service in a municipality in southern Brazil. Data collection took place between April and September 2016. The selection of participants was performed through theoretical sampling and intentionally. The following participation criteria were adopted: being diagnosed with HIV/AIDS, aged between 15 and 24 years old, registered in the Logistic Drug Control System (Sistema de Controle Logístico de Medicamentos, SICLOM) of the

specialized care service, and being on antiretroviral therapy (ART) for at least 6 months. From this context, pregnant women and postpartum women were excluded.

Participant access was previously agreed with service professionals, pharmacists and infectologists. Young adults who attended the service for medical appointments and monthly withdrawal of antiretrovirals were directed by these professionals to a conversation with the researcher. Interested parties were informed about the objectives of the study and invited to participate. In relation to minors under 18 years old, when present, contact was first made with those responsible and, after consent, contact was established with the young adults who read and signed the consent form.

For theoretical sampling, two sample groups were constituted, totaling 25 participants. The first sample group consisted of 12 young adults with HIV/AIDS who were on ART. The guiding question for this group's interviews was: how are you doing treatment for HIV/AIDS? From the data collection with these young adults, some assumptions emerged, among them: The beginning of treatment is a difficult time marked by strong side effects and the fear of getting sick and dying; Living with HIV/AIDS in youth can interfere with treatment adherence; Not accepting the diagnosis influences adherence to treatment in young adults; Prejudice and social stigma make it difficult for young adults with HIV/AIDS to adhere to treatment; The support network is essential for young adults' adherence to treatment. Based on these assumptions, the second sample group was formed consisting of nine service professionals (two nurses, four doctors, a pharmacist, a social worker and a psychologist) and four family members (four mothers). Data collection was directed to this group since health professionals and family were the sources of support highlighted by young adults and because they were the people who were referred for accompanying young adults in their treatment.

Data was collected through individual interviews lasting between 20 minutes and 1 hour. The interviews were recorded on an electronic audio device, transcribed and inserted into the NVIVO® *software*, version 10, for coding and organizing data.

The characterization variables of the young adults who participated in the individual interviews included some socio-demographic, clinical and behavioral aspects, such as gender, age, education, marital status, family income, time of ART use (in months) and time of HIV (in months); way HIV was acquired and sexual orientation.

Most of the young adults who participated in this research phase acquired HIV through sexual intercourse. Only two young adults were exposed to HIV at birth.

Data collection and analysis were guided by the constant comparative method proposed by one of the streams of the grounded theory which is made up of three steps.[20] In the first step a horizontal reading of the data was made and, line by line, the first codes that were compared to other codes were selected, coming from new data (open coding). Thus, the first substantive and theoretical codes and their respective categories were formed. In the second stage of the analysis, the comparison of substantive and/or theoretical codes with new codes from new data was performed. In the third stage, concepts were compared to concepts, i.e., the central category or core variable was identified, and selective coding began. It is worth mentioning that the elaboration of the memos helped the researcher in the integration of the theoretical codes. Throughout this process, saturation of the categories was verified, that is, the incidents began to recur and, therefore, there was no formation of new categories, which pointed to the theoretical saturation of the data.

In this article, we chose to discuss two categories that supported the central category: "Adopting a behavior of adherence to treatment even when not accepting living with HIV/AIDS in youth." The choice of categories was based on the points that elucidated concepts consistent with the principles of the theoretical framework used in the study, i.e., the Complexity Theory that helped the researcher understand the adherence to treatment of young adults with HIV/AIDS as a complex phenomenon.

All participants signed the Free Informed Consent Form and, when necessary, the Agreement Form. To ensure anonymity and to preserve the identity of the participants, their names were replaced by codes, i.e., the letters Jov (Young individual), Pr (Professional) and Ma (Mother) followed by an ordinal number corresponding to the sequence of interviews (Jov1, Jov2... Jov12... Pr1, Pr2... Pr9... Ma1, Ma2... Ma4). Any and all information that could identify interview participants was altered to preserve their identities.

RESULTS

According to the characterization variables of the young adults who participated in the first sample group, it was identified that most were male, who declared themselves homosexual, aged between 15 and 24 years old, with complete high school, single, family income between one and three minimum wages. The time of diagnosis and treatment ranged from 6 to 180 months and sexual intercourse was the main form of transmission of the infection.

Data analysis allowed evidence of two categories which were constructed by integrating a set of subcategories, presented in Chart 1. These categories and subcategories supported the understanding of treatment adherence of young adults with HIV/AIDS from the perspective of Complex Thinking, since aspects that constitute the multiple dimensions of the adherence phenomenon were elucidated based on the principles of the complexity theory.[4]

Chart 1 – Categories and subcategories.

Categories	Subcategories
Multidimensional and complex aspects that permeate the process of adherence to treatment of young adults with HIV/AIDS.	- Fear of death and experience of antiretroviral side effects; - Silence/Revelation of the diagnosis; - Integrating knowledge and uncomplicating treatment; - The dichotomy between Being Normal/Being Different; - The secret of treatment.
Organizational, individual and social aspects that enhance and/or weaken the adherence to treatment of young adults with HIV/AIDS.	- Sharing of care actions among the multidisciplinary health team of the specialized care service; - Living with HIV/AIDS in youth and Being young with HIV/AIDS; - The experience of prejudice and social stigma against HIV/AIDS.

Multidimensional and complex aspects that permeate the treatment adherence process of young adults with HIV/AIDS

One of the initial points of adherence to treatment of young adults with HIV/AIDS involves aspects linked to coping with living with HIV/AIDS and the initiation of treatment. Both situations are considered complex because they include issues involving human multidimensionality, among them, inherent to the fear of death (autobiological/mythological) and the experience of side effects to antiretrovirals (biological):

> [...] *By the time I found out, the only thought I had, I didn't know much about HIV* [...] *my concern was to have AIDS and die* (Jov1);

> [...] *At first it was difficult, because I rejected the medicine a little. And, I was sick* (Jov2).

The experience of young adults with strong side effects at the beginning of treatment arouses in them the desire to abandon and/or discontinue their treatment. This shows that the experiences may indicate and/or modify the behavior of these youngsters regarding adherence:

> [...] *Yeah, I wasn't into it, I say that at first, because the medicine gave me a lot of reaction, but not now* [...] *It was because of the side effects, which were very strong. I couldn't take it occasionally* [...] *There was a time when I was almost a week without taking the medicine* (Jov7).

The above incidents are situated on a global level, that is, they are immersed in a context that encompasses other conflicts, linked to the discovery of HIV, living with a chronic transmissible disease and an intense social stigma. This clarifies that not only the parts are in the whole, but also, the whole is inserted in the parts, that is, adherence to the treatment of young adults encompasses aspects that make up living with HIV/AIDS, as well as living with HIV/AIDS encompasses aspects related to treatment adherence and, in this interrelation, the whole is understood.

The silence of young adults about their diagnosis and the indecision to reveal their condition or not justify the need to contextualize and globalize the problems experienced by these young people and thus realize the importance of social support, especially at the beginning of treatment:

> [...] *At the beginning of the treatment we really need someone, I was alone, me and a diagnosis, which could be my death sentence* [...] *if you don't have family, a friend, the people in the clinic, but you must have someone* [...] *Very difficult, a dilemma, I thought of telling, but at the same time, I knew it wouldn't be accepted, maybe, I don't know* [...] *It's very hard, just living in the skin to understand, I can't explain* (Jov12).

The integration of knowledge about the disease and treatment over time complicates treatment for young adults, that is, the process of accepting treatment becomes part of the life of young adults with HIV/AIDS, as they come to understand that over time, with a correct treatment follow-up, recurrent symptoms of antiretroviral use become absent or minimized. In addition, the fact that examinations and medical consultations become instruments that will enlighten them about their health condition, making them safer in relation to treatment, as highlighted in the following statements:

> [...] *Today, I have much more disposition than before.* [...] *when you get the results, you feel more like continuing the treatment* (Jov9);

> [...] *The doctor telling me how it went, my family telling me how it went, me researching a lot, I've seen it's not that seven-headed beast* (Jov7).

The information gained by young adults over time has enabled them to re-analyze their health and treatment. This helped the young adults to continue their care and made the situation more acceptable since at the beginning of treatment they associated this with "a seven-headed beast", i.e., something that causes strangeness, synonymous with complication, with ignorance and, therefore, a cause for concern and fear. However, as they become enlightened and build knowledge from living with the disease and treatment, with the positive results the process becomes more acceptable and natural.

In this way, young adults after the initial phase of treatment (usually the first year) refer to it as something normal, habitual, a routine:

> [...] *Now take medicine, go to the doctor, the exams* [...] *seems like a normal thing* (Jov2).

For mothers and health professionals, as young adults accept their treatment, they begin to commit not only to treatment management, but also to care for themselves:

[...] *They take on treatment when they begin to understand the importance of adherence, take more care* (Pr4);

[...] *She came to accept more, decide things* [...] *these things to come here, go consult. Taking more care of oneself* (Ma4).

Young adults emphasized that at the beginning of the treatment they felt "different from the others", but over time they began to perceive themselves as "equal to the others", that is, they considered themselves healthy as any other young person who does not live with HIV/AIDS. This was also highlighted by family members. The non-impairment of the social routine, the absence of symptoms and the non-exposure of the diagnosis of HIV/AIDS were some of the aspects pointed out by the young people as necessary to feel "equal to the others", according to the following speeches:

[...] *Taking the medicine, you'll have a normal life, just like everyone else* [...] *Nowadays, you don't realize who is positive serum, who is on the cocktail* [...] *they are fat people, thin people, they are normal* (Jov6);

[...] *Especially at the beginning, until they understand that they can lead a normal life, it's hard, it's very hard, he was different from others* (Ma4).

The dichotomy between the "Being Normal" and the "Being Different", perceived in the discourse of young adults, shows the union of two contradictory but inseparable notions in the same reality. This dialogical relationship allows us to conceive the decision to continue the treatment, even without accepting the diagnosis of HIV/AIDS. This decision is linked to the importance of staying "healthy", that is, the normalization of their health and greater longevity. Young adults use clinical marker results to assess their health, and when these results are positive, they ensure that they are "Normal/Healthy":

[...] *Now with the treatment, normalized my health, the doctor said the virus is zero* [...] *it is for the improvement of my health* (Jov1);

[...] *Goal, undetectable viral load, somehow, they feel a little more normal when they reach that goal* (Pr7).

Complexity, besides uniting, reconnecting and contextualizing, must also recognize the singular and the individual. In the speeches of young adults their preference to keep their treatment secret was remarkable so as not to have their diagnosis revealed, as exemplified below:

[...] *I prefer not to talk, it's my thing, if I talk, I will suffer prejudice from people* (Jov11).

In the context of complexity, respect for this individuality/uniqueness, that is, the secret of treatment, is linked to an ethics of solidarity that comprises without condemnation which was perceived in the statements of some family members and professionals:

[...] *She says she's ashamed to get in here, I'm so sad about it, so I try to tell her that she can't think so, but it's hard. And then, when I can, I come and get it* (Ma4);

[...] *We know they are ashamed to enter here; they do not want to expose themselves* [...] *This needs to be considered and respected* (PR1).

Organizational, individual and social aspects that enhance and/or weaken treatment adherence of young adults with HIV/AIDS.

In this category we have a set of internal and external aspects that may be related to organizational, individual and social problems that make up the multiple dimensions of complex thinking. These aspects include individual issues of young adults, as well as aspects linked to the

work organization of health professionals of the specialized care service and issues related to the disease and its social context.

Thus, the following are highlighted: bellow sharing care actions among the multidisciplinary health care team of the specialized care service, living with HIV/AIDS in youth and Being young with HIV/AIDS, and the experience of prejudice and social stigma to HIV/AIDS.

Sharing care actions among the multidisciplinary team of the specialized care service is essential to improve young adults' adherence to treatment, since we are facing a phenomenon with multiple dimensions that depends on this interaction to be understood. Based on the testimony of health professionals, we realized the relevance of transdisciplinarity, but recognized the need for interdisciplinarity and complementarity of care actions:

> [...] *We need an integrated service* [...] *multiprofessional, for us to do a good adherence work* [...] *to understand the whole, which is adherence* (Pr6).

In addition, the strengthening of collective practices was highlighted, since individual and centralizing practices still prevail, which in the light of complexity fragments, separates and reduces, making it difficult to understand/integrate the whole:

> [...] *Look, I'm a fan of more collective activities* [...] *we are still very much in the logic of routing* [...] *If we continue this logic, we will be pushing the patient from here to there and will not solve his problem. On the contrary, it will distress him even more. That's terrible for their adherence* (Pr9).

Living with HIV/AIDS in youth and/or Being young with HIV can weaken adherence to treatment. Young people have their particularities and some of them may interfere with their adherence to treatment, for example: immaturity, impulsivity, the desire to live some emotions intensely, as found in the statements of mothers and professionals:

> [...] *Youth is that moment when every young person must live, has to have freedom* [...] *for him to go back later, live that moment* [...] *When you have no health problem, you go out to a club, you will want to drink, but then the other day, you get better, but when you know you have the treatment, it's different, it's hard* (Ma1);

> [...] *I think overall, it's a worrying group that's hard to deal with* [...] *And then there is the figure of the doctor, giving him a series of routine questions, about life issues, ranging from taking exams, attending appointments, taking medicines, to performing periodic exams.* [...] *and all those responsibilities that they want to experience many times at that age, and they want to do it the way they think it's right, so it's very difficult* (Pr8).

The ability to face uncertainties and tread through an uncertain future is part of the complexity of the phenomenon of adherence to treatment of young adults with HIV/AIDS, since for young adults, living with HIV/AIDS in youth implies living limitations, facing challenges and coping with uncertainties, risk sentiment and vulnerability, especially regarding plans:

> [...] *It's complicated, it's crazy, I'm so young, I want to enjoy my life and sometimes I get limited, so, there are so many things, we trade one thing for another and survive, because it's harder, because you stop and think about the future* (Jov10).

Given the facts and situations, young adults strive to confront HIV/AIDS. In addition to the individual aspects, the relationship with the social realm brings about the aspects surrounding the disease such as the stigma and the character of transmissibility, like, for example, experiencing the prejudice and the social stigma to HIV/AIDS. This makes living with HIV/AIDS even more complex,

since it is not enough to follow the treatment, that is, taking antiretrovirals, performing consultations and examinations, living with HIV/AIDS in youth is to live with the mark of prejudice and social stigma. Often, such situations weaken adherence or even prevent the young adult from following treatment, which can be seen in the expressions below:

> [...] *Prejudice* [...] *this for me is the great difficulty of accepting the diagnosis and consequently adhering to the treatment of these young people* [...] *This is so big, so much bigger, that they can't even open, to really analyze, what the treatment is* (Pr7);

> [...] *Once I decided to tell, and the other day, the whole school was knowing* [...] *sometimes, I would notice the looks* [...] *And then, I don't count, I now protect myself from it* (Jov3).

DISCUSSION

HIV has been affecting young people aged from 15 to 24 years old, single, homosexual, and infected through sexual intercourse.[9,21] This can also be observed in the characterization data of young adults presented in this study. The data also portrays the recent discovery of the diagnosis of HIV/AIDS and the confrontations linked to the beginning of treatment, among them the difficulty of accepting to live with an incurable chronic disease, strongly associated with death and stigmatization.[8,16] Young adults are not always prepared for these confrontations and, in this process, the desire to receive more detailed information about the disease and treatment is awakened, a practice that is paramount in the care of young adults with HIV/AIDS.[16,22]

Complexity allows for a better understanding of human problems, including those linked to HIV/AIDS.[23] When analyzing the adherence to treatment of young adults with HIV/AIDS from the perspective of complex thinking, the presence of some complex situations in the lives of these young people were observed, among them coping with living with HIV/AIDS, experiencing the effects of antiretroviral drugs at the beginning of the treatment, "Being Young" with HIV/AIDS and having to adhere to the treatment of a chronic condition, among other situations that constitute, therefore, a complex whole.

The complex whole encompasses an adherence behavior that is now influenced by the subject himself who is a product and producer of the society in which he is inserted.[12,23] It is understood, then, that adherence to treatment of young adults with HIV/AIDS is not reduced to a singular behavior, but to a behavior influenced by several aspects which, when integrated, form the whole. Such behavior is dynamic/sensitive/volatile, influenced by internal and external factors that, at the same time, can strengthen or weaken treatment adherence.

Taking antiretrovirals means facing difficulties, feeling better and having quality of life. The subjects understand the importance of medicines; however, there are factors linked to their social life and feelings that can influence adherence.[24] This interconnection of people living with HIV/AIDS with the social realm is based on the dialectic binomial of autonomy/dependence which highlights that the system is only based on a relationship of dependence with the surroundings.[4] Morin's contradiction and dialogic attitude enables us to know complex phenomena and, therefore, the adherence of young adults to treatment.[14,23]

Young adults take an ambivalent posture (dialectical relationship between being bad and being good) regarding treatment, they report that treatment brings limitations and difficulties, but it is necessary for maintaining their health and for a better life.[25] Moreover, the dichotomy between "Being Normal" and "Being Different" demonstrates the union of two contradictory but inseparable notions in the same reality. The "Normal" and "Different" Beings were also central issues pointed

out by the participants of another study, the “different” being associated, mainly, with the limitations imposed by living with a chronic disease, among them, taking medicines.[22]

Human beings are autonomous, but their autonomy depends on the external environment, they develops their autonomy depending on their culture.[23] For the young adults to have an adequate adherence it is essential to strengthen their autonomy and for this, they need to know and understand their diagnosis.[17] Young people with HIV and AIDS learn to care for themselves over time, especially after understanding the reasons for treatment.[26] Based on their responsibility, they gain autonomy for their care, but they reproduce a professional discourse that can make the understanding of their situation superficial.[17]

Young adults emphasized the need to receive information about their illness and treatment clearly, without fantasies, as they believe that things do not become superficial. It was observed that this information contributes to the acceptance of these young people to treatment since the integration of this information allows them a new analysis of their health and treatment status and, therefore, a better understanding of the importance of treatment adherence to living with HIV/AIDS. The acquired knowledge does not add up, but feedbacks on previous knowledge which allows to rethink in a new context.[4–5,23]

Despite advances in the diagnosis and treatment of HIV/AIDS, young people still associate AIDS with death.[26–27] This arouses in young adults a constant fear of dying.[16,26] The initial description of HIV and AIDS, highlighted in the media as a debilitating, frightening and fatal disease enhances such sentiment.[26] The man-death relationship refers to a problem of human multidimensionality. Man fears death because with it the individual loses his individuality.[23,28] In addition to the fear of death, young adults expressed feelings such as the fear of falling ill, hospitalizations, spreading the diagnosis, not being accepted by people, and experiencing social stigma.[16,21] Another point highlighted by the study participants was the difficulty in experiencing the side effects of medications, especially at the beginning of the treatment. Side effects to antiretrovirals are mentioned in the literature as being the main difficulty that young adults present at the beginning of their treatment.[17]

Stigma, discrimination and social rejection are considered a barrier for young adults living with HIV/AIDS.[16,26] The young adults in this study expressed negative experiences of stigma and discrimination when their diagnosis was revealed to some colleagues and family members. Therefore, acceptance of the diagnosis does not always occur on the part of young adults but, even in the face of emotional and psychological disturbances arising from facing the diagnosis, they are concerned with its treatment, as it is related to prolongation and quality of life.[16]

Health professionals participating in the study reported that the basic pillar for adherence to treatment of young adults with HIV/AIDS is acceptance of the diagnosis, but the prejudice and the still marked social stigma in the context of HIV/AIDS can make it difficult to accept this condition.[16,26] The young adults and family members also emphasized that prejudice and stigma collaborate to keep the secret of treatment and diagnosis, as young people do not experience these situations in their social context. For many young people, the diagnosis of HIV is a condition that should be kept secret, and non-acceptance of the disease is considered a barrier to good treatment adherence.[22]

In the speeches of young adults the decision to continue treatment emerged, even in the face of difficulties. Young people mention the desire to continue their treatment for the desire to have their health normalized and to survive. To this end, they strive for the pursuit of normalcy since they aim for a normal life, that is, a life common or equal to other young people who do not live with HIV/AIDS.[16,22]

The role of health professionals and family members becomes paramount in this process, with family and professional help being recognized by young people with HIV/AIDS as part of their care and necessary for adherence. Family support is especially important in discovering the diagnosis, as lack of this support is an obstacle that young adults encounter when they are diagnosed with HIV.[16]

The presence of dialog in the relationship of family/adolescent care is another point to be highlighted, as well as the access to information about their health condition and treatment provided, mostly, by family members and/or health professionals.[17]

The young adult with HIV/AIDS needs to be conceived from complexity, that is, we need to contemplate it in its multidimensionality.[12] To do this, the health professionals who care for young adults with HIV/AIDS should broaden theirapproach beyond the clinical aspects; pay attention to the specific demands of adolescence and youth regarding treatment adherence; perform care actions that take into account the uniqueness of these young people, as well as care practices centered on young adults and their families and perform interdisciplinary follow-ups.[17] It is necessary to identify and work on the difficulties of adherence, to adopt strategies that enhance team communication with the family, to value young people's autonomy and to encourage greater listening and dialog about the disease in the family context.[25]

Thought reform is challenging: we live in an environment where knowledge is separated, fragmented and compartmentalized. This implies the invisibility of complex sets, interactions and feedbacks between the parts and the whole. This hyperspecialization prevents us from seeing the global and the essential.[19] Interdisciplinarity is identified as a *sine qua non* condition for the development of innovation. However, it is still realized that many realities are not prepared for this.[29]

The work environment and the importance attributed by health professionals to their practices are pointed as dimensions that influence interdisciplinary practices. Health professionals from the specialized care service should integrate the thinking and making of the multidisciplinary team and realize the need for complementarity of their practices, which, in the context of this study, refers to the strengthening of adherence to treatment of young adults with HIV/AIDS. Power to do is conditioned by wanting to do.[12] It is important that there is an interdisciplinary follow-up of these young people and the development of practices focused on the care of these young people, adolescents and their family.[16–17]

Living with HIV/AIDS in youth is not a simple matter, but a complex situation, immersed in different contexts and permeated by the intertwining of multiple situations that can, at the same time, complement each other as they repel each other. And in this coming and going, we experience limits, overcoming, confrontations and uncertainties. Therefore, it is necessary to reform thinking, since complex thinking faces uncertainties in order to clarify the strategies that permeate the uncertain world in which these young people are inserted.[19,23] It is also important to respect the individuality of these young people and to exercise an ethics of solidarity, that is, one that understands misunderstanding, without condemnation, and that contributes to the humanization of human relations.[28]

Being young with HIV/AIDS refers to a Being of drive and desire that is part of a social whole; a trinitarian being constituted by its individuality, its biological species and, at the same time, a social being. Therefore, being young with HIV/AIDS is a complex Being. To such end, it is necessary to recognize the biological, organizational, political, individual, cultural and social aspects that permeate the lives of young adults with HIV/AIDS, including adherence to treatment.

This study has limitations because its results are not generalizable; they partially portray the complexity of treatment adherence for this portion of young adults who participated in this study. Further studies with this population are suggested to understand this complex and changing phenomenon of treatment adherence.

CONCLUSION

Adherence to treatment of young adults with HIV/AIDS is understood as a complex, dynamic, multifactorial and constantly changing phenomenon. This process involves aspects such as fear of becoming ill, physical and social death, rejection of loved ones, as well as fear of discrimination and stigma. Silence of the diagnosis and non-acceptance of living with HIV/AIDS are part of this process. But even in the face of these difficulties, young adults decide to continue their treatment because of their intense desire to normalize their health, to live a long life and to be equal to other young people who do not live with HIV/AIDS.

Treatment adherence for young adults should be understood and managed by health professionals. For this, it is necessary to get out of the logic of the reductionist paradigm and move on to a complex logic, that is, it is necessary to reform thinking, to (re)think and to (re)build daily conducts, actions and strategies aimed at adhering to the treatment of young adults living with HIV/AIDS, among which the adoption of health actions for beyond the clinic, that is, actions that consider the uniqueness of young adults in view of the complexity that is adherence to HIV/AIDS treatment.

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NOTES

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CONFLICT OF INTEREST

No any conflict of interest.

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