



# Accompaniment to the promotion of life projects of HIV-positive young people. A complex qualitative study

## Acompañamiento a la promoción de proyectos de vida de jóvenes seropositivos. Un estudio cualitativo complejo

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### ABSTRACT

The diagnosis of infection with HIV constitutes a disruptive vital event in the lives of young people. The HIV-positive condition is frequently perceived as a death sentence, in addition to presenting multiple barriers during daily life, such as stigma, self-stigma, discrimination, isolation, and symptoms of anxiety-depression. Especially the configuration of personal identity and planning for the future, positively and realistically, constitute two severely affected processes, hence the importance of promoting the life projects of HIV-positive young people through comprehensive care. The study was carried out using a qualitative design in two stages, one with a phenomenological design and the other through the focus group and thematic analysis. The main results point to the importance of encouraging goals that promote therapeutic adherence, facilitate psychological well-being, help social integration, and favor the structuring of a solid support network. In addition, guidelines are offered for better preparation of proposals for the promotion of life projects in this population. The article ends with recommendations for future studies.

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## INTRODUCTION

For several years, a better understanding of the pathophysiological characteristics of HIV, as well as its effects on the person, has facilitated the development of better prevention and diagnostic systems, treatment guidelines, and devices to accompany people carrying the virus (Addington & Cheung, 2020; Cobb et al., 2020; Huang et al., 2021; Worku et al., 2020). In particular, with the advent and subsequent development of antiretroviral therapy, life expectancy and quality of life have improved considerably, which has also favored efforts to understand in greater depth the psychosocial impacts on daily life, identity, and the way these people perceive the world (Cai et al., 2020; Okumu et al., 2021; Rzeszutek et al., 2021). Thus, constant monitoring of CD4 count and the combination of highly active antiretroviral therapy (HAART) with supports and support systems has offered renewed hope for this population (Getanda & Vostanis, 2022; Gitahi et al., 2022; Laurenzi et al., 2023; Vancampfort et al., 2021).

However, experience in praxis and the most relevant studies in the literature show that subjects infected with the virus do not always manage to represent their condition in the most adequate way. For many, rather than a chronic health condition that is transmissible and requires monitoring, it constitutes a mortal sentence and a stage prior to the end of life. This reality is influenced by cultural, educational, social, and social issues created by the very culture of the healthcare facilities where they are cared for (Kelly et al., 2022; Liu et al., 2022; Yusuf & Agwu, 2021). Issues such as being considered patients of a life-threatening disease and the predominance of care processes focused on the pathological, not the preserved and salutogenic, have a significant influence on whether these individuals cope with the diagnosis and the necessary adherence to treatment inadequately.

Although it is not certain that this state of misunderstanding of HIV-positive status is generated in the health sector, it is largely evident that it is there that it is sustained and reproduced. Moreover, the way in which the HIV-positive person intentionally explores his new condition or responds to stereotypes that are common in society, family configurations, or workplaces is affected. Consequently, the representation of the condition starts from a negative connotation and causes the emergence of coping mechanisms that do not favor the development of the personality, limit resilient attitudes, and do not contribute to health care, understood to its full extent.

Especially in young people, the diagnosis and the initiation of the course of action (treatment, interconsultation, support groups) induce a complex disruption of daily life, as well as of their expectations, goals, and dreams (McGrady et al., 2021; Merrill et al., 2022; Newman et al., 2022). Understanding this reaction involves examining their beliefs about their life, worldview, and other qualities specific to their psychological age and social position. It is also necessary to consider the high achievement rate in adherence to treatment, to general recommendations for overall health care, which affects the normal course of life and involves numerous adaptations.

These individuals are known to suffer from anxiety, depression, stress, fears, and insecurities, with a high prevalence rate (Getaye et al., 2021; Haag et al., 2022; Kalomo et al., 2022; Small et al., 2022; Velo et al., 2022). In particular, in those without a strong social support network, these negative experiences may be exacerbated. In addition, the stigmas associated with HIV, related to promiscuity, homosexuality or irresponsible sexual behavior, certain death or constant risk of infection, marginality, and the social value of the person, lead to self-rejection and avoidance behaviors (Armoon et al., 2022; Hascher et al., 2023; Kasande et al., 2022; Mathew et al., 2020; Sallabank et al., 2022).

As can be seen, this is a very complex situation and requires multidisciplinary care, joint efforts, and the sum of wills so that the person carrying the virus can count on all the resources and support he/she requires to face his/her condition and the changes in his/her life. One of the main work strategies is health education, awareness of adherent behavior, and life reorganization. Because the affectations are seen in all spheres of the person's life, the life project constitutes an important theoretical and methodological resource to help these people understand themselves in their new role, be aware of their own identity, and help achieve social inclusion in all contexts; this last aspect with high rates of depression in primary health care.

A review of the main foundations and background of the project's care yielded the need to deepen its psychological configuration and the relationship with other important categories, such as worldview and meaning of life (Pérez-Gamboa et al., 2023). Another important issue has to do with the degree of development of the life project evaluated and diagnosed in different populations -commonly students of different educational levels- since it showed deficiencies in the awareness of identity; the elaboration of goals and plans; the fulfillment of actions aimed at achieving their motivational scale; motivational narrowness expressed in poor motivation in the spheres of life; as well as an accentuated tendency to think in the present.

As a result, it is assumed that various authors consider the life project as a psychological structure or system of special relevance, which provides support for the fulfillment of goals that express what the person hopes to achieve and is, therefore, also an articulating axis of learning for life (Esteban-Guitart & Gee, 2023; Pérez-Gamboa et al., 2023). Particularly linked to learning, the process of reconfiguring personal identity and understanding the new place occupied in society constitutes a bridge for the establishment of quality relationships with oneself, with others, and with the symbolic spaces in which they interact on a daily basis.

In short, the aim is to develop guidelines that favor educational and social work with HIV-positive young people, an effective accompaniment during their vital learning process marked by the HIV virus carrier status, and the adoption of social insertion processes that mitigate the presence of stigmas and the marginalization of which they are often victims. This paper presents the main results of an experience of orientation, in its diagnostic phase, in health education and the life of HIV-positive young people through integral attention to their life projects. It concludes with the essential guidelines to be considered for the design of intervention projects, and public and health policies, among other possible alternatives aimed at improving the services provided to this population.

## METHODOLOGY

### Approach and design

The study was conducted based on a purely qualitative approach aimed at understanding, describing, and analyzing the life experiences of HIV-positive young people attended in the context of primary health care in the city of Sancti-Spíritus, Cuba. In accordance with the pretensions of the research, a two-stage study was designed, the first one with a phenomenological approach focused on achieving a deep description of the characteristics of the life project of the HIV-positive young people participating in the research. This exploration sought to identify the essence of the understanding of the life project, from the constructions made by the young people, from the gradual reduction of their experiences. For this, multiple antecedents identified in the international scientific literature were taken into consideration, works of high quality and impact with similar research intentions (Chemutai et al., 2020; Dhlakama et al., 2023; Malungani et al., 2021; Moyo et al., 2022).

The second stage was aimed at the triangulation of the results, for which a design based on the use of the focus group (two meetings) was carried out, whose main data were processed through thematic analysis, shared through messaging services in information packages for analysis, using the specialized software in qualitative research ATLAS.ti. Organizing the thematic analysis in this way allowed authors 2 and 3 to explore the data and establish codes and fundamental themes to triangulate with author 1's own experiences, a process supervised by author 4.

The above was necessary due to the high emotional load generated by the study, the difficulties in maintaining a high standard of objectivity and reliability, as well as the impact of maintaining the process of bracketing executed by this author during the first phase, which is why she was assisted in the transcription and initial processing by author 4. This decision was made based on the in-depth study of the recommendations provided by experts in the field, not only because of the practical benefits and their contribution to the reliability of the research results but also for purposes related to the researcher's own well-being and the better processing of empathic experiences (Dörfler & Stierand, 2021; Sinfield et al., 2023; Stolz, 2020; Thomas & Sohn, 2023).

### Context, ethical issues and sample

One of the main characteristics, identified by the first author and reported to her by several gatekeepers encountered during the first phase (medical specialists, nursing staff, and the Psychology Department), was the tendency of HIV-positive young people to be suspicious, not to participate voluntarily in group devices and not to ask for help. These qualities were projected as a "secrecy" associated with their condition, so the process of choosing the physician, recruiting for the research, and selecting a place to conduct the interviews were extremely complex. These aspects were considered and included in the phenomenological design to respond to the ontology of the participants, alleviate tensions, and ensure reduction (Ataro, 2020; Pedersen, 2020; Satsanasupint et al., 2022; Thomas, 2021).

These circumstances and characteristics led to the decision to work in an unidentified room of the Camilo Cienfuegos Provincial General Hospital as a consultation for HIV-positive patients (dermatology, cardiology, and other available consultations were used). In addition, it was agreed not to disclose in any research report data that could in any way identify the patients, the medical records, the primary health care center from which they came, or other indicators of the identification system.

It should be noted that during this study, the participants were not considered as patients in order not to reproduce stigmas associated with their health-disease process, so their identity was protected through the use of coders (first initial plus numerical code). In addition, it was guaranteed that any future reference to the results reports would not contain sensitive information that could reveal the identity of the participants. This protocol was established by informed consent and was contrasted with the most relevant proposals found in the literature on confidentiality and data protection (Dougherty, 2021; Moriña, 2021; Surmiak, 2020; Taquette and Borges da Matta Souza, 2022).

Finally, in the first stage, the sample consisted of 13 HIV-positive young people (four women and nine men) between 23 and 35 years of age. It should be noted that the study began with 15 participants, but two resigned due to personal reasons. In the second stage, we worked with seven of the participants (two women and five men), while the remaining six did not agree to participate in group devices for fear of breaking the secrecy and exercised their right to leave the research.

## RESULTS AND DISCUSSION

The study of the configuration of the life project requires examining how goals, plans, and series of actions are articulated but also exploring aspects such as the person's self-image, his or her autonomy in decision-making, and the adjustment of his or her behavior to reality (Pérez et al., 2021). This involves exploring the meaning that HIV-positive young people construct about their project, but also about the reality that surrounds them, their aspirations, and the bifurcations created in their lives by the contagion.

With special emphasis on the life project, the representation as an HIV-positive youth, and the needs attributed to a possible social inclusion or approach to the "normal" functioning expected for youth, the spheres and indicators of the conceptual framework studied were studied (Pérez et al., 2021; Pérez-Gamboa et al., 2023). The main issues addressed are presented below, with a particular focus on the description but also through the discussion of essential aspects drawn from the triangulation.

### **Theme 1: Contagion, new life and readjustment of the personal sphere**

The irruption of the contagion, the condition identified as "terminal illness" and the quasi-mandatory nature of complying with medical indications provoked in the participants an important identity readjustment, although this did not occur automatically, but gradually and with a mixture of advances and setbacks, all participants reported having reached a state of exacerbated protection of their emotional well-being, their overall health (especially in terms of eating habits and sleep hygiene) and an approach to self-determination and independence that they lacked, at least at that level before the diagnosis.

The readjustment was appreciated primarily in the changes inserted in the course of daily life but also in the mourning before the "loss" of health, which was marked by stigmas, lack of knowledge, and insufficient accompaniment by health personnel. The participants explained the new degree of development in different ways, and although the death sentence was reproduced, all agreed that having to watch over medication, self-care, and not being able to indulge in bad habits helped them put themselves at the center of decisions.

However, it should be noted that this growth does not always appear in such a way in all HIV-positive young people, as some of the participants refer to the existence of known stories in which some people, upon learning of their diagnosis, simply "threw themselves to die". One participant, a medical doctor in practice with some biosafety adjustments, reported knowing several people he had treated as patients whose reaction to the diagnosis had been precisely the opposite of what was expected. Another detail shared by this participant was the perceived relationship between schooling and adherence; an aspect that did not appear in any other testimony.

Despite its importance in maintaining the person's well-being, this salutogenic orientation meant, in each case, a considerable and desired distancing from the usual social circles prior to diagnosis, the renunciation of non-"flattering" aspects, such as promiscuity or a hectic nightlife. With the exception of one participant, the remaining participants, especially females, assured that these adjustments were for the better and did not report nostalgic experiences. Similar to what was previously stated, stories were told of opposite cases where the readjustment had provoked anxiety, depression, or nostalgia at the "loss" of their former self.

From this description of the relationship between personal sphere adjustment and asylum-secrecy about the condition, it was possible to identify and explore the relationship between adjustment and the remaining spheres.

As a central tendency in the interviews, these goals associated with health care were identified as vital goals located very high in the motivational hierarchy; hence, because of their regulatory possibilities, they were not perceived negatively in relation to the “self-imposed” limitations.

This categorization of self-imposed expresses the representation that these young people harbor about their autonomy and self-determination insofar as they reveal aspects that are elements of therapeutic adherence manuals in the case of HIV, which they had managed to personalize in a manner adjusted to their own realities. This revelation made it possible to understand that, unlike other populations of young people where the aforementioned goals or the personal sphere do not appear in this hierarchy, in the case of HIV-positive young people, the functioning of the personal sphere constitutes a crossroads for the other spheres of life and fulfillment. This means that the way in which the personal sphere is readjusted, both psychologically and in daily behavior, will directly influence the other spheres.

Consequently, the life event (contagion) constitutes the basis on which identity is transformed, and adaptive and executive resources are produced to achieve better coping. With the passage of the different stages of adaptation, the new identity consolidates and establishes itself as the basis of the worldview of the HIV-positive young person, which retains components, pre-event, but are clearly influenced by a new sense of life. As already mentioned, this new meaning does not imply acceptance of the condition, which continues to be experienced as negative and stigmatizing, but its influence regulates the design and fulfillment of goals in other spheres, especially in the recreational and social spheres.

In general, there was a tendency towards personal fulfillment and achieving goals that were not stagnant or postponed. Regarding marginalization and social discrimination, it was appreciated that, in a certain way, these processes can appear objectively but also have a self-provoked component. Finally, it was evaluated that the correct use of time and the realism of their conceptions allowed them to assume a critical position in the face of their condition, even in the presence of self-stigma and the reproduction of misguided beliefs about it.

## **Theme 2: Risks, rejection and secrecy, the profession as a dimension of life**

Although the degree of schooling varied, from technical to university professionals, the professional sphere was seen as one of the most conserved and highly relevant. This is not only due to the characteristics of the psychological and social stage, where work is especially important in relation to economic stability and socialization but also because the participants showed a high hierarchy in the goals perceived as part of self-realization.

A key aspect identified in the narratives was that unlike in the personal sphere where the diagnosis involved changes and ruptures, in the professional sphere the identity configurations were maintained almost identically (“I am a good worker”, “I always wanted to dedicate myself to hairdressing”). Therefore, the preserved vocational aspects contributed to a positive representation of the profession, which was highlighted by the fact that the negative experiences narrated were related to specific situations typical of the working life of any organization or to the rupture of secrecy (in two cases).

In contrast, a negative connotation was found in the representation of the professional sphere, although related to the profession itself, namely, the presentist nature of the goals, the limited future projection of this sphere and the mention of truncated goals, without the researchers’ discussion of the cases showing any objective criteria to support this truncated nature.

Another important factor at work, described by all the participants in their narratives, was the contribution of the work-professional sphere to the fulfillment of their life goals. This was especially appreciated in relation to the order that the profession confers to life, taking into account that the economic aspects were described in a disparate way, with greater importance in the private sector workers and particularly impoverished in the state sector as a result of the country’s economic situation.

With regard to the difficulties already mentioned, it is necessary to dwell on the impact of secrecy on the condition of social relations within the labor organization. In particular, in those participants who had shown tendencies to extroversion before the diagnosis, experiencing a clear conflict between the need to maintain secrecy and the representation of ideal behavior to achieve it, the adjustment to their condition was difficult. Another highlighted aspect was the maintenance of biosecurity measures to avoid infecting others or preventing behaviors that would expose the limitations. Examples include going out at night, consuming alcoholic beverages, or bathing in a river.



### **Topic 3: Family rejection or acceptance of my true self**

The acceptance-rejection duo defined the main narrative line in this area. To a large extent, this was due to two fundamental situations, the presence of stigmas associated with HIV and the family's attitude towards the orientation of the HIV-positive young person. As could be seen in the narratives of both heterosexual and homosexual participants, the family's approach to the diagnosis was tinged by beliefs related to sexual behavior, possible "aberrations" or other aspects left over from the global public dissemination of the HIV pandemic.

Although families appeared as an important element in the social support network, multiple verbalizations referred to the fact that this could not always be considered an ally, at least not in its full composition. Especially the male members of the family configurations, commonly of the traditional type, were pointed out as producers of negative experiences and conflicts, while, in the opposite case, especially mothers and sisters, as sources of support.

Another essential aspect of this sphere is that, although no significant projective richness appeared, the few joint goals enjoyed a high hierarchy as long as they did not interfere with the goals of the two spheres previously described. This meant that, despite the rejection of some members, the HIV-positive young people interviewed saw in the "family" an important space for fulfillment and support.

Finally, it became evident that this sphere presented a special relationship with the love sphere since the creation or maintenance of one's own family, even without the presence of children, was seen as an important goal for the participants. However, the fluctuation between positive/negative experiences referred to by the same inducers was maintained because the perceived impossibility of having children, at least in a "natural way", affected the participants considerably. It should be noted that only one participant had children before the infection (which was caused by infidelity), but at the time of the study, she was single and satisfied with her own family.

To conclude the description of the family-love relationship, it was noted that the status of a stable partner was highly desirable and as an extension of the vital needs of the personal sphere. In addition, negative experiences related to current legislation on adoption, protection of LGBTI and HIV-positive rights were described.

### **Theme 4: Partnership, loneliness and HIV**

Although at this stage of life, the planning of time, the arrival of the first child, and the exploration of different partners are aspects that can appear in a conflictive manner, the participants studied agreed that stability was the clear goal, while loneliness, a "necessary evil" when it could not be obtained. Due to the beliefs associated with HIV, having offspring did not appear as a relevant goal, and this was justified by verbalizations that reproduced the stigma of the death sentence or the impossibility mentioned above of adopting.

A particularly relevant aspect was the "shadow of secrecy", described by four participants whose partners did not initially know their HIV-positive status. In these cases, rather than mentioning what the other participants commented about life as a couple (including the three singles), the narratives were directed to the negative aspects related to biosafety, the secretive and limited lifestyle in terms of opportunities, and similar descriptions.

In the case of the three singles, loneliness is not perceived as a detriment to their happiness but as a desirable condition that favors their stability and emotional well-being. Therefore, the love sphere is subject to how the personal sphere is configured and regulated, the beliefs associated with HIV, and aspects that are specific to individual life trajectories.

In the case of participants with a partner, they emphasized that their status was a barrier to the relationship, especially to the spouse's happiness, but praised qualities related to understanding and acceptance. In these cases, the factors associated with the selection and duration of the partner relationship were marked by personal qualities, above others, such as economic solvency or physical attractiveness.

### **Theme 5: Society, daily life and isolation**

The socio-political sphere was seen as very limited and low hierarchy. Despite the growing importance given by other populations, HIV-positive young people showed little attraction to current news and described a marked rejection of monitoring the state of the country and social issues. As was the case in other spheres, HIV-positive young people stated that "keeping up to date" was a source of negative experiences. As mentioned several times, the tendency is towards isolation and non-participation in social activity or movements such as activism or of a religious nature.

Regarding the perception of belonging, experiences related to health promotion and disease prevention projects were identified but always marked by secrecy and isolation. In a general sense, social relations were categorized as of little importance, and there was a marked apathy toward social processes.

### **Theme 6: Tranquility and stable life**

Finally, the recreational culture sphere was identified as the most limited in terms of goals and hierarchy. As previously described, these results differ from those expected at this stage of life, but they make sense due to the influence of the personal sphere and its goals on the remaining spheres of the life project. Unlike what was diagnosed in other youth populations, the research participants rejected recreational modalities associated with parties or substance intake, as well as mentioned preferring others such as watching series and movies, reading, listening to their favorite artists or “old music”, etc.

In several participants, recreation was categorized as rest, demonstrating the subordination of this sphere to personal life and the maintenance of adherence. As a discrepant result concerning the relationships between spheres described above, these limitations were not experienced as negative; hence, cultural and recreational aspects, although they appeared as very low in the narratives, were considered positive elements of their daily lives.

### **Guidelines to consider in the design of orientation experiences for the promotion of life projects of HIV-positive young people**

From the discussion of the results and the thematic analysis carried out, guidelines were produced that the authors consider contributing to intentions and alternatives for the promotion of life projects in HIV-positive young people. Although these are far from generalizable and universal, based on contextual adaptations and the implementation of evaluation and diagnostic processes in each case, their consideration could act as an important starting point. The following are the general guidelines:

1. The uniqueness of the HIV-positive young person must be understood, as well as his or her experiences of the condition and the demands it places on him or her.
2. Identify the social processes where the presence of stigma and self-stigma act to the detriment of participation and individual well-being.
3. To promote processes of acceptance, commitment and empowerment that favor the transition towards a new identity configuration.
4. To guarantee an adequate accompaniment to the adaptation, the appearance of crises and the awareness of social beliefs that act against the emotional well-being and are reproduced by the HIV-positive young person.
5. Promote awareness of the objective, subjective, and inherited limitations in social reproduction.
6. To prepare professionals who are socially responsible for assisting HIV-positive young people in the identification of aspects related to the communication of the diagnosis, the treatment of situations of marginalization, or other similar situations.
7. To prepare seropositive young people to inform their condition, identify the adaptive needs related to their relationships with others, especially with their recent partner, and normal interaction with groups or individuals in contexts of ignorance of their condition.
8. Promote the strengthening of social support networks as long as they do not affect therapeutic adherence, as well as participation in health promotion and disease prevention projects is recommended.
9. The integration of HIV-positive young people into discussion groups or social projects should be gradual, ideally advised by a health specialist (psychologist or physician), and their participation should be reevaluated with some frequency.

## **CONCLUSIONS**

Comprehensive health care for young people living with HIV is an unavoidable need, so it is essential to recognize the presence of processes of marginalization, stigma, and self-stigma. Since adequate adherence to treatment in combination with HAART contributes to maintaining the health of these individuals, helping and accompanying them to chart a future in accordance with their vital needs and goals can favor their psychological well-being and quality of life.

This requires that they can access health services in an unprejudiced manner, as well as be oriented regarding the aspects that are significant to them. This requires raising awareness among health professionals, HIV-positive

people and their support networks, as well as public policy makers, of the need for spaces and alternatives that favor this comprehensive care.

For future studies, mixed designs are recommended, fundamentally aimed at integrating a deep and inductive understanding of the life situations of HIV-positive young people and the development of measurement instruments that contribute to the diagnosis and generalization of the results. In this last aspect, it is suggested not only to develop and validate questionnaires for the study of the life project and its spheres but also those categories that condition it, such as isolation, stigma or self-stigma.

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