

Communication of the diagnosis of HIV infection: experience of young people

Érika Eberline Pacheco dos Santos¹, Aline Cammarano Ribeiro¹, Stela Maris de Mello Padoin¹, Maria Clara da Silva Valadão², Cristiane Cardoso de Paula¹

1. Universidade Federal de Santa Maria, Santa Maria/RS, Brasil. 2. Hospital Universitário de Santa Maria, Santa Maria/RS, Brasil.

Abstract

This qualitative research aimed at identifying the elements of the communication process of HIV infection diagnosis in the experience of ten participants from Southern Brazil aged between 15 and 24 years old that was conducted via content analysis based on the theoretical categories of Lasswell's model. The channel was the medical consultation; the context was determined by the type of exposure (vertical or horizontal); the noises presented veiled issues and uncertainties; the failures involved situations that led the young person to suspect the diagnosis; and the effects involved immediate emotional reactions that dissipated over time. Communication in adolescence was punctual and triggered by family members with support from professionals, indicating the need to improve the communicative process. The communication of the HIV diagnosis is usually postponed by family members when it comes to children or adolescents, which violates the principle of autonomy by disregarding the right to know.

Keywords: Young adult. Adolescent. HIV. Acquired immunodeficiency syndrome. Health communication.

Resumo

Comunicação do diagnóstico de infecção pelo HIV: experiência de jovens

Esta pesquisa qualitativa foi conduzida com dez participantes da região Sul do Brasil com idade entre 15 e 24 anos e visou identificar os elementos do processo comunicativo do diagnóstico de infecção pelo HIV em sua experiência, por meio de análise de conteúdo a partir das categorias teóricas do modelo lasswelliano. O canal foi a consulta médica; o contexto foi determinado pelo tipo de exposição (vertical ou horizontal); os ruídos apresentaram questões veladas e incertezas; as falhas implicaram as situações que levavam o jovem a suspeitar do diagnóstico; e os efeitos envolveram reações emocionais imediatas que se dissipam com o tempo. A comunicação na adolescência foi pontual, indicando a necessidade de qualificar o processo comunicativo, e desencadeada por familiares com apoio de profissionais. A comunicação do diagnóstico de HIV geralmente é postergada pelos familiares quando se trata de criança ou adolescente, o que fere o princípio da autonomia, por desconsiderar o direito de saber.

Palavras-chave: Adulto jovem. Adolescente. HIV. Síndrome de imunodeficiência adquirida. Comunicação em saúde.

Resumen

Comunicación del diagnóstico de infección por VIH: experiencia de los jóvenes

Esta investigación cualitativa fue realizada con diez participantes de la región sur de Brasil con edades entre 15 y 24 años y tuvo como objetivo identificar los elementos del proceso comunicativo del diagnóstico de infección por VIH en su experiencia; a través del análisis de contenido a partir de las categorías teóricas del modelo lasswelliano. El canal fue la consulta médica, el contexto fue determinado por el tipo de exposición (vertical u horizontal); los ruidos presentaron preguntas veladas e incertidumbres, los fracasos implicaron las situaciones que llevaron al joven a sospechar el diagnóstico, y los efectos implicaron reacciones emocionales inmediatas que se disipan con el tiempo. La comunicación en la adolescencia fue puntual, indicando la necesidad de calificar el proceso comunicativo, y desencadenada por familiares con apoyo profesional. La comunicación del diagnóstico del VIH suele ser postergada por los familiares cuando se trata de niños o adolescentes, lo que perjudica el principio de autonomía, porque ignora el derecho a saber.

Palabras clave: Adulto joven. Adolescente. VIH. Síndrome de inmunodeficiencia adquirida. Comunicación en Salud.

The authors declare no conflict of interest.

Approval CEP 909.983

The human immunodeficiency virus (HIV) epidemic is recognized as a public health problem due to the individual and social impact of an infection with no cure, permeated by prejudice, uncertainty, and inequality¹. The percentage of diagnosis notifications in young people aged 15 to 19 and 20 to 24 years old, from 2009 to 2019, increased 64.9% and 74.8%, respectively². The prevalence of infection in young adults points to the juvenilization of the epidemic, adding to the number of children in the vertical exposure category in transition to adolescence and youth³ who, at some point in their lives, experience the communication of their diagnosis.

Regardless of exposure category and age, this moment has repercussions on the daily living of people with HIV and, in the case of young people, affects the beginning of their sexual life, adherence to treatment, motivation for self-care and containment of the disease⁴⁻⁶. Situations in which family members communicate the diagnosis, young people face barriers such as fear of negative psychological reactions, thus requiring support from health professionals⁷. According to a study conducted with young people, after the communication of the HIV diagnosis they begin to seek ways to overcome difficulties related to daily living with HIV⁸.

Most of the times these individuals suffer from the stigma of the infection, and although peer support can help them cope with negative emotions; support services are needed to help them cope with the disease⁹. It is crucial that post-disclosure care can offer comprehensive information on HIV prevention and sexual and reproductive health¹⁰. Thus, the infected person's communication process also considers emotional support, clarification regarding the context of relationships and sexual behavior, and access to supplies such as condoms¹¹.

Recommendations suggest HIV diagnosis to be communicated as a process¹², in a gradual and continuous way, ensuring the person the right to know their own condition, promoting well-being, and causing fewer negative effects. Given the complexity of this process, family members must have the ability to communicate the situation in a timely and clear manner. Moreover, the skills

of professionals are also needed, since, at times, they face ethical dilemmas between ensuring the young person's right to information and supporting the family¹³.

Such process also brings ethical challenges of disclosure according to the autonomy and informed decision of the young person¹⁴. It also includes a continuum of care to ensure the autonomy and commitment of family members, healthcare professionals, and sometimes members of the family's support network and peers⁵.

The recognition of autonomy by health professionals involves the need for young people to receive clear and accessible information that considers their understanding of the message, and it is important that there are subsidies for them to decide how to conduct their health and life¹⁵. This study is thus aimed at identifying the elements of the communication process of HIV infection diagnosis in the experience of young people. From the communication model proposed by Harold Lasswell^{16,17}, we intend to point out perspectives that improve and ethically subsidize the communication of the serologic condition

Method

This is a qualitative study, consistent with the type of research, which focuses on the meanings of relationships (stories, beliefs, representations, motives, perceptions), resulting from the social interpretation of experiences¹⁸. The data collection scenario was a specialized HIV care service linked to a university hospital located in the municipality of Santa Maria, state of Rio Grande do Sul (RS), Brazil. This hospital is part of the 4th Regional Health Coordination and is a reference in the region.

Participants were intentionally selected while awaiting medical consultation in the specialized service, according to the following inclusion criteria: age between 15 and 24 years, HIV diagnosis, and being under antiretroviral (ARV) therapy. They were included regardless of the exposure category, which included both sexual exposures, prevalent in the adolescence and youth, and vertical exposure, which tends to present greater challenges in communicating the diagnosis. The exclusion criterion was patients not knowing

their own diagnosis – cases in which the information was provided by a family member or caregiver.

Data collection was performed from March to June 2015 and, since then, two other objectives of this matrix project were met, focusing on the experience¹⁹ of young people and ARV use, as well as the expectation²⁰ with the treatment, using the phenomenological approach.

Face-to-face individual in-depth interviews were conducted in a private room where participants felt at ease. For this, we used a script with open questions based on the accumulated research experience with this population and on the HIV theme. Sessions lasted 40 minutes on average and were recorded – after agreement –, transcribed according to the original speech, and coded with the letter Y (young person) followed by a number (example: Y1).

The script considered aspects related to daily living and future plans, and the interviews began with an informal conversation. Thus, when the participant was more at ease, the interviewer would launch the topic of communicating the HIV status (or AIDS, disease, problem, virus – as named by the participant) and the care with treatment and health. The questions aimed at introducing the subject and allowing each young person to speak freely about their experience, being adapted to each interview.

The adjustments to the interviews do not refer to a pilot test, but to a sensitization study. This terminology epistemologically fits the qualitative approach to knowledge production, which considers the potential of questions to generate narratives around the research objective²¹.

There were no difficulties in data collection, which was conducted by one of the authors with experience in the theme of the study and training in interview techniques. Participants and the interviewer interacted, as the meetings were developed along with university extension activities promoted by the research group to which the interviewer was linked. The interviewer knew the young individuals and was known in the service, which improved the conduction of the interviews and the understanding of the statements, not hindering the participants' answers.

The number of participants was not determined in advance, but based on a concomitant

analysis of the data collection. Interviews were closed as soon as the response to the research objective was reached. There was no loss or withdrawal of participants during the study, just one refusal due to difficulties with public transportation to the city of origin.

In total, ten participants with the following characteristics were included in this study: three males, aged 16 to 19 years, and seven females, aged 17 to 22 years old. Six of them contracted the virus through vertical transmission, being one from cross breastfeeding. There was diversity as to the age at which they learned of the diagnosis and started treatment, and two were married and had children.

The thematic content analysis by theoretical category¹⁸ applied to the analytical referential presented an integrated and circular vision of the communication flow in its communication model^{16,17}. The considered categories were classified according to the elements of the communication process: sender, receiver, context, message, channel, noise, failures, and effects²³. Thus, the transcription of interviews was made in full, highlighting each element, and grouping and describing each statement in categories.

The bioethical aspects on research with human beings contemplated in Resolution 466/2012, of the National Health Council (CNS) were considered. To avoid risks and discomfort when talking about experiences, the interviews were started in a relaxed manner, with broader questions about personal data. If there was any discomfort, the interview would be terminated and the participant referred to the service team for assistance, under prior agreement between the researcher and the team. However, no interviews needed it.

Results

The elements of the communication process^{16,17} are presented according to the established categories: channel, context, noise, failures, and effects (Table 1). It is noteworthy that the “message” element referred to the diagnosis of HIV infection is inherent to all categories.

Table 1. Theoretical categories of the communicative process

Elements	Definition	Summary of the young people's testimonies
Channel	Means by which the message is communicated	Medical appointments
Context	Aspects of the lives of the people (senders and receivers) involved. Contemplates the set of circumstances in which the message to be sent is produced.	Exposure category (sexual or vertical transmission of HIV) Follow-up in specialized service Use of antiretroviral drugs Hospital admissions Opportunistic infections Death of biological parents due to AIDS
Noise	Situations that impair the way the message is understood. There are four types of communication noise: physical, physiological, psychological and semantic.	Physiological noise (failures in HIV testing and counseling) Semantic noise (hiding the truth)
Failure	It happens when the message is not communicated by the sender to the receiver.	Young people suspect the diagnosis because of antiretroviral use and consultations, and are vulnerable to accidental disclosure (when they find out on their own, inadvertently, or by others)
Effects	Repercussions after communication.	Over time, they got used to the diagnosis Became reassured to have treatment Feelings like fear, sadness, isolation for a while

As for the communication channel, in the case of two participants, the disclosure occurred through conversation between the physician (Y3, Y5), family member and the young person in consultation, when it was explained how HIV is transmitted and why to take antiretroviral drugs and go to consultations (Y1). For one young person, this communication occurred gradually and procedurally (Y6), whereas for two others it was made at a specific moment (Y2, Y8) in pregnancy or childbirth. The others (Y4, Y7, Y9, Y10) did not discuss the communication channel, as they found out about their diagnosis indirectly.

“My doctor took us (the young woman and her mother) to a small room and told us. They (professionals) said that (the transmission of HIV) it happened during breastfeeding, because I had it (HIV) since I was little (...)” (Y1).

“The doctor took me to the room and just told me” (Y3).

“The doctor talked a lot (...)” (Y5).

“They (the doctor and my grandmother) sat with me and talked to me nicely (...) it was little by little

(...) they explained to me why I come here and why I take medicine” (Y6).

“He (doctor) yelled from the hallway (of the delivery room at the time of my birth) to my mother (...) came into the room and said that I had the virus (HIV). Then he sent me back here (specialized service) and here they talked more to my mother” (Y8).

The context considered the factors influencing the disclosure or discovery of HIV serological status. Participants reported hospital admissions, opportunistic infections and death of biological parents from AIDS or stated that they had heard their parents talking to professionals about HIV and ARV medications. Those who had children indicated that pregnancy was decisive for communicating the diagnosis and, in cases of prenatal failure, the delivery.

“(I had) A very strong pneumonia (...) I was down for almost a month I think (...) they did exams (...) and discovered (HIV). I was about...14 (years) or so” (Y1).

“In pregnancy (I did the test) (...) I started (the treatment) almost in the middle of my pregnancy” (Y2).

"It was like a huge blow (the mother's death). I was 10 (years old). (...) I had already lost my father. And both doomed by the disease (AIDS). And soon after that I found out that I had HIV" (Y3).

"I found out because of a urine infection, I was very bad. (...) I did a lot of exams (...) I had the diagnosis" (Y5).

"When I started to study, then I learned about it when I was 10, 11 (years old), we already started to think" (Y7).

"I was pregnant (...). I knew when I gave birth to (child's name)" (Y8).

"I found out when they brought me here (specialized service), and I heard them (professionals) saying that I had to take the medicine to be well. (...) I was about 10, 11 years old" (Y9).

"Because my mother passed away and then I found out" (Y10).

There was noise in the communication in the cases in which the truth was hidden or obscured in some way. Certain experiences characterized semantic noise, as in the moment the participants questioned why they had to take the medication and their family member answered "one day you will know" (Y3) or when the professional told them that the young person has a "virus" (Y1), but didn't say it was HIV. In Y2's situation this noise was physiological, as even having done several HIV tests during pregnancy, the young woman could not be sure if she was infected and the diagnosis was confirmed only after the birth of the child.

"They said I had to take them (ARVs), that I had to do it, that's all. I asked why and they told me: 'one day you will know'" (Y3).

"She (the doctor) said that I had a problem, I had a virus. At the time she said it, I couldn't imagine what it was, I thought it was something else, but later she told me (that I had HIV)" (Y1).

"During my pregnancy, when I went to do the test, the results of my exams always came as indeterminate. Then they sent me here (service). And only after I got him (the child), they showed that I had HIV" (Y2).

Communication failure occurs when the transmission of the message does not happen. It was expressed by young people via reports of situations that led them to suspect the diagnosis, such as ARV use, routine visits to the hospital, family members' conversations with health professionals about HIV, or reading the diagnosis in some hospital document. In the accounts of Y6 and Y7, it is noted that the participants considered themselves immature to understand the diagnosis and, because of this, their family members did not reveal the diagnosis to them, fearing their reaction.

"The thing is that I didn't know (why they went to the hospital) (...). To me it felt like we were just going out (going to the hospital) because I didn't know, I was very young, but mom was not (elderly adoptive mother) and she didn't have the courage to tell me for fearing of my reaction" (Y6).

"I didn't know what it was. (...) I used to come (to the hospital) and stayed in the little room playing, thought my mother who was going (to consult). I would stay 'I'll stay here (in the little room)' but she (mother) would say 'oh no, you have to come with me, it's you who is going to see her, ok? (...) my mother used to bring me (to the hospital), I was suspicious (...). I came to the doctor, I didn't know why, since I was little and didn't get it" (Y7).

"I already suspected (...). I was taking them (ARVs) since I was five. I didn't know why, but I took them" (Y3).

"I found out by reading a piece of paper and I realized I had it - 'patient has to be treated for HIV' (it was written on the paper) - I thought, yes, 'this person is me' (...). Then I went to the nursing home and found out, for there were other people in my situation (having HIV). (...) I went the doctor every day and I didn't know why" (Y4).

"I saw mom talking about coming here (to the hospital). Mother didn't tell me about it (HIV), but sometimes I heard her talking (to other people). (...) then I heard them (the professionals) saying that I had this disease (AIDS)" (Y9).

The effect of communication involved responses from the professional, the family and the child. For young people, these responses refer

to the reactions they had after the discovery of the HIV diagnosis, which were negative for some, characterized by feelings such as fear, shock, sadness, isolation, depression and non-acceptance for some time. Other young people perceived the discovery as normal and over time became accustomed to the diagnosis, being reassured of the existence of therapy that enables them to be healthy.

“At the time I didn’t accept it, but then I understood. I never thought it would happen to me! And that I would have to take medicine and do the treatment” (Y1).

“I was afraid (of transmitting HIV to the baby), because I started taking (ARVs) in the eighth month” (Y2).

“When I found out, I isolated myself. As time went by, I opened up, there were days I would get a little depressed, and then I would think about stopping taking the medication” (Y3).

“It was normal (the discovery of the diagnosis), I wasn’t scared, I didn’t get rebellious, I didn’t do anything wrong. I just accepted it! As I accept myself until today (...). I didn’t have any surprise” (Y4).

“In the beginning (when she received the HIV diagnosis), it was a shock until I came to my senses – ‘gee, I have a disease!’ – it took me a while. (...) then I was very calm. I was not pessimistic, I was optimistic, because I am sick, there is no way back, but there is treatment” (Y5).

“I was sad, you know (when they told me the diagnosis of HIV). (...) for me, it was a novelty. I didn’t believe it, I didn’t like it. I continued to take my normal medication. I understood that for me to be healthy, to live well, I needed to take these medicines” (Y6).

“I don’t know, now I got used to it (going to the appointments), it is part of it” (Y7).

“It was a shock (finding out the diagnosis). A shock like all patients get when they discover something serious. But afterwards it was ok” (Y8).

“Sometimes I don’t even worry about it (the HIV diagnosis). (...) sometimes I willfully forget it” (Y9)

Discussion

The Convention on the Rights of the Child guarantees children, adolescents and young people the right to receive information about their diagnosis, medical condition, treatment and prognosis, respecting their level of understanding²⁵. This guarantee addresses access to information aimed at promoting the interests of these developing persons, especially their physical, emotional, cognitive, and social well-being¹². Each individual has the right to receive information about their condition in order to make informed decisions²⁶.

By analyzing the communication of the HIV infection diagnosis from the elements of the communicative process, this study enables the understanding of the experience of young people. Thus, it offers subsidies to qualify the monitoring of this process and guarantee the right to know one’s own HIV status, considering autonomy and self-care.

Even if for the participants of this study the communication of the HIV diagnosis occurred in a single moment, studies with parents and health professionals point out that it must be done in a procedural way²⁷⁻³², with the support of a multiprofessional team and respect for the timing of children and adolescents, according to their questions^{28,33-34}. In addition, it is important that the individual knows the diagnosis as early as possible, preferably during childhood in situations of vertical transmission. This allows them to learn early on issues that permeate their HIV status, so that negative feelings such as fear, anxiety, shame, and guilt become less relevant.

Autonomy enables people to make choices about their own lives, and is understood as part of human dignity. Regarding children, adolescents, and young people living with HIV, the principle of autonomy is respected when they are informed and learn about their diagnosis in a timely manner. Thus, offering truthful and appropriate information to the developmental stage is a strategy for caring for these people.

As they know their diagnosis, the need for treatment, and importance of adherence, they become less vulnerable to getting sick. Moreover, the knowledge of the serological

situation enables the understanding, acceptance, and coping with this chronic condition³⁵. Thus, it is emphasized that the right of young people is violated if they are unaware of the health and disease process that affects them, which makes the communication of the diagnosis crucial for the continuity of HIV care.

The *Universal Declaration on Bioethics and Human Rights*, regarding the principle of autonomy and individual responsibility, states that *the autonomy of individuals to make decisions must be respected if they can be responsible for such decisions and respect the autonomy of others. Special measures should be taken to protect the rights and interests of individuals who are not capable of exercising autonomy*³⁵. Thus, young people have the right to receive objective information concerning their lives and to progressively exercise the responsibilities that will allow them access to autonomy.

To ensure the right to know the diagnosis and the principle of autonomy, it is important to consider personal and institutional sources of support in the communicative process. Furthermore, it must be taken into account that communication can occur over a period of time, during several conversations, in different environments and with different people, or in response to new events – for example, when the person's health is affected by HIV and/or a family member who is also HIV-positive becomes ill¹².

To help family members and professionals understand the information, videos, toys, drawings, books, brochures, analogies, and even computer tools such as social networks and websites, among others, can be used^{30,32,34,36,37}. Some family members also communicate their own HIV diagnosis first, so that young people realize the importance of ARV use and that it is possible to live with the virus while maintaining quality of life, projects, and plans for the future³³.

According to international¹² and Brazilian³⁸ recommendations, communication of the diagnosis should be individualized, considering the particularities of each child, adolescent, or young person, including level of understanding, stage of development, and social and family contexts. The communication channel needs to convey reliable guidance to the population, especially in such uncertain times when there

is excessive production and dissemination of information – a phenomenon called infodemic – sometimes false, unethical, and irresponsible.

In the case of children, the most effective channel for the disclosure of the diagnosis is the playful one, always avoiding the use of striking words, such as HIV. For adolescents, the disclosure can be virtual and procedural, with a direct approach, for understanding and reflection on the disease. The virtual means involves computer tools, as well as dialogues to clarify doubts, while the procedural means use questions in which clues are given so that adolescents discover their diagnosis, starting from what they already know.

During the HIV communication process, issues regarding HIV transmission^{29,33,39} medication intake, healthcare follow-up, and routine laboratory tests should be addressed. Moreover, constant evaluation of children and adolescents' understanding of the information is required³³.

The communication of the diagnosis is not an isolated event, but a step in the process of adaptation of the child, adolescent, or young person, as well as of family members and/or caregivers and the community to the disease and the life challenges it brings. It is a process that goes towards the development of autonomy, permeating a permanent and progressive educational path of co-responsibility between family, health and education services, and society to form an autonomous and independent subject in adult life⁴⁰.

Regarding the context, the reports of the experience of the participants revealed that the diagnosis was communicated in specific situations of follow-up in the specialized service, causing mistrust regarding the serology for HIV (Y1, Y3, Y6). For young people who were still not undergoing treatment (Y5, Y8), it was done punctually. Thus, it is understood that the communication of the HIV diagnosis depends on the context in which young people are inserted.

Studies converge as to the factors that triggered the knowledge of the HIV diagnosis by these young people, such as pregnancy⁴¹, death of a relative⁴², use of medication⁴³, and treatment, or the feeling of being sick⁴⁴. The discovery during pregnancy or childbirth makes this moment complex, because women

have difficulties in accepting the diagnosis and the impediment to breastfeeding and adhering to treatment. Thus, they choose to hide their HIV status and use mechanisms such as not thinking about the disease, isolating themselves and looking to their children, family, and health professionals for help to cope with this moment⁴¹.

When the disclosure occurs by the death of a relative (Y10), a study also shows situations in which adolescents with HIV use ARVs believing it is to treat another disease, discovering their own diagnosis and that of a relative only after the death⁴². In addition, questions from children and adolescents about taking the medication can be considered clues to revealing them their HIV status and serology. Regarding the discovery of the disease, an epidemiological study⁴⁴ showed that this situation motivates the person to seek healthcare services and perform the HIV test, which evidences the search for one's own well-being.

The circumstances that influenced the communication of the HIV diagnosis were varied, denoting that this process depends on the context experienced by the child, adolescent or young person. Moreover, in the context element of communication, the principle of autonomy can also be observed when they question the use of medicines and their HIV status and express the desire to hide this information³⁵. This knowledge allows the young person the autonomy to make choices related to self-care and communication to others, with decisions made based on emotional, instrumental, informational, and cognitive support.

Avoiding the name of the disease using nicknames and synonyms, or not offering explanations for questions about the use of medication are behaviors that generate noise, especially when communicating with children, impairing the understanding of the message. Such attitudes of family members have different motivations, including protecting the child from suffering caused by the disease or its prognosis.

Other reasons for delaying the communication of the diagnosis are the emotional reactions and insecurity of family members about the understanding of information by children, especially the diagnosis. Concern about stigma and fear of blame in situations of vertical transmission also exists^{29,33,34}.

Some healthcare professionals find it worrisome that family members hide the truth from the child³⁴; others prefer the information to be softened in order not to cause hopelessness⁴⁵. To understand this situation, one must take into account that family members and/or caregivers fear that children will face stigma, creating a major barrier to communication. This fear often delays the decision to disclose the diagnosis, postponing accountable decisions based on the young persons' autonomy.

When the sender is a family member, miscommunication is often due to fear of negative emotional consequences⁴⁶, the fact that the diagnosis is taboo³⁰ and the feeling that the receiver is not ready to be communicated²⁸. In the case of children and adolescents, from the perspective of health professionals, the failures occur because they are suspicious of the diagnosis, even without having been communicated⁵.

This kind of situation is preventable, because, if the family represents the receiver (child/adolescent) bond and is prepared with the help of health professionals, the communication of the infection can be less traumatic and does not result in situations of accidental disclosure³⁷, which can trigger negative emotional reactions and resistance to treatment. Communication failures imply the heteronomy of the young person, that is, the subjection of the young person to the will of others, whether family members or professionals, who postpone or silence the young person's right to know the diagnosis. Therefore, failures in the communication process result in the absence of autonomy to assume responsibilities and define life projects.

By recognizing that vulnerability does not annul autonomy or capacity⁴⁷, professionals reiterate that the right of children and adolescents to information is one of the most recurrent in daily healthcare, revealing the importance of promoting autonomy and person-centered care⁴⁸. Even if parents want to protect their children by hiding information that they consider distressing, overwhelming, or harmful, healthcare professionals have a duty to make them aware that this kind of attitude can be more harmful and contrary to the best interests of the child. Honoring the desire for protection can isolate the person, who will not have the support of caregivers to discuss their feelings, fears, and anxieties.

Effects of the communication process are feelings related to the diagnosis: anxiety, fear of dying soon; feeling of isolation, feeling that they are the only people with HIV; and fear of being stigmatized. This intensifies when they understand that it is an incurable disease and worry about having to take ARVs for the rest of their lives^{5,30,49}. Thus, when they learn the truth, young people become frightened and afraid for having something that others do not, deciding to hide their condition for fear of people's reaction.

When they recognize that such situation brings rules and limits, they accept to take the medicines and, with time, learn to take care of themselves. They understand that they are normal people but, at the same time, different due to having the virus, requiring medicines and visits to the hospital⁵⁰.

There is evidence that the communication of the diagnosis by allowing the patient to participate in their own care brings health benefits, such as improvement in the notion of responsibility, awareness of health promotion, adherence to treatment and biopsychosocial development. Moreover, there is little evidence of psychological or emotional damage resulting from communication, and the immediate emotional reactions dissipate with time¹².

The right to information is essential for autonomy. Therefore, since the communication of the HIV diagnosis occurred late or punctually for the young people in this study, one may infer that the right to autonomy was violated, which can have negative effects on self-care.

In addition to the benefits for the persons themselves, the diagnostic communication has a positive impact on family members and/or caregivers and health service professionals. For family members, it strengthens the relationship with the young persons and improves psychological aspects, such as feelings of guilt and lack of self-confidence. For professionals, it reduces absenteeism from appointments and increases participation in support groups, as young people become more committed to self-care³⁸.

The sender is the one who communicates and the receiver – in this case, the young persons – the ones who receive the message. In some situations, the role of sender was played by family

members with the help of physicians (Y1 and Y6); in others, only by professionals (Y2, Y3, Y5, Y8). Nevertheless, there were no reports from the young people about having been communicated only by family members.

For some young people, there was no sender (Y5, Y7, Y9, Y10), because they discovered the diagnosis as they matured, in the transition from childhood to adolescence, through events such as: death of parents, listening to conversations between the team and family members, living with other young people with the same diagnosis and reading a hospital document. It is recommended that the family always be the sender, with the support of health professionals.

Communication of the diagnosis should be done by a person with a relationship with the individual, mainly the mother or father, but it is common for grandparents, uncles, or older siblings to do this. Regardless of the family member, the participation or guidance of the health service, especially the multiprofessional team, is relevant, so that each one contributes according to their competencies, either in the preparation of the family members or in the communication itself. Health service professionals must be prepared to listen, to approach the subject calmly, to be sensitive when communicating the difficult news, to provide comfort, consolation and confidence, and to develop a bond, considering feelings, concerns, and consequences⁵¹.

This study was limited to the experience of young people who were doing health monitoring in a public HIV reference service linked to the Unified Health System (SUS) in southern Brazil. However, the results presented can be considered for evidence-based practice in settings with similar characteristics. Thus, other studies may analyze different services and regions, revealing other aspects and contributing to the understanding of HIV as a theme.

Final considerations

The communication process of the HIV infection diagnosis in the experience of young people had, in the sender category, family members with support from professionals and, sometimes, only professionals. Communication was mostly

developed during adolescence, from dialogue with family members or during consultations at the health service. However, the communication of the diagnosis happened in a single moment of information and in diverse and complex triggering contexts, such as pregnancy, opportunistic infections, hospital (re)admissions and death of biological parents. These situations diverge from the recommendation that a process be set up to promote well-being and minimize negative effects.

The semantic and physiological noises were permeated with veiled questions and uncertainties. The failures prevented the right to know by omission of information or implied the discovery of the diagnosis by third parties or indirectly, such as listening to someone else's conversations or by reading information in service records or prescriptions, for example. The effects resulting from this process were expressed by fear, sadness, and non-acceptance or disturbance resulting from the understanding of the infection and treatment and were related to the way it was developed.

To guarantee the right to know the diagnosis in a timely manner, the process involves ethical commitment from the senders of such communication, preferably the family with the support of health professional(s), especially those with a link to the young person. To do so, it is necessary to invest in the development of the family's skills, so that they understand the importance and benefits of sharing information and strategies to communicate clearly and gradually.

Similarly, professional development is needed in order to minimize ethical dilemmas, such as paradoxical situations in which the family decides to omit the young person's diagnosis, contrary to the right to know, or when the young person wishes to disclose it to a third party and the family imposes to keep it as a secret. Overcoming these challenges and dilemmas makes it possible to qualify this process and promote family support and continuous patient care, considering their experience, in order to avoid failures, noise, and negative effects.

We thank Dr. Bruna Pase Zanon and Dr. Luiza Cremonese for their contribution in applying the Lasswellian model to the database analysis.

References


1. Miziara LAF, Andrade SMO. O significado do HIV/Aids na vida de crianças e adolescentes que vivem com a doença. *Bol Acad Paul Psicol* [Internet]. 2016 [acesso 16 fev 2021];36(90):16-30. Disponível: <https://bit.ly/2Z9UBi6>
2. Brasil. Ministério da Saúde. Boletim Epidemiológico AIDS/DST [Internet]. 2020 [acesso 16 fev 2021];(n esp). Disponível: <https://bit.ly/3jqRPwd>
3. Amaral RS, Carvalho STRF, Silva FMAM, Dias RS. Soropositividade para HIV/AIDS e características sociocomportamentais em adolescentes e adultos jovens. *Rev Pesq Saúde* [Internet]. 2017 [acesso 16 fev 2021];18(2):108-13. Disponível: <https://bit.ly/3Bf03hf>
4. Namukwaya S, Papparini S, Seeley J, Bernays S. "How do we start? And how will they react?": disclosing to young people with perinatally acquired HIV in Uganda. *Front Public Health* [Internet]. 2017 [acesso 18 fev 2021];5:343. DOI: 10.3389/fpubh.2017.00343
5. Okawa S, Mwanza-Kabaghe S, Mwiya M, Kikuchi K, Jimba M, Kankasa C *et al.* Adolescents' experiences and their suggestions for HIV serostatus disclosure in Zambia: a mixed-methods study. *Front Public Health* [Internet]. 2017 [acesso 18 fev 2021];5:326. DOI: 10.3389/fpubh.2017.00326
6. Gabbidon K, Chenneville T, Peless T, Sheared-Evans S. Self-disclosure of HIV status among youth living with HIV: a global systematic review. *AIDS Behav* [Internet]. 2020 [acesso 18 fev 2021];24(1):114-41. DOI: 10.1007/s10461-019-02478-9
7. Britto C, Mehta K, Thomas R, Shet A. Prevalence and correlates of HIV disclosure among children and adolescents in low-and middle-income countries: a systematic review. *J Dev Behav Pediatr* [Internet]. 2016 [acesso 18 fev 2021];7(6):496-505. DOI: 10.1097/DBP.0000000000000303

8. Silva LAV, Duarte FM, Alves GR. Sociabilidades “positivas” em rede: narrativas de jovens em torno do HIV/ Aids e suas tensões cotidianas. *Physis* [Internet]. 2017 [acesso 18 fev 2021];27(2):335-55. DOI: 10.1590/S0103-73312017000200009
9. Small E, Nikolova SP, Zhou Y, Okumu M. Exploring factors associated with HIV secondary stigma among adolescents and young adults in Uganda: a cross-sectional study. *Glob Public Health* [Internet]. 2021 [acesso 19 fev 2021];6:1-12. DOI: 10.1080/17441692.2020
10. Gitahi N, Camlin C, Mwanja V, Ngure K, Auerswald C, Bukusi E. Psychosocial needs among older perinatally infected adolescents living with HIV and transitioning to adult care in Kenya. *PLoS One* [Internet]. 2020 [acesso 19 fev 2021];15(7):e0233451. DOI: 10.1371/journal.pone.0233451
11. Grainger C. Understanding disclosure behaviours in HIV-positive young people. *J Infect Prev* [Internet]. 2017 [acesso 10 fev 2021];18(1):35-9. DOI: 10.1177/1757177416680871
12. World Health Organization. Guideline on HIV disclosure counselling for children up to 12 years of age [Internet]. Geneva: WHO; 2011 [acesso 19 fev 2021]. Disponível: <https://bit.ly/3C5g0Ys>
13. Watermeyer J. “Are we allowed to disclose?”: a healthcare team’s experiences of talking with children and adolescents about their HIV status. *Health Expect* [Internet]. 2015 [acesso 19 fev 2021];18(4):590-600. DOI: 10.1111/hex.12141
14. Negrini SFBM. Revelação do diagnóstico de HIV/AIDS na infância: impactos, cotidiano e perspectivas de jovens infectados verticalmente [tese] [Internet]. São Carlos: Universidade Federal de São Carlos; 2017. Disponível: <https://bit.ly/3jphIC2>
15. Campos A, Oliveira D. A relação entre o princípio da autonomia e o princípio da beneficência (e não-maleficência) na bioética médica. *RBEP* [Internet]. 2017 [acesso 10 de set 2021];(115):13-45. DOI: 10.9732/P.0034-7191.2017V115P13
16. Lasswell HD. Communications research and public policy. *Public Opin Q* [Internet]. 1972 [acesso 19 fev 2021];36(3):301-10. DOI: 10.1086/268012
17. Lasswell HD. The structure and function of communication in society. *İletişim Kuram ve Araştırma Dergisi* [Internet]. 2007 [acesso 10 fev 2021];(24):215-28. Disponível: <https://bit.ly/3Gjnp98>
18. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. São Paulo: Hucitec; 2014.
19. Santos ÉP, Ribeiro AC, Langendorf TF, Paula CC, Padoin SM. Vivências de jovens em terapia antirretroviral para o HIV: estudo fenomenológico. *Av Enferm* [Internet]. 2019 [acesso 11 nov 2021];37(3):323-32. DOI: 10.15446/av.enferm.v37n3.78804
20. Ribero AC, Motta MGC, Senhem GD, Zanon BP, Santos EEP, Mutti CF. Experiences of adolescents with HIV: perspectives for improving health care. *Research, Society and Development* [Internet]. 2020 [acesso 11 nov 2021];9(7):e415974194. DOI: 10.33448/rsd-v9i7.4194
21. Moré CLOO. A “entrevista em profundidade” ou “semiestruturada”, no contexto da saúde: dilemas epistemológicos e desafios de sua construção e aplicação [Internet]. In: Atas do 4º Congresso Ibero-Americano em Investigação Qualitativa e do 6º Simpósio Internacional de Educação e Comunicação; 5-7 ago 2015; Aracaju. Aveiro: Ludomedia; 2015 [acesso 10 set 2021]. Vol. 3. p. 126-31. Disponível: <https://bit.ly/3m4oNEY>
22. Minayo MCS. Amostragem e saturação em pesquisa qualitativa: consensos e controvérsias. *Revista Pesquisa Qualitativa* [Internet]. 2017 [acesso 19 fev 2021];5(7):1-12. Disponível: <https://bit.ly/3nfUkm9>
23. Martino LMS. Teoria da comunicação: ideias, conceitos e métodos. Petrópolis: Vozes; 2017.
24. Brasil. Ministério da Saúde. Resolução nº 466, de 12 de dezembro de 2012. Aprova diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. *Diário Oficial da União* [Internet]. Brasília, 12 dez. 2012 [acesso 19 fev 2021]. Disponível: <https://bit.ly/3m1Zwuw>
25. Fundo das Nações Unidas para a Infância. Convenção sobre os direitos da criança [Internet]. 1989 [acesso 10 set 2021]. Disponível: <https://uni.cf/3pqxSto>
26. South Africa. National Department of Health. Disclosure guidelines for children and adolescents in the context of HIV, TB and non-communicable diseases [Internet]. Pretoria: NDH; 2016 [acesso 10 set 2021]. Disponível: <https://bit.ly/3nj2WC2>


27. Ekstrand ML, Heylen E, Mehta K, Sanjeeva GN, Shet A. Disclosure of HIV status to infected children in South India: perspectives of caregivers. *J Trop Pediatr* [Internet]. 2018 [acesso 19 fev 2021];64(4):342-7. DOI: 10.1093/tropej/fmx079
28. Hayfron-Benjamin A, Obiri-Yeboah D, Ayisi-Addo S, Siakwa PM, Mupepi S. HIV diagnosis disclosure to infected children and adolescents; challenges of family caregivers in the Central Region of Ghana. *BMC Pediatr* [Internet]. 2018 [acesso 11 fev 2021];18:365. DOI: 10.1186/s12887-018-1330-5
29. Murnane PM, Sigamoney SL, Pinillos F, Shiau S, Strehlau R, Patel F *et al.* Extent of disclosure: what perinatally HIV-infected children have been told about their own HIV status. *AIDS Care* [Internet]. 2017 [acesso 11 fev 2021];29(3):378-86. DOI: 10.1080/09540121.2016.1224310
30. Zanon BP, Paula CC, Padoin SMM. Revelação do diagnóstico de HIV para crianças e adolescentes: subsídios para prática assistencial. *Rev Gaúch Enferm* [Internet]. 2016 [acesso 11 fev 2021];37(n esp):e2016-0040. DOI: 10.1590/1983-1447.2016.esp.2016-0040
31. Lencha B, Ameya G, Minda Z, Lamessa F, Darega J. Human immunodeficiency virus infection disclosure status to infected school aged children and associated factors in bale zone, Southeast Ethiopia: cross sectional study. *BMC Pediatr* [Internet]. 2018 [acesso 11 fev 2021];18:356. DOI: 10.1186/s12887-018-1336-z
32. Myburgh H, Calitz E, Railton JP, Maluleke C, Mashao E, Ketelo P *et al.* Breaking down barriers to tell: a mixed methods study of health worker involvement in disclosing to children that they are living with HIV in rural South Africa. *J Assoc Nurses AIDS Care* [Internet]. 2018 [acesso 11 fev 2021];29(6):902-13. DOI: 10.1016/j.jana.2018.04.009
33. Lorenz R, Grant E, Muyindike W, Maling S, Card C, Henry C, Nazarali A. Caregivers' attitudes towards HIV testing and disclosure of HIV status to at-risk children in rural Uganda. *PLoS One* [Internet]. 2016 [acesso 11 fev 2021];11(2):e0148950. DOI: 10.1371/journal.pone.0148950
34. Sariah A, Rugemalila J, Somba M, Minja A, Makuchilo M, Tarimo E *et al.* "Experiences with disclosure of HIV-positive status to the infected child": perspectives of healthcare providers in Dar es Salaam, Tanzania. *BMC Public Health* [Internet]. 2016 [acesso 11 fev 2021];16:1083. DOI: 10.1186/s12889-016-3749-7
35. Motta MGC, Kinalski DDF, Schneider V, Antunes BS, Evangelista GT, Costa VM. Participação no cuidado em saúde: a voz da criança e do adolescente que vivem com HIV. *Sustinere* [Internet]. 2020 [acesso 10 set 2021];8(2):417-36. DOI: 10.12957/sustinere.2020.48012
36. Klingberg S, King R, Seeley J, Lubwama R, Namuganga M, Nabiryo B *et al.* Courage and confidence to stop lying: caregiver perspectives on a video to support paediatric HIV disclosure in Kampala, Uganda. *Afr J AIDS Res* [Internet]. 2018 [acesso 15 fev 2021];17(3):273-9. DOI: 10.2989/16085906.2018.1521850
37. McHenry MS, Apondi E, McAteer CI, Nyandiko WM, Fischer LJ, Ombitsa AR *et al.* Tablet-based disclosure counselling for HIV-infected children, adolescents, and their caregivers: a pilot study. *Afr J AIDS Res* [Internet]. 2018 [acesso 15 fev 2021];17(3):249-58. DOI: 10.2989/16085906.2018.1509101
38. Brasil. Ministério da Saúde. Protocolo Clínico e Diretrizes Terapêuticas para manejo da Infecção pelo HIV em crianças e adolescentes [Internet]. Brasília: Ministério da Saúde; 2018 [acesso 10 set 2021]. Disponível: <https://bit.ly/3C6kY75>
39. Galano E, De Marco MA, Succi RCM, Silva MH, Machado DM. Interviews with family members: a fundamental tool for planning the disclosure of a diagnosis of HIV/aids for children and adolescents. *Ciênc Saúde Colet* [Internet]. 2012 [acesso 10 fev 2021];17(10):2739-48. DOI: 10.1590/S1413-81232012001000022
40. Paiva MLSC. O processo de (in)dependência do adulto jovem. *Cadernos CERU* [Internet]. 2020 [acesso 10 set 2021];31(2):149-56. DOI: 10.11606/issn.2595-2536.v31i2p149-156
41. Fernandes PKRS, Miranda KCL, Rodrigues DP, Vasconcelos LDPG. Revelação diagnóstica para o HIV no pré-natal: dificuldades e estratégias de enfrentamento das mulheres. *Rev Enferm UERJ* [Internet]. 2017 [acesso 10 fev 2021];25:e12114. DOI: 10.12957/reuerj.2017.12114
42. Agostini R, Maksud I, Franco T. "Essa doença para mim é a mesma coisa que nada": reflexões socioantropológicas sobre o descobrir-se soropositivo. *Saude Soc* [Internet]. 2017 [acesso 10 fev 2021];26(2):496-509. DOI: 10.1590/s0104-12902017170072

43. Motta MGC, Ribeiro AC, Issi HB, Poletto PMB, Pedro ENR, Wachholz NT. Diagnosis disclosure to children and adolescents living with HIV/AIDS: implications for the family caregiver. *Rev Enferm UERJ* [Internet]. 2016 [acesso 10 fev 2021];24(3):e4787. DOI: 10.12957/reuerj.2016.4787
44. Ribeiro LCS, Freitas MIF, Tupinambás U, Lana FCF. Diagnóstico tardio de infecção pelo vírus da imunodeficiência humana e fatores associados. *Rev Latinoam Enfermagem* [Internet]. 2020 [acesso 10 fev 2021];28:e3342. DOI: 10.1590/1518-8345.4072.3342
45. Afonso SBC, Minayo MCS. Relações entre oncohematopediatras, mães e crianças na comunicação de notícias difíceis. *Ciênc Saúde Colet* [Internet]. 2017 [acesso 20 fev 2021];22(1):53-62. DOI: 10.1590/1413-81232017221.14592016
46. Kalembo FW, Kendall GE, Ali M, Chimwaza AF. Socio-demographic, clinical, and psychosocial factors associated with primary caregivers' decisions regarding HIV disclosure to their child aged between 6 and 12 years living with HIV in Malawi. *PLoS One* [Internet]. 2019 [acesso 20 fev 2021];14(1):e0210781. DOI: 10.1371/journal.pone.0210781
47. Albuquerque A. Ombudsman do paciente: direitos nos cuidados em saúde. *Rev. bioét. (Impr.)* [Internet]. 2018 [acesso 10 set 2021];26(3):326-32. DOI: 10.1590/1983-80422018263251
48. Eler K, Albuquerque A. Direitos humanos da paciente criança. *Cad Ibero Am Direito Sanit* [Internet]. 2019 [acesso 10 set 2021];8(1):36-52. DOI: 10.17566/ciads.v8i1.509
49. Havermans T, Tack J, Vertommen A, Proesmans M, Boeck K. Breaking bad news, the diagnosis of cystic fibrosis in childhood. *J Cyst Fibros* [Internet]. 2015 [acesso 20 fev 2021];14(4):540-6. DOI: 10.1016/j.jcf.2014.12.005
50. Brum CN, Paula CC, Padoin SMM, Souza IEO, Neves ET, Zuge SM. Revelação do diagnóstico de HIV para o adolescente: modos de ser cotidiano. *Esc Anna Nery Ver Enferm* [Internet]. 2015 [acesso 20 fev 2021];19(4):679-84. DOI: 10.5935/1414-8145.20150091
51. Zanon BP, Cremonese L, Ribeiro AC, Padoin SMM, Paula CC. Comunicação de más notícias em pediatria: revisão integrativa. *Rev Bras Enferm* [Internet]. 2020 [acesso 15 fev 2021];73(supl 4):e20190059. DOI: 10.1590/0034-7167-2019-0059

Érika Eberline Pacheco dos Santos – PhD student – erikaeberline@hotmail.com

 0000-0002-2130-4228

Aline Cammarano Ribeiro – PhD – aline.cammarano-ribeiro@ufsm.br

 0000-0003-3575-2555


Stela Maris de Mello Padoin – PhD – stela.padoin@ufsm.br

 0000-0003-3272-054X

Maria Clara da Silva Valadão – PhD – mclaravaladao@yahoo.com.br

 0000-0002-6252-3152

Cristiane Cardoso de Paula – PhD – cristiane.paula@ufsm.br

 0000-0003-4122-5161

Correspondence

Cristiane Cardoso de Paula – Universidade Federal de Santa Maria. Av. Roraima, 1000, prédio 26, sala 1.336, Cidade Universitária CEP 97105-900. Santa Maria/RS, Brasil.

Participation of the authors

Érika Eberline Pacheco dos Santos and Stela Maris de Mello Padoin conceived the project, researched the literature on the subject, and collected the data. Érika Eberline Pacheco dos Santos, Aline Cammarano Ribeiro, Stela Maris de Mello Padoin, and Cristiane Cardoso de Paula analyzed the data and wrote the article, and with Maria Clara da Silva Valadão performed the final revision.

Received: 2.28.2021

Revised: 8.31.2021

Approved: 10.19.2021