Original Article

PERSONAL COMMUNICATION PSYCHOLOGICAL APPROACH AND RESILIENCE IN PEDIATRIC HIV

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SUMMARY
When dealing with disclosure, the primary function of the approaching process is to help each patient build a personal meaning of what, in the field of health, we call adherence to treatment. Some of our patients display these psychic processes more firmly; others start them and stop at some point, and a remaining group never starts them, remaining in a merely passive posture. These differences probably depend on the family environment and the emotional resources (the willingness to resilience) that are available in each case. With our approaching process, we intend to respect and not overwhelm these differences.

Key words: resilience HIV AIDS Pediatrics.

INTRODUCTION

Many years ago, when I began my clinical practice at the hospital, and I was trying to find certain parameters to specify my specific function, it was frequent that one of the most experienced pediatricians asked me for information about the "psychological structure" of the patients we attended to. newspaper. At his insistence, I felt faced with a situation of difficult exit, since the eventual responses that I could concoct to that demand contained a psychoanalytic language (for example: referring to a psyche in constitution, or to certain drives and identifications, etc.) , which gave me the impression that it was not what that doctor wanted to receive from me.

That request raised an internal objection to answering, something that I myself could not understand. Some time later I understood that a good part of my discomfort was due to the pediatrician summoning me to prioritize the static, the structure, when the most noticeable thing in childhood is not the supposed stability of the structure, but rather how transformation processes unfold , of psychic change.

In fact, in my experience it was already well known how many of my Hospital patients carried out psychic work through which they generated various hypotheses, of increasing complexity, with the purpose of giving the virus psychic flesh, transmuting it into an object that can be grasped by thought and emotional experience.

Another relevant issue was the challenge of participating in interdisciplinary research (Hirsch et al ., 2010) in which we proposed to evaluate, in boys, girls and puberty affected by HIV, the quality of adherence to medical treatment and the theories they built in relation to the causes for which they received medication.

In the investigations, the problem of studying complex psychological problems reappeared, including the way in which these boys and girls psychically process the condition of organic patients and, at the same time, find a language, a terminology that, as far as possible , do not be closed or hostile towards the professionals who work by our side and who wish, with our contribution, to enrich their own point of view in relation to the patient.

The term resilience, with growing social circulation, made me consider the possibility of its use insofar as I could give it a precise meaning (and thus avoid the obstacle that merely descriptive terms entail when it comes to fine-tuning the rigor conceptual).

The definition of resilience that guides this work is as follows: "it is a capacity of the psyche to capture the traumatic - thanks to some link support - creating new psychic conditions" Zukerfeld and Zonis Zukerfeld (2011).

In this text we are going to focus on two issues that are of crucial importance for the psychologist and pediatrician to have elements to help patients develop a vital posture, according to resilience:

1) Raise awareness of the importance for children with HIV to actively support the task of generating representations and feelings regarding organic pathology. This task should be one of the goals of therapeutic work.
2) The way of handling the work aimed at the diagnostic unveiling is of crucial relevance so that in these children the psychic position according to the resilience is affirmed

1) THE PSYCHOLOGICAL PROCESSING OF HIV AFFECTATION IN BOYS AND GIRLS

I. HISTORY OF AN APPROACH MODALITY

When I was presented, at the beginning of the nineties, the opportunity to work in a public Hospital in the Pediatric ward, caring for children affected by the HIV virus, I had a mixed feeling that brought together a diffuse joy and a clear feeling of anguish.

Shortly after starting I detected one of the reasons for my anxiety.

How could I, a psychoanalytically oriented psychologist, build on my basic training and rely on that theory to provide a contribution to these patients who, in those early days, lived between organic pains and the threats of death?

In fact, locating the purpose of our task in the room was not easy, nor was it a direct derivation of any book.

The need to find the profile of our work arose from specific problems.

The most significant began to emerge when some of the hospitalized children, once they had established a transfer with the therapist, spontaneously drew figures in which the fantasy of contagion seemed to be expressed, and above all, that of the disease, and even of the disease fate they believed they were heading.

These productions, these messages, opened a door to dialogue (what is happening to me? How can you help me? What can I expect? How did I get sick?)
That included me and at the same time exceeded me.
At that time interdisciplinary work becomes important.
The team of pediatricians, traditionally trained, had no disposition neither for this joint work, nor to listen to their patients and, in the diagnostic communication, they only considered the adults responsible for them as interlocutor.

A group of professionals from various disciplines began to question ourselves about what we should do with respect to what the drawings suggested: the desire of children to hear about their body, about illness, about medication.
We realized that our inaction could reinforce the defenseless state in which they found themselves.
We were doing work in two directions:
1) Towards the families, trying to find out how the issue had been handled within that framework. For the most part, they recognized that, when faced with the questions they were asked, they could not find satisfactory answers and were relieved that we could help them to elaborate the possible answers.
2) A consultation towards the laws or codes. There was no reference about how to proceed from psychology in these situations. They were "adult-centered" laws, this led to the conclusion that children were not contained in the Law. They were sick boys or girls and were outside the body of the law. We had to go back to the Convention on the Rights of Child [1] , which in its article 12, mentions:

1. The governments shall guarantee to the child who is in a position to form his own judgment the right to express his opinion freely in all matters affecting the child, with due regard being given to the views of the child, depending on the age and maturity of the child. little boy.
2. To this purpose, the child shall be given the opportunity to be heard, in particular, in any judicial or administrative proceeding that affects the child, either directly or through a representative or an appropriate body, in accordance with the procedural norms of national law. (UN, 1989)

II. THE FUNCTION OF FIGURABILITY AS AN ACHIEVEMENT OF SOUL VITALITY

The vertical involvement of a child's body by HIV has an affinity with what we usually understand in psychoanalysis as traumatic neurosis (Freud, 1920g).
The overwhelmed system in this case is the infantile immune system and the overwhelming factor is the virus from the maternal body, which leaves the transmission of a pathology as sediment, an indelible organic mark.
For those who are going through this vital trance, a key challenge for their resilience is to avoid the risk that traumatic neurosis, which has been looming since the history of the contraction of organic pathology, becomes enthroned as the dominant psychic structure.
To a large extent, this is so because the contagion occurs at a moment of maximum helplessness, before the possibility of appealing to any defense (immunological or psychic), of having the ability to register experiences or emotions and generate representations of the fact.
Thus, the initial state of helplessness is structural, not random.
This lack of raw material for the work of thinking, is a requirement for the mental vitality of each one. When they have vital resources, it is noted that they overcome this obstacle and conquer figurability (Botella, 2014, Goldberg, 2018); that is, they generate psychic material suitable for thinking about organic disease in relation to one's own body.
It is possible to infer that the effort linked to the drive to seize traumas (Freud, 1920g), the desire to understand the truth (Freud, 1937d, Bion, 1962) and the desire to heal (Freud, 1933a, Maldavsky, 1996) facilitate the creation of this figurative function, which has as an essential contribution that the looming traumatic neurosis is not the prevalent psychic outcome.
If in a person who contracted HIV in their adolescence or adulthood, we notice a push to psychically process how they got to such a situation, they can find scenes, memories, of certain psychic decisions, which can become the object of their self-criticism.
For example: “A few years ago I 'was in anyone': with my group of friends we felt that nothing could happen to us. All day we were partying. Nor when they gave me the diagnosis gave much ball. But after this hospitalization, I think a token fell on me ”.

In the context of a psychotherapeutic process, a story of this type is possible in an adult who tries to deploy a duel of a position (that of "partying all day") on the way to investing a new psychic perspective that takes into account the admission of organic disease in one's own body and the inescapable requirement of medical treatment to ensure health care.

What I want to emphasize is that in adult patients the possibility of establishing causal links between a set of memorable events (in the previous example, the experiences of the time when it was all the holiday) and a set of effects (it "fell the record ”that he is ill), is something that facilitates psychic work.

Vertically infected boys and girls, who are trying to rescue themselves from the risk of a traumatic neurosis taking hold in their subjectivity, have a prior and primary task: to create emotions and representations with which they can later construct thoughts.

Therapeutic work, as I understand it, has as one of its fundamental tasks to contribute to creating emotions and representations so that the aforementioned psychic processing can be captured.

III. BUILDING THE LINK. A CHALLENGE FOR THE HEALTH TEAM

The structural condition that places boys and girls who contract HIV vertically in a situation of organic and emotional helplessness, added to the requirements of medical treatment that includes naturally invasive practices (diagnostic tests, blood draws, controls, etc.), contribute to the development of specific affective states in the initial transfer modality that they establish with the treating interdisciplinary team.

These include automatic anguish, panic, helpless rage, and self-pity. In these circumstances, the procedure of the hospital establishment may have a negative effect if its modality of professional practice only considers compliance with medical precepts (biologist perspective) and dismisses the contribution that empathy and willingness to explain those practices can make to girls and boys who -to strengthen their resilience capacity- need to find a firm contextual foundation, which to a large extent may be the human attitude of the adults in charge.

The hospital approach carried out with a reductionist criterion -for example, the biologist- increases the risk of making the condition of structural helplessness chronic by perpetuating the trauma activated during the transmission of HIV: one's own body in the place of a defenseless object in the face of hyper-powerful forces that they discharge their toxicity, their tensions, on him. In more propitious circumstances, the group of trafficking professionals contributes to generating in these boys and girls higher quality bonding modalities, within which the willingness to resilience may flourish.

IV. A LINKING PROPOSAL: ACTIVE WAITING

The complexity of the situation of reconciling objectively invasive professional practices (among them, I highlight the extraction of blood), with the requirement of becoming trustworthy for boys or girls placed in a patient situation, does not affect all acting professionals equally.

A therapist, by being exempted from participating in the aforementioned medical acts, can take advantage of such a situation to promote a bonding modality that makes a difference, that qualifies the most coercive practices (medication intake, for example)

Mariela is a four-year-old girl. The AIDS disease is in advanced stage. Her relationship with medical practices is characterized by furious, ultimately powerless reaction. Proof of this is how she reacts to the entrance of any professional to his box: she turns on his back, huddles, yells.

Faced with this situation, my approach to approaching her is what I call active waiting.

In fact, it consists of forbidding me to go through the door of Mariela's box, to deploy a task from the very threshold of the door.

The latter is reflected in approaching that place daily (before or long after the rigorous medical examinations), greeting her, making her eyes meet my presence, waiting for a response in a short time and, immediately, leaving.

On some occasions I even notice that in the visual encounter her usual harsh gesture is disarmed.

When one morning, after seeing me, she hides his face behind the pillow.

I understand that a new possibility opens up, that of playing to present and remove the face.

In the following days she began to summon me by name, first to occupy my place of play from the threshold of her box, a short time later she asked me to enter the interior of the room to play with her.

In summary, active waiting consists of a linking proposal in which the therapist is configured in a non-invasive stimulus, open to the call by his patient, and responds from his disposition to tenderness and creativity.
It is one of the specific modes of the psychologist's role in relation to other professionals, which can be used for the benefit of their patients.

2) THE TASK OF DISCLOSURE IN CHILDREN AFFECTED BY HIV INTRODUCTION

The term disclosure (Adaszko, 2006) is often used to account for the phenomenon by which a child patient becomes aware of his or her condition of being affected by some organic pathology.
The task of diagnostic disclosure in the pediatric setting has at least two different approaches. One has the modality of an act; the other, that of a process. We explain both.
Those who carry out the disclosure as an act, take into account a factor to which they give maximum relevance, for example, the chronological age of the patient.
They consider the age of 12 or 13 as an auspicious time. In this way, when the patient reaches that age, the team of professionals begins the unveiling.
Among the fundamentals that guide this procedure there is one that we wish to highlight.
The information has a univocal direction: from the knowledge of the professional it is directed towards the ignorance of the pubescent.
The content and the amount of information that patients require is assumed to be similar in all cases.
Those of us who work on the disclosure as a process, aim to create a bond of trust with the patient and their family.
We do it from the moment they begin to be treated at the Hospital. This approach involves a good part of the members of the Chamber: it is an interdisciplinary work.

Our specific function as psychologists is to create and sustain over time a space for dialogue and play in which these boys and girls make an effort to master their traumas, their desire to know, their desire to heal.
In short, its vitality.
Adopting this way of working was not the product of an abstract decision. On the contrary, the impact of certain concrete experiences has weighed heavily.
In this regard, I remember that many years ago, Jesica, a 5-year-old patient with advanced AIDS, at a certain moment drew a human body, within which a spider occupied all the space "of the belly" (see Figure 1).
After giving me time to look at it, she said the following sentence: "This is you. This is a spider inside my body ".
In other words, Jesica describes that my body encompasses the spider and herself.
The pattern of the spider, colonizing, growing disproportionately inside the body, was a way of processing its current organic state, characterized by the increase in viral load and the laziness of the immune system.
It should be considered then that this graphic challenges us with respect to the unveiling, but in a specific way: the drawing already contains a certain knowledge regarding what is happening inside the body (in this case, the assumption that there is a foreign object to the own body that grows inside him without control).
Once we emerged from the surprise that this material (and others with similar characteristics) produced us with the team of the room headed by Dr. Hirsch, Head of the Pediatric Area, we began to sketch our style in the practice of disclosure to the that we conceive, worth the redundancy, as a process.

Drawing 1: The girl, after drawing, says that the body has a spider (it is observed that the animal grows and exceeds the limits of the body).

Here are some of the principles that guide our practice regarding the management of information with our patients:

- Our approach does not have a univocal direction: the child affected by HIV is an active subject that produces its own questions , its own theories of what is happening to it. The professional has to develop an aptitude to listen to these questions and, only afterwards, develop a strategy regarding them (sometimes the child requires us as a witness, at other times he requires that we provide objective information).
- It is possible to facilitate, in our patients, the disposition to an interrogative attitude, encouraging them to wonder and ask us. For example, when they show us the mark left by the needle with which they took blood, we ask: "Did someone ever tell you why they draw blood?", "Do you know what they do with your blood after they take it from you? room?". We position ourselves as allies of your desire to know. We try to empower it. We know that, if a child's desire to know is met with indifference, lies or stereotypical responses from adults, their thirst for knowledge can be quenched, perhaps forever. And he can decode that medical treatment and procedures constitute a mere exercise of violence of which his body is a support. In this case, they may believe that they only have two options: submit, without understanding the measures and procedures imposed on them, or display frequently secret acts of rebellion (feign obedience and repudiate it by flushing the medication down the toilet).
- Working with significant adults is very important. We tend to explain to them the importance of truth in the psychic time of childhood, in their willingness to adhere. Of course, a truth dosed according to the unique needs of each person. If we are going to provide you with new information, we first agree with your family members about what we intend to tell you. It is very important that there is coherence between the different sources of consultation that you may have.
- We try to ensure that our desire to inform does not advance or lag behind the capacity of understanding and receptivity of each child subject. Decisions regarding keeping ourselves as witnesses of their acquired knowledge, in providing required information, or simply waiting for the conditions to mature to do something of this, occur in the spontaneity of each link with the patient and their family.

Finally, this task unfolds in scenes (game, dialogue). Our goal is that each one of them constitutes a true emotional experience. That it starts or relaunches the effort to psychically digest the most arduous aspects of this pathology, among them, that HIV still has no cure.

II. FROM EXTREME HELPLESSNESS TO THE ABILITY TO ASK: A SUBJECTIVE ACHIEVEMENT

Our patients are, for the most part, boys and girls who contracted HIV through maternal transmission (during pregnancy and / or early breastfeeding), a period of time prior to the possibility of putting up any defense (immunological or psychic).

Therefore, they do not have memories or experiences of the time when the transmission took place.

We ask ourselves: How to think about something if there are no representations on which to support thinking?

This is the greatest obstacle to developing mental work, to producing your own questions.

Our task as psychologists is to capture the potential of certain acts of the patient (drawings, motor activities in the game, certain phrases) to allude to or condense something of the history of the helplessness of the child in relation to the basic organic pathology and / or or to the traumas of his family group, impossible to name with words.

Let's see specifically how the game can be a facilitator to start the unveiling process.

III. TWO CLINICAL EXAMPLES

Waldo is a three-year-old boy who was breastfed until a few months ago. Receive HIV transmission vertically.

In encounters with me there are frequent moments of disconnection and an oral autoeroticism in which it began anxious and ended drowsy.

Among his “games”, one catches my attention: he takes a toy bottle and brings it to his mouth, over and over again, in silence.

I ask him what he takes, Waldo answers clearly and eloquently: "cockroaches."

After a while he produces a modification: he offers me the bottle with cockroaches.

I answer him: "I don't take cockroaches, I spit them out." My answer seems to surprise you.
Then, seeing me dramatize the act of spitting several times, he begins to pretend that he himself is the one who spits cockroaches.
This game gives rise to others in which a greater vitality of the baby is evident. Start drawing pictures of cockroaches. Along the same lines, he asks questions about the role of the medication and takes it with more confidence than in the past. All these decisions (drawing, asking questions, ingesting the medicine) are testimony that Waldo is psychically alive.
Something very different when being disconnected and, in that state, making decisions such as swallowing cockroaches. It is possible to see, I think, that the play scenes facilitate the display of the desire to know, the vitality of the soul, the desire to heal.

VIOLETA IS 5 YEARS OLD.

A few days ago, she began taking specific medication to help strengthen her immune system. In one session he tells me that he usually vomits the medicine.
She also informs me that she sleeps badly in the Hospital Room. So I ask her what happens at night. To my surprise, she replied that at night "a bug grabbed my leg." I offer to draw it, and it does. Then I ask her to draw her "leg", the one that the bug grabs him.
Violeta takes the marker again and adds it. Subsequently, she draws the sheet with which he covers the leg and the bug. An instant later it occurs to him as a way of defending himself to “cut the bug with a scissors”. She takes a scissors from the game box and makes the cut in the sheet of paper, separating his leg from the bug.
To my questions, she answered that the bug, which is bad, wanted to play with her leg. Then it occurs to her to keep the bug in a box.
I tell her that it must be very difficult to sleep if she thinks that after falling asleep, she will be defenseless against the bugs.
In this and other sessions we talked about the work that medication does inside her body; something similar to what she expects from scissors.
That is, it cuts the growth of bugs, takes care of people's health, both when they are awake and when they are asleep, then it is possible to sleep more peacefully, without fear of bugs.

Waldo and Violeta's psychic acts (spitting, drawing, telling, cutting and saving, and counting) flesh out emotional experiences that are constructed in the context of a facilitating bond.
In relation to disclosure, the primary function of the process approach is to help each patient build a personal meaning of what we call adherence to treatment from the health field.
Some of our patients deploy these psychic processes more firmly, others initiate and stop at some point, and a remaining group never initiate them, remaining in a merely passive posture. These differences probably depend on the family world and the mental resources (the disposition to resilience) that are available in each case.
With our process approach we intend to respect and not overwhelm these differences.

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