

# *Transitioning with illness: bonds and disconnections between adolescent cancer survivors, their families and the hospital*

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**Abstract:** This article aims to understand the impact of the illness experience on child and adolescent cancer survivors and their families during life transitions and to examine the role that the hospital institution can play during these transitions. A study using a psychoanalytic method was conducted in a public, philanthropic hospital that is considered a reference in pediatric oncology. In-depth interviews were conducted with 12 adolescents and their mothers. Analysis of the interviews was based on the psychoanalytic framework of Freud and Lacan and resulted in two reading keys: (1) the effects of the reality on the survivors and their mothers and the effects of undifferentiation in the imaginary register and inhibition to maintain their own project in the future; and (2) the effects of alienation on the subjects and their bodies caused by the idealization of the hospital institution and its biomedical knowledge. Analysis of the interviews revealed problems related to the nature of the bond between the interviewees and the hospital institution. Based on this research, the institution under study was interested in establishing a psychoanalytically oriented transitional clinic to help young people upon discharge from the institution, primarily through their social reintegration.

► **Keywords:** Psychoanalysis. Pediatric Oncology. Transition. Biomedical knowledge.

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## Introduction

The increasing survival rate of patients with chronic diseases in childhood and adolescence has led to the transition process of these adolescents from pediatric care to adult care becoming an emerging area of research in the health field (ANELLI *et al.*, 2017).

In the biomedical paradigm, transition is viewed as a multidimensional process that aims to promote adolescents' autonomy over their health care (ROHATINSKY, 2018). Actions such as the establishment of transition clinics, the publication of guidelines, statements, and other initiatives are being taken by the scientific community to minimize the problem (HART, 2019).

Young adults with a history of disease in childhood and adolescence may experience significant deterioration in care, such as worsening treatment adherence and even treatment discontinuation after transitioning to adult care, which is a public health concern (WIEMANN *et al.*, 2019). Following this logic, pediatric oncology has seen an increase in the number of patients referred to as "survivors" in the scientific literature, and the transition of these adolescents to adult health services and their counter-referral to other levels of health care has become a challenge.

Despite the numerous international publications on this topic, the vast majority of research is quantitative and mainly aims to promote the health autonomy of individuals based on training and skill improvement. These studies are mainly oriented towards therapies based on neuroscience, cognitive behavioral psychology and positive psychology (TOBIN *et al.*, 2018; HART, 2019; WIEMANN *et al.*, 2019).

According to Birman (2010), the imperative of happiness at any cost prevails in contemporary times, which has brought the cult of the individual and his autonomy to center stage and elevated it to a moral value. From a health perspective, quality of life has therefore become an imperative dictated by scientific discourse, and research has begun to consider the improvement of self-esteem and the autonomy of the individual as the end goods to be achieved. The problem with this reading is that the subjective dimension of the human being, with all its idiosyncrasies and conflicts, is left aside, as if the suffering resulting from the experiences were a rational choice and the person could return to "normal" through reprogramming.

From this perspective, the transition from adolescence to adulthood usually appears as a marker of transition between health services. The concept of adolescence

used in these studies often naturalizes adolescence as a developmental phase and normalizes the idea of a crisis that all must pass through (DE SOUZA, 2020; NASCIMENTO; LOIOLA, 2018).

Adolescence as a developmental stage is a recent Western invention that has been heavily influenced by the normative findings of psychology and pedagogy (ARIÈS, 1981). Like adolescence, the normalization of a crisis in this stage is also a Western construction (CAMPOS, 2014).

In contrast to a developmental psychological reading, Lacanian psychoanalysis works with the concept of subjective constitution from a logical reading that assumes a different temporality. In clinical listening of both children and adolescents, the direction of treatment aims at the subject of the unconscious (PACHECO, 2012).

For psychoanalysis, adolescence is a time of (re)actualization of conflicts experienced in childhood, rather than a different psychic structure. The entry into puberty, which is permeated by bodily changes, puts the child's sexual theories to the test, and the pubescent comes into contact with a non-knowledge regarding the reality of sex. Ideals are (re)constructed. Sexuality, previously performed self-erotically, is now experienced in pairs, and the impossibility of a complete relationship between the sexes is experienced. (ALBERTI, 2009).

Interest in the subject arose from clinical listening to patients who cannot respond to this hegemonic discourse of science. These are adolescents with stable oncological disease who, despite all the encouragement from the team, remain "paralyzed" and connected to the hospital for follow-ups, sometimes weekly, because of chronic pain for which there is no organic justification.

The aim of this article is to offer reflections that, through a psychoanalytic reading, take into account the subjectivity that results from the effects of the experience of illness and to ask: what subjective solutions can adolescents and their families develop in the face of the experience of illness? How can hospital institutions and health care professionals proceed as patients transition from pediatrics to adult services without medicalizing yet another area of their lives?

## Methodology

The study was conducted by a psychoanalyst using a psychoanalytic method based on listening to the unconscious dimension of language (SAURET, 2003). Psychoanalysis was defined by Freud (1923 [1922]/1996) on the basis of three axes:

[...] (1) a method of investigating psychological processes that are hardly accessible in any other way; (2) a method [used on this investigation] of treating neurological disorders; and (3) a collection of psychological information obtained in this way and gradually condensed into a new scientific discipline (FREUD, 1923 [1922]/1996, p. 253).

The Freudian prerogative aggregates within the framework of psychoanalytic research, treatment, investigation, and theory. Thus, psychoanalytic research becomes inseparable from intervention (NOGUEIRA, 2004, p. 83).

For the research discussed in this article, transference, a phenomenon considered to be the driving force of all analysis, was taken into account. According to Freud, transference is the name psychoanalysis uses to describe what happens in the relationship between the patient and the psychoanalyst. It is "the reincarnation of an important figure from his childhood or past, and consequently transfers to him feelings and reactions that undoubtedly apply to this prototype" (FREUD, 1940 [1938]/1996, p. 189). However, transference is not a plausible phenomenon that occurs only in the traditional analytic setting.

Freud (1919 [1918]/1996) foresaw that psychoanalysis wouldn't be limited to the private sphere but would reach the public sphere as well, and that it would need some changes in its practice to do so. Lacan (1967 [2003]), in turn, formalized psychoanalytic praxis outside the traditional setting through two concepts: the intension, or clinical operators, and the extension, or psychoanalysis in the world. Psychoanalysis in intention grounds extension, that is, the clinical operators are the same regardless of where psychoanalysis is practiced.

In light of this, new research designs guided by the clinical operators of psychoanalysis, namely, the analyst's desire, the ethics of psychoanalysis, and transference, allow for greater freedom in terms of research with the psychoanalytic method, as long as rigor is maintained (SAURET, 2003).

The instrument used for data collection was the in-depth interview, which functions on the basis of psychoanalysis in extension and intension as an expansion of the preliminary interviews, a usual step at the beginning of any analytical treatment (SAURET, 2003). Although the interview time is not comparable to the analytical process, it is worth noting that the transference modality in this study was infused with the respondents' prior bond to and knowledge of the hospital setting. The study participants were not in previous analytical treatment with the interviewer, but the psychoanalyst who conducted the interviews was part of the clinical staff of

the hospital. Therefore, for the interviewees, the psychoanalyst could unconsciously more easily take the place of the representative of the institution and its knowledge.

Twelve adolescents between the ages of 15 and 24 and their mothers were interviewed. In conducting the interviews, despite the prior elaboration of the questions, the way of speaking chosen by the participant was respected in order to allow free association, the fundamental rule of psychoanalysis (LACAN, 1958 [2008]). The number of interviews conducted and the duration varied according to the language needs of each participant.

The interview consisted of three distinct moments. In the first, mother and child were together. The triggering questions were about the representation of youth and adulthood. In the second moment, with the mother only, the following topics were addressed: (i) how the mother imagines her child in the future and (ii) the impact of illness and pain in the social environment. In the third moment, with the teenager only, the highlighted themes were: (i) how he imagines the future, (ii) how he deals with the physical changes of puberty, (iii) fears and anxieties, (iv) how love encounters were for him, and (v) the impact of illness and pain in the social environment.

Table 1 shows the number of interviews conducted with each participant at different stages of the interview. To protect the identity of the adolescents and their mothers, fictitious names were used in this study.

**Table 1.** Number of interviews conducted with each study participant. Sao Paulo, 2019

1st Stage		2nd Stage		3rd Stage	
Mother and child	N. of interviews	mother only	N. of interviews	teenager only	N. of interviews
Barbara and mother	1	Carla	3	Barbara	6
Fatima and mother	1	Geisa	2	Fatima	2
Roberto and mother	1	Renata	2	Roberto	3
Karen and mother	1	Gisele	2	Karen	2
Larissa and mother	1	Liliane	2	Larissa	2

continue...

1st Stage		2nd Stage		3rd Stage	
Mother and child	N. of interviews	mother only	N. of interviews	teenager only	N. of interviews
Marcia and mother	1	Silvia	2	Marcia	2
Sonia and mother	1	Lorena	2	Sonia	3
Beatrix and mother	1	Carolina	2	Beatriz	3
Ivete and mother	1	Ivana	3	Ivete	3
Alice and mother	1	Juliana	2	Alice	2
Bianca and mother	1	Mirela	3	Bianca	4
Lucio and mother	1	Daniela	3	Lucio	2

**Source :** Rabelo, 2019.

Note: Fictitious names were used.

The present study remained faithful to the psychoanalysis policy advocated by Lacan (1958 [1998]), of listening to the subject of the unconscious. The decision to include the mother in the study was made at the tactical and strategic level. Lacan (1958 [1998]), in establishing fundamental points in the direction of treatment, criticized post-Freudian analysts who abandoned clinical rigor, a Freudian legacy, in exchange for a rigid systematization of technique.

Lacan (1958 [1998] p. 594), in supporting the pillars of the clinic, gave the analyst a free hand with regard to tactics "in terms of the timing, the number, and even the choice of interventions, to the point that it seems that the rule has been arranged entirely so as not to impede in any way the freedom of movement". In terms of strategy, the analyst is less free because the strategy is directly related to the management of the transference, but it is still free because the analyst tracks the effects of his interventions.

Involving the mother in the research was primarily transference management with the team, as the adolescents were phenomenologically described by the professionals as "spoken by the mother". Team members did not believe these youths could speak without their mother. Once the research began, this management proved fundamental to the adolescents' agreement to speak alone. All interviews were recorded and then transcribed. After the process was completed, clinical follow-up was offered to all interviewees, which was accepted by 10 of the 12 participants.

The role of parents in child rearing is a recurring theme in psychoanalysis. The first child case treated by Freud (1909 [1996]), that of little Hans, was by the child's father. Although there is currently a broad consensus in psychoanalysis that the child and adolescent are the subjects of analysis in the transference, according to Lefort & Lefort (1985), management including parents is necessary because it is unlikely that a child and/or adolescent will come to the session alone and be able to bear the costs, not only monetary, of analytic work (FARIA, 2016; PACHECO, 2012; PEUSNER, 2016).

Only mothers were included in the study because they were the only caregivers of the adolescents who participated in the study. It is likely that this has socio-historical reasons that will not be addressed in this article. Even considering this characteristic, it is important to emphasize that for psychoanalysis, motherhood is a function that has nothing to do with gender or biological parents (PACHECO, 2012).

All patients who were being followed up at the pain clinic at the time of data collection, were not receiving chemotherapy, had a minimum score of 80 on the Karnofsky Scale<sup>1</sup>, and had suffered from chronic pain for at least six months were included in the study.

Patients with neurologic and psychiatric comorbidities were excluded from the study. The age selection criterion of the patients was in accordance with the United Nations (UN) definition, which sets the chronological limits of adolescence between 15 and 24 years (EISENSTEIN, 2005). This criterion was chosen because in the studied institution patients over 21 years old are treated in the outpatient clinic for pain. In this study, the definition of chronic pain lasting longer than six months was used for research purposes in accordance with the International Association for the Study of Pain (IASP) guidelines.

This study was submitted and approved by the Research Ethics Committee of the Federal University of São Paulo (CEP/UNIFESP), under No. 1.455/2016, through CAAE No. 61290016.7.0000.5505.

## Results and discussion

Adolescents' identification data, oncological diagnosis, and treatments performed up to the time of the interview are shown in Table 2, and mothers' identification data, social class, and confirmation of receipt of support services are shown in Table 3.

**Table 2.** General data of the participating adolescents (n=12). Sao Paulo, 2019.

Name	Age (years)	Sex	age diagnosis	Diagnosis	Treatment
Barbara	24	F	17 years	Non-metastatic osteosarcoma	Chemotherapy Surgery and endoprosthesis
Fatima	21	F	18 years	High grade glioma	Chemotherapy Radiotherapy Surgery resection
Roberto	20	M	9 years	Myofibroblastic tumor	Surgical resection
Karen	20	F	7 years	Neurofibromatosis type 1	Surgical resection
Larissa	18	F	Four months	Paravertebral neuroblastoma 3	Radiotherapy Chemotherapy Tumor resection
Marcia	21	F	15 years	Grade II meningioma	Surgical resection
Sonia	22	F	11 years	Neurofibromatosis and bilateral optic glioma	Chemotherapy Surgical resection
Beatriz	18	F	16 years	Non-metastatic osteosarcoma	Chemotherapy Surgery and endoprosthesis
Ivete	15	F	10 years	Craniopharyngioma	Surgical resection Radiotherapy
Gabriela	15	F	12 years	Osteosarcoma	Chemotherapy Surgery and endoprosthesis
Bianca	21	F	10 years	Dercum syndrome	Chemotherapy Surgical resection
Lucio	24	M	10 years	Neurofibromatosis Fusocellular Sarcoma	Chemotherapy Surgical resection

**Source :** Rabelo, 2019.

Caption: F – female; M - male

**Table 3.** General data of the participating mothers (n=12). Sao Paulo, 2019

Identification	Age (years)	marital status	Social class (EBEP)	LOAS benefit
Carla	44	Married	B2	No
Geisa	43	Married	C2	No
Renata	49	Widowed	C1	Yes
Gisele	42	Widowed	C1	Yes

continue...



Identification	Age (years)	marital status	Social class (EBEP)	LOAS benefit
Liliane	42	Married	B2	Yes
Silvia	45	Widowed	B1	No
Lorena	51	Married	B2	No
Carolina	43	Divorced	C1	Yes
Ivana	43	Divorced	B2	Yes
Juliana	42	Married	C1	No
Mirela	43	Divorced	THE	Yes
Daniela	65	Widowed	B2	No

**Source:** Rabelo, 2019.

Note: Fictitious names were used. LOAS: Organic Law for Social Assistance

Data analysis was based on the psychoanalytic framework of Freud and Lacan and resulted in two reading keys: (1) the effects of the Real on the survivors and their mothers and the consequences of undifferentiation in the imaginary record and inhibition to maintain a project of their own in the future, and (2) the effects of alienation on the subjects and their bodies produced by the idealization of the hospital institution and its biomedical knowledge.

### First reading key: the effects of the Real on the survivors and their mothers and the consequences of undifferentiation in the imaginary record and inhibition to maintain a project of their own in the future

The oncological diagnosis is recognized as an event in the body that reveals the human condition: its finitude. However, humans have the need to repress this truth (FREUD, 1916 [1915]/1996). Lacan (1955-1956 [1985]) cautioned along the same lines, emphasizing that it is not possible to look directly into the sun or death, which underscores the human need for mediation in the face of death.

Under this assumption, the revelation of finitude caused by oncological disease requires unique subjective solutions that are unconsciously constructed to protect the subject from the anxiety unleashed.

Anxiety, which Lacan (1962-1963 [2005]) calls the only affect that does not lie, arises when the symbolic coordinates of the subject are shaken. In triggering anxiety,

it is as if the Other ceases in its function as a "compass" "when suddenly every norm is absent, that is, both that which constitutes the anomaly and that which constitutes the lack, when suddenly that is no longer absent, then at that moment anxiety begins" (LACAN, 1962-1963/2005, p. 52). Lacan capitalized the Other concept to distinguish it from others as fellow beings. The Other is considered the discourse of the unconscious, the treasury of the signifier, the place from which identifications come, which often precedes the subject and under which it must be located (LACAN, 1966 [1998]). In anxiety, the Other appears as the Real, inconsistent, and the subject experiences a suspension of itself "that makes us appear as objects, revealing the non-autonomy of the subject" (LACAN, 1962-1963/2005, p. 58).

The main psychoanalytic concept used in the creation of this reading key was the Real. According to Faria (2019), the Imaginary, the Symbolic, and the Real in Lacanian theory formed the epistemological axis on which Lacan built his teaching and clinic. The Imaginary fulfills the illusory function of the completeness of the self, the Symbolic, based on language, maintains the structure of unconscious desire, and the Real is that which escapes symbolization. Both the impossible and that which never ceases to be inscribed in the symbolic chain are features of the register of the Real. "The impossible is the Real" (LACAN, 1969-1970 [1992], p. 175).

In several parts of the interviews we could see traces of this experience affecting the Real.

I think there was a blockage in me that I can't even identify what happened, through all this, you know? To this day, I'm still like that, wondering. (Mother of patient Karen, age 20).

In light of this experience of meaninglessness brought on by the oncologic diagnosis, feelings of guilt were expressed repeatedly in the interviews.

I feel guilty, I think it's because I wanted a girl so badly and didn't know how to ask properly, and then she came like this. (Mother of patient Karen, age 20).

Sometimes there are things we do that we can't even tell the psychologist. That was before I was sick, only me and the person who did it know. I shouldn't have done it if I could turn back time. Every time it goes through my mind, I can't forget it. (Patient Roberto, 20 years old).

Soler (2002) writes about the epistemic character of guilt, emphasizing that in the face of misfortune, a pain that has no meaning, imposed as Real, from the action of taking responsibility for the path of failure, as well as that of error, the

subject can build a meaning and leave the void. Guilt in this context is an attempt to make sense of this disturbing reality that is present in the experience of illness.

Another construct: attempts to name the unpredictable, the contingency that the illness experience revealed, were displaced by other fears that may sound irrational to the ears of the health care team.

I live for her. As for me, she wouldn't even go to school, the secretary often argued with me. My life is shut down with her. I don't let her out of the house because she might catch a bacterium. (Mother of patient Ivete, 15 years old).

Another phenomenon that was repeated in the interviews and heard as a subjective solution was a kind of bond between mother and child that is permeated by the trace of indifferentiation in the Imaginary record. Becoming one with two bodies can also alleviate the helplessness triggered by the experience of illness in an imaginary way.

I pray to God that he stays alive while I'm alive. We're at war together, if we must die, we die together. (Mother of patient Roberto, 20 years old).

And I stopped breathing a little myself to breathe for her [...] I think she has to get it in her head that she has me for her and she for me. (Mother of patient Beatriz, 18 years old).

The excerpts "If we must die, then we die together" and "I stopped breathing a little myself in order to breathe for her" show the attempt to relieve the agony through the child's body.

On the part of the adolescents, the interviews revealed that the approval of this demand for imaginary completeness is a subjective position that denounces a nullification in the name of maternal love.

Sometimes my mother says pretty hard things. I get upset, but I don't say anything. God has given me two ears to hear more and one mouth to say less. For example, when I'm sitting down, I want her to sit down. I may be in pain but I want to get up so she can sit down. (**Patient Ivete**, 15 years old).

She wants to protect me too much. To be honest, it makes me uncomfortable. She wants me to be by her side all the time. This bothers me, but I can't say it. There's not a moment when she goes to one place and I go to another. (**Patient Roberto**, 20 years old).

The moment of the interview in which the mother was asked to imagine her child in the future, or how the adolescent imagined him or herself in the future, was marked by silence, and often a concern related to illness emerged that justified the impossibility of letting them plan out of the hospital context.

If God hadn't given me this disease, I'd already be my own woman, now, with this disease, I'm nothing left. (Patient Beatriz, 18 years old).

I don't learn much, teachers pass me just because I've health problems. I want to work, but what boss will pay the employee, I'm here almost every day. My mother will try to get me a pension (Patient Roberto, 20 years old).

I don't have friends, it's hard to have friends at my age. When I was studying, nobody really talked to me because of my health problems. They were disgusted. They said that I'd pass on my health problem to them. (Patient Sonia, 21 years old).

The transition from adolescence to adulthood also appeared in the interviews as something remote, massively permeated by the experience of illness.

To live with the disease, with the pain and adolescence, all mixed together, you can't. Because you're in pain, you're a teenager and you're sick, so it's different. You're sick, that's the focus, you're a teenager going into an adult phase, and you're not going to live the adult phase now. That's why the adult phase doesn't mean anything to me. (**Patient Beatriz**, 18 years old).

For me there's no difference, I've been coming here since I was 17, I spend a lot of time here. (**Patient Bianca**, 24 years old).

I don't like my teenage years very much, I was quite distant from the high school class. There was segregation, there was bullying against me because of my illness. It's like there's a wall between me and what people usually do at that stage. I don't know about the adult phase yet. (**Patient Lucio**, 24 years old).

The subjective solutions, referred to in the Imaginary record as indifferentiation, experienced in the mother-child relationship and the inhibition to maintain one's project in the future, are often denounced by pediatricians and other professionals accustomed to caring for children and adolescents with a long history of illness. However, they use different terms and readings. These professionals often refer to these patients as regressed, infantilized, and some use the term "symbiotic relationship with the mother." In reference to the mother in these cases, one often hears that she speaks for the child. Faced with these situations, team professionals are constantly confronted with moral judgments about how families "use" the disease, accusing them of persisting in this position just to continue receiving care, or slipping into a reading of mothers as martyrs and fixating on the feeling of pity.

In view of this, the consideration of the subject of the unconscious can be an important tool for the health sector, since it brings a logic inherent in the position of the subject, which makes it possible to read the positioning of patients and their families other than through morality and judgment. The possibility of changing

the view of the institution is essential so that the staff do not stigmatize or oppose patients, helping them to resume their lives and disconnect from the institution (CASTAÑO et al., 2013).

## Second reading key: the effect of alienation on the subject and his body through the idealization of the hospital institution and biomedical knowledge

Due to the long duration of cancer, the intensity of treatment, and the fact that often the onset of the disease is in childhood, a common phenomenon in pediatric oncology is the paralysis of survivors and family members in the experience of the disease. Faced with this situation, they disconsider their own knowledge of what happened to them and adopt a passive attitude toward the physician.

Jones, Parker-Raley and Barczyk (2011) conducted a survey of childhood cancer survivors and found that it was difficult for some young people to build a future and have their own identity after cancer treatment. Other research showed that some survivors did not feel cured and were trying to build a new sense of normality to fit into society (CANTRELL; CONTE, 2009).

Research examining survivors' perceptions of cancer treatment showed that they were very grateful to the facility but complained about the subordinate role they played during treatment. They also showed concern about their social health and pointed to an imbalance during treatment that emphasized the physical aspect to the detriment of psychosocial health (FREDERICK et al., 2017; SVEDBERG et al., 2016).

Barrett, Mullen, and McCarthy (2020) conducted a qualitative study of adult survivors of childhood cancer showing the recurrence of mental health diagnoses after treatment. Participants related the occurrence of crises to the experience of cancer. Almeida (2017) interviewed survivors of central nervous system tumors in her doctoral research and found problems processing the experience of illness. Some survivors were unable to regain their physical integrity and continued to feel ill; others were still in trauma and unable to grieve the losses resulting from treatment.

In analyzing this phenomenon through a psychoanalytic reading, it is found that institutions, as well as the parents, are strong representatives of the Other for the subject because of the established power relationship. To this power, which already exists in the institutions, is added the consistency of biomedical knowledge, and

thus there's the danger of installing a modality of transference with the institution, operating above all with the figure of the doctor, which at the same time produces in the subject a very massive alienation in biomedical knowledge, leading to a phenomenon of petrification of his being in the sick signifier.

When Freud wrote about the dynamics of transference, he asserted that transference experienced in institutions can be even more intense "[...] it occurs with the greatest intensity and in the most undignified forms, and achieves nothing less than mental servitude [...]" (FREUD, 1912 [1996], p. 113). Freud (1912 [1996]) therefore also stated that in these cases the transference does not act as a resistance that causes the patient to leave the institution, but ends up imprisoning him and causing him to be held by the institution because it keeps him away from life.

Lacan, in turn, also focused on the study of transference, especially with regard to its treatment, and he continued to elaborate new developments in his work. For the present study, based on the analysis of the relationship that the survivor and his family can establish with biomedical knowledge, we have used the moment in the Lacan's (1973 [2003]) work that states that transference is the love of the subject for the knowledge of the Other, more precisely, the belief in the consistency of this knowledge, embodied in the context of analysis in the figure of the psychoanalyst and in a health care institution in the figure of the professionals.

The basis for the construction of this reading key was the concept of the Other and the relationship between the logical operators of subjective constitution (alienation and separation) and the concept of transference.

For Lacan, alienation and separation are logical operations that occur simultaneously. Alienation, according to Lacan (1964 [2008]), is the fate that destines us to humanize ourselves. The operation of separation is linked to the registration of the Real. Therefore, according to Lacan, the state of the subject of the unconscious is always in the order of the subjective division between the need to alienate the signifiers of the Other and the experience of the lack of being, because this knowledge, however consistent it may seem, cannot explain the whole dimension of being.

It is important to emphasize that the approach proposed in this article does not deal with the primary alienation that, together with the process of separation at the moment of subjective constitution, installs the condition of absence of being, but with the secondary alienations that produce identifications among other results of the subject in order to deal with its condition of absence (ZANOLA, 2018).

The operations of alienation and separation are also used in the psychoanalytic setting to think about the course of an analysis and the analyst's handling of the transference during this process (GUEGEN, 1997). It is important that the analyst be aware of the dangers inherent in the phenomenon of transference. Lacan (1964 [2008]), in the face of these dangers, emphasized that the psychoanalyst must take the place of the subject he thinks he knows in the transference. When the psychoanalyst starts from this supposed knowledge rather than from full knowledge, he or she enables important changes in the analysand's relationship to knowledge, and at the end of the analysis process, the psychoanalyst must leave the idealized place of knowledge that he or she has taken during the analysis of this process. Safatle (2017), based on Lacanian interpretation of the transference phenomenon, emphasizes that thinking about the fate of transference can be a source of emancipation because it exists wherever there is power and identification.

The report of the mother of the patient Beatriz shows how the transference modality with the health facility and its knowledge can have iatrogenic effects on the subject and his family members.

My colleague's sister suffers with her teeth because she cannot go to another hospital. Another dentist doesn't take care for her teeth because she has cancer and the poor thing is struggling and can't make it. Here she has everything, she even has whitening, she has everything. Here she has all the support. I myself thank God. I'll never have anything to say. It's too good here. She says she doesn't want to get old, no. She doesn't want to turn 21 so she doesn't lose her place. (**Mother of patient Beatriz**, 19 years old).

The same patient requested hospitalization from the team because she had difficulty controlling her chronic pain and expressed a desire to live in the hospital to various professionals. Both the desire not to grow up and the desire to live in the hospital denounce the iatrogenic effect that the institution can produce when it embodies for the subject the aspect of an omnipotent Other.

In interviews, patients and their mothers said that they owed their lives to the institution and that they wouldn't know where to go if something happened to the hospital. Excessive gratitude may indicate an indebtedness filling on the part of the grateful subject that makes him or her unable to negotiate and submit to the demands of the institution. The following report illustrates this situation.

I once talked about my health problems in a job interview. You can only do that if you fit your appointments once a week into your vacation or day off. Sometimes I have an appointment three times a week. Sometimes I think about not having a regular job because

of this hospital life I have. We depend on a job to have an income and to survive. This causes bad thoughts and anxiety. The doctor once said that I'm a high-risk patient, so I have to keep this frequency, I always have to be monitored. (**Patient Leonardo**, 24 years old).

One point that stands out in Leonardo's position is that at no time, did he consider talking to his doctor about the difficulties he faced in the interview or about the conflict he sees between the need to work to survive and the requirement of the hospital to control the disease. Leonardo is very grateful to the doctors who saved him and throughout the interview adopted a passive attitude towards what he was told and required to do by the institution. It seems that he identified himself in a petrified way with the signifier "high-risk patient" and therefore has nothing to do that could make it flexible.

Another speech that illustrates the consequence that biomedical knowledge can embody in the subject is the account of patient Larissa's mother.

I didn't take photos of L. and I couldn't celebrate her birthday. The doctor said that there's a time when the disease comes back, five years. When she completed 5 years, we celebrated for two days, because for me she was born on that day." (**Mother** of patient **Larissa**, 19 years old)

For some survivors, dealing with the risks of possible late effects of cancer treatment can seem like a shadow and lead their lives to a dead end, as illustrated by the speeches of patient Leonardo and patient Larissa's mother.

Based on the concept of quaternary prevention, the possible iatrogenic effects produced in subjects can be problematized by moving from disease control to excessive risk management. This is done by medicalizing life in the name of prevention (JAMOULLE; GOMES, 2014).

It is worth noting that the proposal is mainly to discuss the responsibility of the institution in the face of the phenomena of paralysis of life and petrification of the being in the sick signifier. However, it is not possible to ignore the involvement of the subject in the emergence of these phenomena. It is therefore an ethical discussion about the positioning of the institution, in which there are no guarantees about how the subject will position itself.

Based on this research, the institution under study was interested in establishing a transitional outpatient clinic to support the transition process of patients and their families, mainly aimed at social reintegration. The intervention methodology is based on the psychoanalytic theories of Freud and Lacan, on the concept of transference and



the ethics of psychoanalysis, and on the proposal of a dialog between psychoanalysis and the field of humanities in health care, especially philosophy and literature.

The singular aspect in relation to the position of the subjects and their history makes generalizations impossible. However, the reading keys that emerged from the analysis of these interviews allow expanding the discussion of the transition process beyond the informative level.

## Conclusions

The transition must go beyond the information plan based on biomedical knowledge so as not to lead to the medicalization of another area of young people's lives. It is important that, at the end of treatment, the physician "drops out" from the idealized position he or she has held at other stages of treatment so that new connections with other important people in the survivor's life can be made.

Analysis of the reports suggests that it is extremely important to expand the concept of transition to include culture change in pediatrics. The transition process for these young people needs to be gradual over the course of treatment, with interventions that recognize the effect of the passage of time on them, their families, and the health care team, regardless of the fact that they are ill.

Cancer survivors are recognized by the scientific community as a vulnerable population, but there are still few public policies to help them. For this reason, there is a need for increased debate and reflection on care practices and interventions for this population.

The conclusion is that an intervention methodology needs to be developed that broadens the transition process, including the perspective of becoming ill, and is not limited to the transition from adolescence to adulthood and/or the transition from pediatric to adult care. When these transitions emerged in the study, they appeared as a still distant future; on the other hand, illness-related difficulties emerged with great intensity, denouncing the need for care from the beginning of treatment.

Through new encounters and disagreements, further bonds and disconnections can occur beyond the experience of the disease. And in the junction of new experiences with the experience of illness - which is no longer seen as "the only experience" - those affected can build not only their knowledge of what happened to them, but also their own theories of love, sex and death, without biomedical knowledge prevailing, thus avoiding the petrification of the being in the ill signifier.<sup>2</sup>

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## References

- ALBERTI, S. *Esse sujeito adolescente*. 3. ed. Rio de Janeiro: Rios Ambiciosos; 2009.
- ALMEIDA, M.D. *Sobreviventes de câncer infanto-juvenil: contribuições da psicanálise e novos dispositivos clínicos*. Tese (Doutorado) - Programa de Pós-Graduação em Psicologia, Universidade de São Paulo. São Paulo, 2017.
- ANELLI, C. G. *et al.* Challenges in transitioning adolescents and young adults with rheumatologic diseases to adult Care in a Developing Country - the Brazilian experience. *Pediatr Rheumatol*, v. 15, n. 1, p. 47, 2017.
- ARIÈS, P. *História social da criança e da família*. Rio de Janeiro: Zahar, 1981.
- BARRETT, P. M.; MULLEN, L.; MCCARTHY, T. Enduring psychological impact of childhood cancer on survivors and their families in Ireland: A national qualitative study. *Eur J Cancer Care (Engl)*, p. 2-10, 2020.
- BIRMAN, J. Muitas felicidades?! O imperativo de ser feliz na contemporaneidade. In FREIRE FILHO, J. (org.) *Ser feliz hoje: reflexões sobre o imperativo da felicidade*. Rio de Janeiro: FGV, 2010, p. 27-47.
- CAMPOS, G. F. V. A. *Adolescência: de que crise estamos falando?* Dissertação (Mestrado) - Programa de Estudos Pós-Graduados em Psicologia Social, Pontifícia Universidade de São Paulo. São Paulo, 2014.
- HART, L. C. *et al.* What Care Models Have Generalists Implemented to Address Transition from Pediatric to Adult Care? a Qualitative Study. *J Gen Intern Med*, v. 34, n. 10, p. 2083-2090, 2019.
- CASTAÑO, G., *et al.* Saúde Coletiva e Psicanálise: entrecruzando conceitos em busca de políticas públicas potentes. In: ONOCKO-CAMPOS, R. (org.). *Psicanálise e Saúde Coletiva – Interfaces*. 2.ed. São Paulo: Hucitec, 2013, p. 17-38.
- CANTRELL, M. A.; CONTE, M. T. Between being cured and being healed: the paradox of childhood cancer. *Qual Health Res*, v. 19, n. 3, 312-322, 2009.
- COSTA VAL, A., *et al.* Psicanálise e saúde coletiva: aproximações e possibilidades de contribuições. *Physis*, v. 27, n 4, 1287–1307, 2017.
- EISENSTEIN, E. Adolescência: definições, conceitos e critérios. *Adolescência e saúde*, v. 2, n. 2, p.1-2, 2005.

- FARIA, M. R. *Introdução à psicanálise de crianças: o lugar dos pais*. São Paulo: Toro, 2016.
- FARIA, M. R. *O real, simbólico e imaginário na obra de Jacques Lacan*. São Paulo: Toro, 2019.
- FREDERICK, N. N. *et al.* Preparing childhood cancer survivors for transition to adult care: the young adult perspective. *Pediatr Blood Cancer*, v. 64, n. 10, 2017.
- FREUD, S. (1909 [1996]). Análise de uma fobia em um menino de cinco anos In: *Edição Standard Brasileira das Obras Psicológicas Completas de Sigmund Freud*, vol. X. Rio de Janeiro: Imago.
- FREUD, S. (1912 [1996]) A dinâmica da transferência. In: *Edição Standard Brasileira das Obras Psicológicas Completas de Sigmund Freud*, vol. XII. Rio de Janeiro: Imago.
- FREUD, S. (1916 [1915]/1996). Sobre a transitoriedade. In: *Edição Standard Brasileira das Obras Psicológicas Completas de Sigmund Freud*, vol. XIV. Rio de Janeiro: Imago.
- FREUD, S. (1916-1917 [1996]). Conferência introdutória XXIV (O estado neurótico comum). In: *Edição Standard Brasileira das Obras Psicológicas Completas de Sigmund Freud*, vol. XVI. Rio de Janeiro: Imago.
- FREUD, S. (1919 [1918]/1996). Linhas de progresso na terapia psicanalítica. In: *Edição Standard Brasileira das Obras Psicológicas Completas de Sigmund Freud*, vol. XVII. Rio de Janeiro: Imago.
- FREUD, S. (1920 [1996]). Além do Princípio de Prazer. In: *Edição Standard Brasileira das Obras Psicológicas Completas de Sigmund Freud*, vol. XVIII. Rio de Janeiro: Imago.
- FREUD, S. (1923 [1922]/1996). Dois verbetes de enciclopédia. In: *Edição Standard Brasileira das Obras Psicológicas Completas de Sigmund Freud*, vol. XVIII. Rio de Janeiro: Imago.
- FREUD, S. (1940 [1938]/1996). Esboço de Psicanálise. In: *Edição Standard Brasileira das Obras Psicológicas Completas de Sigmund Freud*, vol. XXIII. Rio de Janeiro: Imago.
- GUEGEN, P. G. A transferência como logro. In: FELDSTEIN, R.; FINK, B.; JAANUS, M. Orgs.). *Para ler o seminário 11 de Lacan*. Rio de Janeiro: Zahar, 1997, p.93–107.
- INTERNATIONAL ASSOCIATION FOR THE STUDY OF PAIN, 1994. Disponível em: <[www.iasp-pain.org](http://www.iasp-pain.org)>. Acesso em 26 setembro 2018.
- JONES, B. L.; PARKER-RALEY, J.; BARCZYK, A. Adolescent cancer survivors: identity paradox and the need to belong. *Qual Health Res*, v. 21, n. 8, p. 1033–1040, 2011.
- JAMOULLE, M.; GOMES, L. F. Prevenção Quaternária e limites em medicina. *Revista Brasileira de Medicina de Família e Comunidade*. Rio de Janeiro, v. 9, n. 31, p. 186–191, 2014.
- LACAN, J. (1955-1956). *O seminário*, livro 3: as psicoses. Rio de Janeiro: Jorge Zahar, 1985.
- LACAN, J. (1962-1963). *O seminário*, livro 10: a angústia. Rio de Janeiro: Jorge Zahar, 2005.
- LACAN, J. (1964). *O seminário*, livro 11: Os quatro conceitos fundamentais da psicanálise. Rio de Janeiro: Jorge Zahar, 2008.

- LACAN, J. (1958). A direção do tratamento e os princípios de seu poder. In: LACAN, J. *Escritos*. Rio de Janeiro: Jorge Zahar, 1998.
- LACAN, J. (1966). A instância da letra no inconsciente ou a razão desde Freud. In: LACAN, J. *Escritos*. Rio de Janeiro: Jorge Zahar, 1998.
- LACAN, J. (1967). Proposição de 9 de outubro de 1967 sobre o psicanalista da Escola. In: LACAN, J. *Outros Escritos*. Rio de Janeiro: Jorge Zahar, 2003.
- LACAN, J. (1969-1970). *O seminário, livro 17: O avesso da psicanálise*. Rio de Janeiro: Jorge Zahar, 1992.
- LACAN, J. (1973). Prefácio à edição alemã dos escritos. In: LACAN, J. *Outros escritos*. Rio de Janeiro: Jorge Zahar, 2003.
- LEFORT, R.; LEFORT, R. *Psicose no adulto e na criança: uma só estrutura*. Conferência proferida na EBP - Seção Bahia e publicada em apostila de circulação Interna. 1985. p. 17-28.
- NOGUEIRA, L. C. A Pesquisa em Psicanálise. *Psicologia USP*, v. 15, n. 1-2, p. 83–106, 2004.
- PACHECO, A. L. P. *Da fantasia de infância ao infantil na fantasia: a direção do tratamento na psicanálise com crianças*. São Paulo: Annablume, 2012.
- PEUSNER, P. *Fugir para adiante*. O desejo do analista que não retrocede ante as crianças. São Paulo: Agente Publicações, 2016.
- RABELO, M. T. P. *Transitar doente e a dor crônica: laços e desenlaces entre adolescentes, familiares e instituição hospitalar*. Dissertação (Mestrado) - Escola Paulista de Medicina, Programa de Pós-Graduação em Pediatria, Universidade Federal de São Paulo. São Paulo, 2019.
- ROHATINSKY, N. Healthcare Transition in Pediatrics and Young Adults with Inflammatory Bowel Disease: A Scoping Review. *Gastroenterol Nurs*, v. 41, n. 2, p. 145-158, 2018.
- SAFATLE, V. Lacan, revolução e liquidação da transferência: a destituição subjetiva como protocolo de emancipação política. *Estudos Avançados*, v. 31, n. 91, p. 211–227, 2017.
- SAURET, M. J. A pesquisa clínica em Psicanálise. *Psicologia USP*, v. 14, n. 3, 89-104, 2003.
- SIGNORELLI, C. *et al.* The impact of long-term follow-up care for childhood cancer survivors: A systematic review. *Crit Rev Oncol Hematol.*, v. 114, p. 131-138, 2017.
- SVEDBERG, P. *et al.* Support from healthcare services during transition to adulthood - Experiences of young adult survivors of pediatric cancer. *Eur J Oncol Nurs*, v 21, p. 105-112, 2016.
- SOLER, C. *O inconsciente a céu aberto*. Rio de Janeiro: Zahar. 2002.
- TOBIN, J. *et al.* Posttraumatic growth among childhood cancer survivors: Associations with ethnicity, acculturation, and religious service attendance. *J Psychosoc Oncol*, v. 36, n. 2, p. 175-188, 2018.

WIEMANN, C, M. *et al.* Development of a group-based, peer-mentor intervention to promote disease self-management skills among youth with chronic medical conditions. *J Pediatr Nurs*, v. 48, p. 1-9, 2019.

VESZ, P. S., *et al.* Aspectos funcionais e psicológicos imediatamente após alta da unidade de terapia intensiva: coorte prospectiva. *Rev Bras Ter Intensiva*, v. 25, n. 3, p. 218-224, 2013.

ZANOLA, P. C. *Alienação e sua travessia na psicanálise lacaniana*. Dissertação (Mestrado) - Universidade Federal do Paraná, Programa de Pós-Graduação em Psicologia. Curitiba, 2018.

## Notes

<sup>1</sup> The scale evaluates performance and classifies patients according to the degree of their functional disabilities or disabilities. The lower the rating on the scale, the worse the expectation of recovery and return to daily activities (VESZ *et al.*, 2013).

<sup>2</sup> M. T. P. Rabelo: study design, data collection, analysis of results, literature review and writing of the article. A. L. P. Pacheco: study design, analysis of results, psychoanalytic theoretical foundation. M. C. Schweiter: study design, data analysis, writing and review of the article. C. A. Len: study design, data analysis and article review.

## Resumo

### *Transitar doente: laços e desenlaces entre os adolescentes sobreviventes de câncer infantojuvenil, seus familiares e a instituição hospitalar*

Os objetivos deste artigo abrangem compreender o impacto da experiência de adoecimento em sobreviventes de câncer infantojuvenil e em seus familiares ao longo dos processos de transição inerentes à vida e, também, explorar o papel que a instituição hospitalar pode desempenhar no decorrer dessas passagens. Uma pesquisa com método psicanalítico foi realizada em um hospital público, filantrópico e considerado referência em oncologia pediátrica. Foram feitas entrevistas em profundidade com 12 adolescentes e suas respectivas mães. A análise das entrevistas embasou-se no referencial psicanalítico de Freud e Lacan, originando duas chaves de leitura: (1) a incidência do Real sobre os sobreviventes e suas mães e os efeitos de indiferenciação no registro Imaginário e de inibição ao sustentar um projeto próprio no futuro; e (2) o efeito de alienação nos sujeitos e em seus corpos produzido por meio da idealização da instituição hospitalar e seu saber biomédico. A partir da análise das entrevistas, foi possível identificar problemáticas relacionadas à modalidade de laço estabelecida entre os entrevistados e instituição hospitalar. Embasados nesta pesquisa, a instituição estudada interessou-se em construir um ambulatório de transição norteado pela ética da psicanálise, visando auxiliar o jovem no desenlace da instituição mediante, principalmente, a sua reinserção social.

► **Palavras-chave:** Psicanálise. Oncologia Pediátrica. Transição. Saber Biomédico.

