

From Omnipotence to Exhaustion: The Perspectives of Adolescents in Drug Therapy¹

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This study aimed at understanding the meaning of chemotherapeutic treatment for adolescents with cancer. It is a qualitative study using Alfred Schütz's social phenomenology as a framework. Seven adolescents were interviewed. Four themes emerged from the analysis of their discourses: Impact of the disease on their lives; The discomfort of treatment; Coping strategies and Projection to the future without the disease. The statements of the adolescents revealed that the experience with the chemotherapeutic treatment affects several possibilities of being-in-the-world-with-the-others. The healthcare team plays a fundamental role in the lives of these adolescents, and this relationship goes beyond the scientific level.

Descriptors: Adolescent; Neoplasms; Drug therapy; Qualitative Research.

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Da onipotência ao desgaste: as perspectivas do adolescente em quimioterapia

Este estudo teve como objetivo compreender o significado do tratamento quimioterápico para o adolescente acometido pelo câncer. Trata-se de pesquisa de natureza qualitativa, com referencial fenomenológico social de Alfred Schütz. Foram entrevistados sete adolescentes. Da análise dos discursos, emergiram quatro temas: impacto da doença em sua vida, o desconforto do tratamento, estratégias de enfrentamento e projeção para o futuro sem a doença. A fala dos adolescentes revelou que a experiência com o tratamento quimioterápico afeta as várias possibilidades do ser-no-mundo-com-os-outros. A equipe que cuida é parte fundamental na vida desses adolescentes, cuja relação ultrapassa o científico.

Descritores: Adolescente; Neoplasias; Quimioterapia; Pesquisa Qualitativa.

De la omnipotencia al desgaste: las perspectivas del adolescente en tratamiento de quimioterapia

Este estudio tuvo como objetivo comprender el significado del tratamiento quimioterápico para el adolescente acometido por cáncer. Se trata de investigación de naturaleza cualitativa, utilizando el referencial fenomenológico social de Alfred Schütz. Fueron entrevistados siete adolescentes. Del análisis de los discursos, emergieron cuatro temas: el impacto de la enfermedad en su vida; la incomodidad del tratamiento; las estrategias de enfrentamiento; y la proyección para el futuro sin la enfermedad. La declaración de los adolescentes reveló que la experiencia con el tratamiento quimioterápico afecta las varias posibilidades del ser-en-el-mundo-con-los-otros. El equipo que cuida es parte fundamental en la vida de esos adolescentes, cuya relación ultrapasa lo científico.

Descriptorios: Adolescente; Neoplasias; Quimioterapia; Investigación Cualitativa.

Introduction

Adolescence is the period between 10 and 19 years, according to the WHO⁽¹⁾. It is considered a phase of transformation of life, marked by bodily and mental changes in which there is an acceleration of cognitive development and the formation of personality⁽²⁾. Adolescents consider themselves omnipotent beings: the ego becomes magnified and there occurs an arrogance and independence towards the experience and advice of their elders. With so many "powers", when faced with opposing forces, such as disease for example, they do the possible and almost the impossible to try to win the struggle, taking from these experiences positive and negative values that are incorporated in their identity⁽³⁾. One of the diseases which affects these young people is cancer. The incidence of all types of cancers in children and adolescents has increased in recent decades and is the third leading cause of death among Brazilian children. The relative survival rates over five years, for all types of cancer, increased from 56% in the period

1974-1976 to 77% in 1992-1998 ($p < 0.05$)⁽⁴⁾. Childhood cancer represents between 1% and 3% of all neoplasms in the majority of populations. The most common type of childhood cancer is leukemia, which represents 25-35% of the cases of cancer in children⁽⁵⁾.

There are many types of cancer in adolescence and often the diagnosis of the disease becomes complex and can occur in the long term, a fact which leads to a consequent delay in treatment initiation, detrimental to survival of the patient⁽⁶⁾. Among the treatments for the disease is chemotherapy, which consists of the employment of isolated chemical substances or compounds in order to treat the malignant neoplasms, interfering in the process of growth and cellular division. Most chemotherapeutic agents have no specificity, because they act on all the cells of the body, resulting in severe collateral effects⁽⁷⁾.

In a previous study with adults we described how chemotherapy is perceived by the patient as a difficult

situation to face, due to the various collateral effects. However, despite the difficulty, the patient rigorously follows the treatment, because they see the treatment as a way to be cured⁽⁸⁾. This treatment alters the body and emotional state, as well as the routine of the patient. Often, the treatment is seen as a source of worry and fear, as it is known as a stigmatized, highly aggressive and almost intolerable treatment. However, the collateral effects of the treatment bring the perception of a disease, which, in spite of these discomforts, can lead to therapeutic success⁽⁹⁾. Chemotherapy is a treatment recognized as a proposed cure for cancer, and its collateral effects are not only acutely present but have delayed repercussions involving growth and development of adolescents during puberty. These effects are even more pronounced when the individual is submitted to associated radiotherapy⁽¹⁰⁾. The collateral effects of the chemotherapy, are perceived and reported by the caregivers of adolescents using antineoplastic drugs, although these caregivers had no great knowledge about the treatment of cancer through chemotherapy, they identified the most frequent adverse effects as: fatigue, anorexia, nausea, alopecia, weight loss and pain⁽¹¹⁾. The impact of the diagnosis for the adolescents and their hospitalization generate painful changes in many aspects, they experience emotional, social, behavioral and existential problems⁽¹²⁾. The disease and the treatment take away the idea of omnipotence from the adolescents and make them recognize their finitude. Cancer can cause the person to change and rediscover a new way of living.

The design of this project grew from the supervised nursing training, in which it was possible to monitor and assist the adolescents when they received chemotherapy and to see their discomfort and perspectives. This study aims to comprehend the significance of the chemotherapeutic treatment for adolescents affected by cancer, and, through their reports, to seek ways to better plan the care actions of the health team.

Methodological framework

In this qualitative study the social phenomenology of Alfred Schütz was chosen. The phenomenological trajectory understands that it is necessary to construct a science that is concerned with the world of lived existence. Thus, the focus should be the subject of the experience, with the meaning attributed according to their perspective, and how the phenomena appear to them. Therefore, the researcher should focus on the subject and their social context⁽¹³⁾. According to Schütz

it is in this social context where man lives and relates with himself, with others and with things. According to the relationships, the lived experiences and acquired knowledge, they form their biographical self, which differentiates them from others and motivates them in their natural attitudes⁽¹⁴⁾.

The interviews were conducted after obtaining the permission of the Research Ethics Committee, in accordance with notice 465/2008-CEP-Botucatu. The authors, adolescents and their guardians, authorized the participation in this study by signing the Terms of Free Prior Informed Consent and answering the guiding question: "Can you tell me how you feel about undergoing this treatment?" . The interview was recorded, transcribed verbatim and, later, deleted. Data collection took place in the Chemotherapy Unit of the Clinical Hospital of the Faculty of Medicine of Botucatu - UNESP. The interviews were performed individually, privately and were conducted according to the phenomenological approach, in which the encounter with the other takes place as an empathic relationship and can therefore penetrate into the world of the other and capture the subjective aspects of their way of experiencing the world. The data were collected from June to September 2009. Seven adolescents were interviewed, aged 11 to 18 years, who had undergone or were undergoing chemotherapeutic treatment; all of them were enrolled in the service at the time. In order to preserve the identity of the subjects, and in accordance with the ethical principles, the adolescents received code names of superheroes.

The analysis and interpretation of data followed the steps proposed by Parga Nina⁽¹⁵⁾; where first a careful reading of the statements was carried out, while the material was unstructured, aiming to grasp the motives reported by the subjects; next, it was sought to identify the specific categories that were presented, and then, to extract portions of the statements that involved the actions of the adolescents, finally, the type of action which was in the analyzed statements was sought. The specific category here has no sense of the logic defined *a priori*, but of that formulated by the researcher from the data obtained. According to Schütz, it will always occur mediated by the biographical situation of the researcher. Finally, a comprehensive analysis of these issues can be performed, according to the ideas of Alfred Schütz.

Results and discussion

The profile of the adolescents interviewed according to age, gender, cancer type and the stage of treatment in which they were, is summarized in Figure 1.

Identification	Gender	Age	Type of Cancer	Situation
He-man	Female	11	Grade II Astrocytoma	1 year since treatment termination
Blade	Female	15	Osteosarcoma	In treatment
Wolverine	Female	18	Wilms' Tumor	1 month since treatment termination
Thor	Female	16	Hodgkin's lymphoma	2 years since treatment termination
Batman	Female	18	Hodgkin's lymphoma	In treatment
Flash	Female	16	Hodgkin's lymphoma	1 year since treatment termination
Superman	Male	15	Acute Myeloid Leukemia	In treatment

Source: Direct research in the hospital records of the adolescents interviewed.

Figure 1 - Characterization of the adolescents according to gender, age, clinic and treatment time. Botucatu, SP, Brazil, 2009

From the attentive analysis of the statements and the observance of their convergence, four central themes emerged: Impact of the disease on their lives; The discomfort of the treatment; Coping strategies, and

Projection for the future without the disease.

Following is a demonstrative diagram (Figure 2) in which the themes and units of meaning explained in the interviews are evidenced in synthetic form.

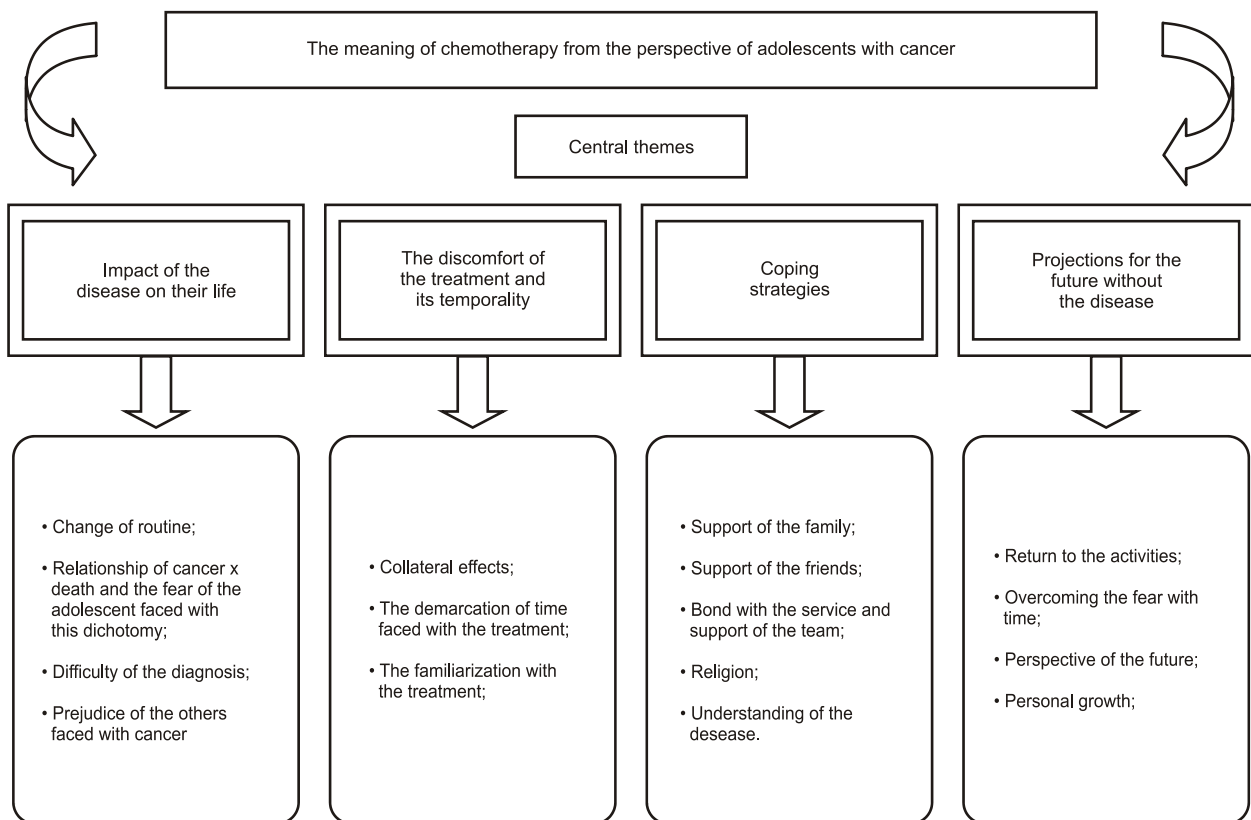


Figure 2 - Diagram of the phenomena unveiled from the experiences of the adolescents regarding the chemotherapeutic treatment

Impact of the disease on their life

In reflecting on the meaning of the treatment, the adolescents also thought about the impact of the disease on their lives and how this causes changes in their way of being. If before they felt "omnipotent", now they fear

for their lives, restricting their quotidian, ceasing to practice routine activities.

[...] I stopped practicing a few things, handball [...]. Doing boxing, I stopped dancing [...] Wolverine.

Chemotherapy is a treatment that contributes to the alteration of the social dynamics, directly influencing

their lifestyle. In addition to modifying the routine, the inclusion of the hospital in their world, becoming part of their life can be perceived. This impact was also reported by other authors^(6,9).

Soon after I discovered (the disease), I started to do everything, so the hospital became part of my life [...]. I went every day Thor.

In this quotidian, the people find a direction, attribute meaning to things, communicate, suffer, are happy, and relate, always based on their biographies. The lived experiences allow the directing of their motives towards life⁽¹⁴⁾. Due to the impact of the disease, the adolescents find themselves disconnected from their past activities and delivered into a new world now focused on their health.

Another dimension of this impact is the relationship between cancer and death and the fear of the adolescents faced with this dichotomy. The cancer may be associated with a death sentence, not only is the treatment difficult but also the disease is seen by many as impossible to be cured^(12,16). Thus, the adolescent is faced with a complicated situation, where death emerges as a possibility. However, this theme also emerges in a subtle, veiled manner.

[...] at first I thought I was going to die [...] Batman

The adolescents withdraw into themselves, they move away from the people they live with, and are afraid to leave the house, because they fear their condition may worsen. Also expressed in the discourses was the experience of the difficulty of the diagnosis.

I was afraid to leave the house [...], more afraid of catching something else, of becoming sick. Then I stayed locked inside the house. Superman.

It started as a pain like a stiff neck and more lumps in the neck were appearing, then these lumps got smaller and disappeared, then I had a puncture done, this showed nothing, and next biopsy was carried out, I was hospitalized and then biopsied and then came the result that it was Hodgkin's lymphoma. Batman.

The adolescents showed in their statements the process they went through to reach the diagnosis of the disease, remembering that the delay of this is an important factor in the patient prognosis, and may lead to a more advanced disease state being encountered.

But before this (the disease), I was told it was sinusitis and then I started taking the medicine, but it did nothing. Superman.

For Schütz, man is biographically situated in the world life, i.e. on which and for which he must act. Thus, he has an understanding of his world, an expression of the experiences and the other knowledge acquired

during his life. His wealth of available knowledge functions as a reference scheme for all interpretation⁽¹⁴⁾. Thus, by passing through a peculiar moment of life, the adolescents feel apprehensive, afraid of the future, since the uncertainty does not allow them to establish a safe scheme of reference. This anxiety is made explicit when the diagnosis is encountered.

Cancer is seen by society as a disease that will destroy the person from the inside, so that the affected patients can sometimes be marginalized by society⁽¹⁷⁾. Cancer is treated with mystification by the population, causing prejudice. Common sense stands against what is elaborated and described about the disease by the specialists.

[...] for those who see from the outside, nobody knows what it is for sure, there are people who are prejudiced, you know, looking sideways like that and keep thinking hey that girl has something. Blade.

[...] I did not play because the teacher was afraid that I might fall. He-man.

The ignorance of the other, faced with cancer, causes the adolescent to rebel in a subtle way, especially when framed in the situation of the patient. Their social worlds are based on a sharing of life with the other, thus the environment is experienced by everyone and one can be an influence in the life of the other.

[...] the others treated me like a patient, [...] the people, if I was standing someone would get up for me to sit [...] Wolverine.

In my city, it was kind of hard because everybody was saying, oh she's bald, she will die [...] there was always someone talking like this. Blade.

Such a situation is perceived and expressed by the adolescents as uncomfortable. They reveal themselves to feel different from the others and they experience a sense of isolation. Over time and with the appropriation of the treatment the adolescents found the motivation to demystify socially pre-established concepts. This feeling of discomfort and prejudice was also described by other authors^(9,18).

The discomfort of the treatment

The collateral effects of treatment were considered difficult by the majority of the patients. However, they also provide the hope of a cure. The first session of chemotherapy was considered by the adolescents as the most aggressive for the body.

In the first chemo, I thought I would die, I was debilitated from the surgery [...], I lost weight 15 Kg so I was really weak, I felt very sick in the first. Wolverine.

In the beginning it was difficult, I was shattered [...] Flash.

The effects of chemotherapy are diverse, some coupled to the quotidian life of the patients and others to the alteration of their image. Nausea and vomiting are the most perceived and often cause metabolic and psychological damage^(7,11).

I started chemotherapy, it was difficult, I would feel really bad, it hurt my body a lot, my back. Superman.

Another aspect that is modified by the treatment is the appearance; the most striking change in the body for the adolescent is alopecia, which is coupled to their self-esteem⁽³⁾. The adolescents, with the change of appearance, feel themselves outside the "limits of normality". The perception of prejudice from the other troubles them and can cause emotional damage⁽¹⁸⁾.

After two weeks, my hair began to fall out, then my father had to shave it anyway. In the beginning, I used a bonnet, but now I don't use it anymore, I don't care anymore. Blade.

[...] the hair was the most difficult situation, not so much from vanity, but what people would think [...]. Batman.

With the change of appearance, after the period of self acceptance, the youths learn to value other qualities that could compensate for the alopecia, characterizing this as a transitory phase. The treatment appears to the patient as a landmark that separated the events before and after the disease⁽³⁾. The youths mark the period of the disease, know how long they are under treatment and take advantage of it by improving their knowledge about the disease.

[...] after about three, four months of chemo. [...] I finished 8 months ago. He-man.

Ah, I have been doing the treatment for one year and seven months. Wolverine.

The adolescents verbalize to monitor their state of health and disease. Constantly, they are exerting a broad reflection regarding the difficulties and strengths of the treatment: "Where is it? What has passed and what lies ahead?" Always guided by the motives that comprise their biographical self⁽¹⁴⁾. Through their experience with the treatment, the youths realize that initially it is rather difficult, but with the passage of time it becomes easier. The youths become familiar with the routine, with the treatment then prepare themselves psychologically⁽⁶⁾.

[...] there are people who think it's kind of difficult in the beginning and such, but it's normal, sometimes I feel sick, sometimes not, but in the beginning it is always kind of difficult, the body reacts and stuff, but after it is [...] accustomed. Blade.

[...] I feel it is difficult (the treatment) because I'm bedridden, but now I have improved, because I have gotten used to the medication and I'm going to be well. Batman.

The familiarization, for Schütz, is given by the relationships with contemporaries from the indirect or direct and immediate experiences of the face to face type⁽¹³⁾. This familiarization with the treatment causes the individual to acquire and sediment the experience throughout its trajectory, facilitating comprehension.

Coping strategies

The family support is identified as fundamental in this coping. The role of the family seems to be to stay together with the adolescents, trying to alleviate the present, helping them in coping with this peculiar moment⁽³⁾. The eyes of all the close people are turned toward the patient, the siblings share this moment.

[...] at home my mother was always with me, my family was always present [...]. Thor.

In the family, I'm the youngest, I have six brothers - and wow! - I was very spoiled. Superman.

Effective communication plays an important role in the comprehension of the other and in the social interaction. But we experience the world in greater or lesser degrees of familiarity, intensity, intimacy and even anonymity⁽¹³⁾. The family is perceived in its "social role" as a fundamental support before an exhausting disease, which places it as a source of support and encouragement for the sick. The friends also exert their support to the sick youths in their quotidian, they treat them the same way as before and they also support them during their time of need.

In my life outside, I had to interrupt the college tuition, but, with my friends, it's normal, they treat me the same way, I have the support of my boyfriend. Batman.

It is in a turbulent period such as this that the youths manage to see who is really by their side. Generally, people without close bonds to the youth show support and solidarity in this moment⁽¹⁹⁾.

So about the people, friends, whatever, many people that you did not expect, were more present, they helped me a lot. Thor.

The world of the school is also the place in which they have more relationships, and these are made present in the period of illness of the adolescent, encouraging them not to desist.

At school it was cool too because at the end of the year, when I started treatment, everyone in my class sent a letter, saying that I was not to give up and such, I thought it was very cool. Blade.

During the treatment, the adolescents create bonds with the team that takes care of them, encouraged in

the quotidian life and in the treatment, and this bond helps the youths believe in the professionals and have confidence in them. But in addition to this, they create an emotional relationship.

Here everyone is great, the doctor, the nurse, whenever we need them, they are here. Thor.

The relationship with the professionals is formed face to face, which enables an exchange of experiences; so that there is a verbalization of fears, anxieties, frustrations and dreams. In this context, the professional can ease the discomfort of the patient.

Oh the doctors and nurses, they are all very good, everything was cool, many people so close, you know, they see us as people [...] Wolverine.

To care for the sick youths, it is essential that a bond is constructed, that uses empathy, putting themselves in the place of the adolescent⁽¹⁹⁻²⁰⁾. As well as the empathetic involvement, which is seen in the statements of the patients, there is compassion from those who care to those to be cared for, though they should not be treated as patients, but their suffering, present in this particular moment, shared and they should be integrally care for, to encompass them in a biopsychosocial sphere⁽²⁰⁻²¹⁾.

Here in chemo, I have no complaints; the people here put themselves in our place and end up seeing our needs and treating us well. Batman.

The care provided by the professionals during the chemotherapy session becomes differentiated, desired by the patients who are there. There is an exchange of experiences in the lived relationships, an exchange of affection. This emotional relationship was described in a previous study⁽²²⁾.

Religion is another source of support for the youths in the health-disease process. The belief that exists reaches beyond the physical barriers, demonstrating their belief in a higher being. In the following statements the thinking of the adolescents is explicit that nothing in life happens by chance, that everything has a purpose, and this, for them, involves God.

I trusted in God. Superman.

[...] it was God who gave me great strength [...] that's why I was so calm. He helped me. Wolverine.

The adolescents revealed that God gave them the confidence essential for them to have hope and to continue fighting to get rid of the disease.

Projection into the future without the disease

Faced with the new situations, the adolescents interpreted the world, solidifying knowledge, motivating themselves, directing their actions and projecting

themselves into the future⁽¹³⁾. An absence from activities during the treatment period is common, because the adolescents, in most cases, present collateral effects and have consecutive sessions of treatment⁽²³⁾. The adolescents are motivated to continue the previous activities; they often find this willpower in the hope provided throughout the treatment and, thus, will return to their routines⁽²⁴⁾. They speak enthusiastically about the activities that they went back to, to develop like the others, and seek what they left behind with the episode of treatment.

Now I go to school, I have fun and play a lot at break time and lead a normal life. He-man.

Now I have gone back to do karate, to get the black belt. And in school, I'm in the 1st year of high school. I think about college, everything, I want to study medicine. Flash.

The youths seem rushed as if they do not want to lose more time in their lives. The reinsertion of them in the activities is critical for the continuation of their cognitive development and their human relationships⁽²³⁾. Due to the coexistence installed between the adolescent and the others, there is an overcoming of the fear and the treatment becomes less frightening. The adolescents become resilient beings, presenting positive adaptations within the context of adversity and become able to recover their normal functional pattern⁽²⁵⁾.

In the beginning, I thought I was dying, now that I'm coming to the end, I think everything has passed. Batman.

Throughout the journey, the youths appropriate the treatment and differentiate what happened at the beginning and what they experience at its end.

[...] I do not care, no, I do not need to know what the others think, what I think is what is important [...]. So the treatment is difficult at first, but you have to think it is for you to get better, to heal. Blade.

Thus, time is what leads the youths to absorb the difficult situation which they have been through and demystifies it as they continue along. They look to the future with optimism, they believe the disease was beaten and that they can resume their daily lives as before.

I'll see if I do prep school, to try for architecture or civil engineering. Wolverine.

The adolescents refer to the disease and how this does not stop them thinking of the future, realizing their dreams and resuming interrupted activities. As they see themselves cured of the disease, they launch into the future, they reveal in their statements a personal growth. The process of becoming ill and encountering a complex situation can cause the youths to change, in

a way that the disease can be understood as a warning sign for a better enjoyment of life, the suffering may help the individuals to rediscover themselves⁽¹⁶⁾. In addition, the personal growth becomes unrivalled in this phase, because the adolescent starts to value their life, giving importance now to small things.

Having cancer is an unexplainable experience, I matured a lot, I have another view of everything. Thor.

I was a bit childish, now I can think in a different way. Flash.

The choices are made through processes, through stages; at each level, there are smaller alternatives to be considered, chosen or rejected. Some decisions sometimes lead back to the first stages, prompting reflections and decisions⁽¹³⁾. Throughout the treatment, the youths go through diverse situations, some that favor them and others that do not; so in this journey, they will mature and overcome the situation of adversity.

Final considerations

The speech of the adolescents revealed that the experience with chemotherapeutic treatment affects the various possibilities of *Being-in-the-world-with-others*. When reflecting on the chemotherapy, the adolescents also expressed their condition of having cancer and how the disease impacts their lives. Facing the treatment brings physical discomfort in its collateral effects, such as hair loss, bone marrow suppression, bodily pain, but it also brings the possibility of healing. The cancer and the treatment make the mental association between the disease and the possibility of death real, as well as the fear in the face of this dichotomy presented. Another aspect observed was that during the treatment, where there is an appropriation of its adverse effects, familiarity with people, with things and with themselves in this new living situation, makes the treatment less frightening, makes it possible to overcome prejudices and modifications in their fears and ways of coping, showing typical characteristics of action.

The relationship that develops between the adolescent and the team goes beyond the scientific. The adolescents name the professionals who cares for them, give them an identity, and, in this interpersonal relationship that develops during the process of care, what is required of the professional is the possibility of going to the other, of *being-with-them* safely, with a mastering of scientific knowledge and also with affection. For the adolescents, the effective care involves human nature and emotional, religious and ethical issues. From

this perspective, new horizons were opened regarding the important points related to caring for this individual in a fragile situation. In their statements, they unveiled a coping with the disease with vivacity, they presented coping strategies; seeking support in a triad: family, team and religion. They recognize the difficult moments, face situations of death, but do not let themselves admit defeat; they resume their activities and have good perspectives for the future without the disease. Finally, to identify the feelings of the adolescents regarding chemotherapeutic treatment and to know the world lived by these individuals allows those professionals who care for them to develop and direct their actions more appropriately in their professional practice.

References

1. World Health Organization. Physical Status: the use and interpretation of anthropometry. Geneva: WHO; 1995. WHO technical Report Series, n. 854.
2. Kourrouski MFC, Lima RAG. Treatment adherence: the experience of adolescents with HIV/AIDS. Rev. Latino-Am. Enfermagem. 2009;17(6):947-52.
3. Enskär K, Bertero C. Young adult survivors of childhood cancer; experiences affecting self-image, relationships, and present life. Cancer Nurs. 2010;33(1):E18-24.
4. Instituto Nacional do Câncer. Câncer na criança e no adolescente no Brasil. Rio de Janeiro: INCA; 2008. 220 p. [acesso 26 maio 2010]. Disponível em: http://www.inca.gov.br/tumores_infantis/.
5. Instituto Nacional de Câncer (BR). Estimativa 2010: incidência de câncer no Brasil. Rio de Janeiro: INCA; 2010. [acesso 26 maio 2010]. Disponível em: <http://www.inca.gov.br/estimativa/2010>.
6. Lanza LF, Valle ERM. Ser-criança-com-câncer em etapa final de tratamento – sua visão de futuro. [Dissertação]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2008.
7. Bonassa EMA. Enfermagem em terapêutica oncológica. 2ªed. São Paulo: Atheneu; 2009.
8. Popim RC, Boemer MR. O que é isto, a quimioterapia? – Uma investigação fenomenológica. Cienc Enferm. 1999;5(1):66-76.
9. Cicogna EC, Nascimento LC, Lima RAG. Crianças e adolescentes com câncer: experiências com a quimioterapia. Rev. Latino-Am. Enfermagem. 2010;18(5):864-72.
10. Alves CHBS, Kuperman H, Dichtchekenian V, Damiani D, Manna TD, Cristófani LM, et al. Growth and puberty after treatment for acute lymphoblastic leukemia. Rev Hosp Clín Fac Med S Paulo. 2004;59(2):67-70.

11. Arruda IB, Paula JMSF, Silva RPL. Efeitos adversos da quimioterapia antineoplásica em crianças: o conhecimento dos acompanhantes. *Cogitare Enferm.* 2009;14(3):535-9.
12. Li HCW, Chung OKC, Chiu SY. The impact of cancer on children's physical, emotional, and psychosocial well-being. *Cancer Nurs.* 2010;33(1):47-54.
13. Capalbo C. Metodologia das Ciências Sociais – a fenomenologia de Alfred Schütz. Londrina (PR): UEL; 1998. 102 p.
14. Wagner H. Fenomenologia e relações sociais, textos escolhidos de Alfred Schütz. Rio de Janeiro (RJ): Zahar; 1979. 319 p.
15. Parga Nina L, coordenadora. Estudos das informações não estruturadas do ENDEF e sua interpretação com os dados qualificados. Rio de Janeiro: IBGF; 1956. v.1.
16. Muniz RM, Zago MMF, Schwartz E. As teias da sobrevivência oncológica: com a vida de novo. *Texto Contexto Enferm.* 2009;18(1):25-32.
17. Cestari MEW. A influência da cultura no comportamento de prevenção do câncer. [dissertação]. Londrina (PR): Universidade Estadual de Londrina; 2005.
18. Costa JC, Lima RAG. Children and adolescents in outpatient clinic chemotherapy: nursing implications. *Rev. Latino-Am. Enfermagem.* 2002;10(3):321-33.
19. Oliveira DC, Gomes AMT, Benite AM, Valois BRG. Cotidiano e adolescência: representações e práticas de trabalho, escola, relacionamentos interpessoais e futuro. *Rev Enferm UERJ.* 2006;14:182-90.
20. Ribeiro IB, Rodrigues BMRD. Cuidando de adolescentes com câncer: contribuições para o cuidar em enfermagem. *Rev Enferm UERJ.* 2005;13:340-6.
21. Araújo MMT, Silva MJP. A comunicação com o paciente em cuidados paliativos: valorizando a alegria e o otimismo. *Rev Esc Enferm USP.* 2007;41(4):668-74.
22. Popim RC, Boemer MR. Oncological care according Alfred Schütz. *Rev. Latino-Am. Enfermagem.* 2005;13(5):677-85.
23. Paterlini ACCR, Boemer MR. A reinserção escolar na área de oncologia infantil – avanços & perspectivas. *Rev Eletr Enferm.* [internet]. 2008. [acesso 26 maio 2010];10(4):1152-8. Disponível em: <http://www.fen.ufg.br/revista/v10/n4/pdf/v10>
24. Bashore L. Childhood and adolescent cancer survivors' knowledge of their disease and effects of treatment. *J Pediatr Oncol Nurs.* 2004;21(2):98-102.
25. Teles SS. Câncer infantil e resiliência: investigação fenomenológica dos mecanismos de proteção na díade mãe-criança [dissertação]. Ribeirão Preto (SP): Faculdade de Filosofia, Ciências e Letras de Ribeirão Preto da Universidade de São Paulo; 2006.

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