

THE WORLD OF THE ADOLESCENT AFTER BEING DIAGNOSED WITH CANCER

O MUNDO DO ADOLESCENTE APÓS A REVELAÇÃO DO DIAGNÓSTICO DE CÂNCER

EL MUNDO DEL ADOLESCENTE DESPUÉS DE LA REVELACIÓN DEL DIAGNÓSTICO DE CÁNCER

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ABSTRACT

This study aimed at understanding the world of the adolescent after a cancer diagnosis. It is a descriptive qualitative study carried out at the Institute of Paediatric Oncology, São Paulo between February and April 2011. Participants were eight adolescents between 10 and 14 years of age. Data were collected during play therapy sessions. It revealed that adolescents' life is significantly changed after illness, hospitalizations, and treatment. A support network is crucial for helping in the coping process. This network comprises family, friends, health institution and pets. Health care team should deliver a humanized care, striving to meet the adolescents' physical, psychological and social needs, as well as encourage family participation.

Keywords: Adolescent Health; Oncology Nursing; Play and Playthings; Humanization of Assistance.

RESUMO

Objetivou-se conhecer o mundo do adolescente após a revelação do diagnóstico de câncer. Trata-se de estudo descritivo de natureza qualitativa, desenvolvido no Instituto de Oncologia Pediátrica, no município de São Paulo entre fevereiro e abril de 2011. Participaram oito adolescentes entre 10 e 14 anos. Os dados foram coletados por meio de sessões de "brinquedo terapêutico" e revelaram que os adolescentes têm mudanças significativas em suas vidas, decorrentes das hospitalizações, da doença e do tratamento. Diante disso, evidencia o quanto a disponibilidade de uma rede de apoio é fundamental para o enfrentamento, sendo a mesma representada pela família, amigos, instituição de saúde e o animal de estimação. Assim, abre-se para a equipe de saúde a necessidade de uma assistência humanizada ao adolescente com câncer, atendendo às suas necessidades particulares, não só físicas como também psicológicas e sociais, incluindo-se a participação da família.

Palavras-chave: Saúde do Adolescente; Enfermagem Oncológica; Jogos e Brinquedos; Humanização da Assistência.

RESUMEN

El objetivo de la presente investigación es conocer el mundo del adolescente después del diagnóstico de cáncer. Se trata de un estudio descriptivo de naturaleza cualitativa llevado a cabo en el Instituto de Oncología Pediátrica de la ciudad de San Pablo entre febrero y abril de 2011. Participaron ocho adolescentes de 10 a 14 años. Los datos fueron recogidos mediante sesiones de juego terapéutico y revelaron que en la vida de estos adolescentes hay cambios significativos, producto de las internaciones, de la enfermedad y del tratamiento. Queda evidente cuán importante es poder contar con una red de apoyo formada por la familia, los amigos, los servicios de salud y hasta por sus mascotas. De ese modo el personal de salud muestra la necesidad de brindar atención humanizada al adolescente con cáncer, atendiendo sus necesidades particulares, no sólo físicas sino también psicológicas y sociales, que incluyen la participación de la familia.

Palabras clave: Salud del Adolescente; Enfermería Oncológica; Juegos y Juguetes; Humanización de la Asistencia.

INTRODUCTION

Child cancer accounts nowadays for 1 to 3% of all malignant tumours diagnosed. In Brazil, as in most developed countries, cancer is the leading cause of death among children and adolescents aged 1 to 19. The incidence of paediatric tumours in the world ranges from 1 to 3% for cases of cancer being the median percentage of 3%.¹

Given its chronicity, cancer inflicts changes in the patient's life and in his family's. It demands adaptations to a new situation and the development of coping strategies, since it influences on biopsychosocial and spiritual dimensions.² Monitoring the patients during the course of the disease requires understanding their different physical and emotional responses, because the experience is pervaded by feelings of mutilation that go beyond the physical. It is an experience of loss and the individuals feel uncertainty about the future. Living with cancer is an intense experience; it means to open up to your feelings; people living with the disease need to learn how to transform weakness into strength.³

Adolescents long for freedom and independence. They want to decide about what to do, the things they like and their life projects. They start to look beyond the family group and take part of other social groups. Such changes generate conflicts and a necessary process of maturation. If they suddenly have to face a cancer diagnosis, then all the natural distress from this stage of life will worsen, with added fear and uncertainties.^{3,4}

Therefore, children and adolescents with cancer should be comprehensively treated: their physical and their psychological and social needs should be well looked after. The treatment has a strong impact on their life. It changes their routine and their habits; it imposes restrictions and isolates them from relatives and friends, all that plus the fear and concern about the evolution of the disease. Nevertheless, they recognize the importance of treatment and curing. The cure of cancer requires specialized nursing care in order to meet those needs.⁵

There is an interest to understand the world of the adolescent after cancer diagnosis because of the important changes in their lives and because there is little scientific production on the subject. The adolescents' worldview is meaningful and should be looked at, since such young people know their own needs and human values.

The concept of "world" relates to the structure of human circumstances in which an individual is born and lives. Chemotherapy promotes a series of transformations in the world of those who receive it: it changes body; it affects emotional states and routines. Patients usually go through the experience with feelings of sadness, fear, anxiety and depression. Despite these adverse effects, chemotherapy is seen as a source of hope for patients and their families.⁵

Based on this, the present study aimed at understanding the world of the adolescent after a cancer diagnosis. The authors hope to lay out subsidies for the nursing planning in order to improve their quality of life, according to the atraumatic care principle⁶ of the National Humanization Policy.⁷

METHODOLOGY

This is a descriptive qualitative study where natural environment is the direct source of data, the researcher is the key instrument and the understanding of behavioural phenomena the research focus. It deals with the universe of meanings, motives, beliefs, values and attitudes, corresponding to a deeper place within relationships.⁸

It was carried out at the Quimioteca, a place for the administration of chemotherapy at the Institute of Paediatric Oncology of the Support Group for Adolescents and Children with Cancer of the Federal University of São Paulo.

The study subjects consisted of eight teenagers with various neoplasms, aged between 10 and 14 years of age, five male and three female, who met the following inclusion criteria: to be between 10 and 14 years old; to be undergoing chemotherapy; those whose health condition allowed them to be interviewed. Adolescents with unfavourable health conditions were excluded.

According to the World Health Organization, adolescent is the individual between the ages of 10 and 19 years. Two stages of adolescence were considered here: the early adolescence (from 10 to 14 years of age) and the late adolescence (from 15 to 19 years of age).⁹ Selection process was terminated when data was considered potentially representative of the phenomenon under study.¹⁰

Data was collected between January and June 2011 after the institution authorised the research in its premises. The Ethics and Research Committee of the Federal University of São Paulo approved the study under protocol No 1.988 / 10 and parents and adolescents signed the term of free and informed consent as recommended by Resolution No. 466/2012. In order to protect the participants' identity, they were assigned another name but, when they were asked if they wanted to choose a new name, only three of them agreed, the other five kept their own.

It is better to learn the world of the adolescent with cancer through play because it acts as an activator and a structuring factor of human relations. Moved to the hospital setting, play is essential to preserve safe and healthy relationships.¹¹

Data collection tool was an interview during play therapy sessions as an outlet for anxiety experiences atypical to their age. Its primary purpose was to enable the youngsters to express their feelings whenever they found it hard to deal with difficult situations.¹² Play therapy used by nurses is endorsed by Federal Nursing Council resolution No 295/2004, which estab-

lishes that it is up to them to use play as therapeutic tool during hospitalization.¹³

They were individual play therapy sessions carried out with the patient in the hospital bed awaiting or receiving chemotherapy; they took between 8 to 52 minutes and began with the following guiding question: "Shall we put together a story of a teenager who comes to know that he has cancer?"

Different objects (rag dolls representing family and health professionals, syringes, needles, catheters on needle, extensions, faucets, micro drop, cotton, tourniquet, IV bottle, hypoallergenic adhesive; household objects and materials for drawing and painting) were made available to dramatize domestic and hospital situations. The process followed the principle of non-directivity, as recommended in the literature.¹²

Sessions were recorded and fully transcribed so as to document verbal and nonverbal manifestations. The mother's voice was heard in one of them bringing additional content about her son's life after the cancer.

The data stemming from the interviews was analyzed through the following stages: thorough reading of contents of play therapy sessions; coding – identification of phrases, subjects or recurring concepts within the *corpus* for the most relevant ones to be analysed; categorization – grouping of codes according to their characteristics becoming representative themes of the phenomenon in question.¹⁴

RESULTS

Based on the data analysis, six thematic categories that will be described and exemplified below emerged.

Living with the uncertainty of cancer – When the teenager begins to feel pain or notice "lumps" or "swellings" in his body, he enters into a terrifying world of uncertainty and insecurity, thinking about diagnosis, making him sad and leaving him dumbfounded, wondering what will come next.

I was having severe headaches and then my mother took me to the ophthalmologist. First, they told me it was a blip. That it would be gone in a jiffy; that I'd only had to wait a little (Romulus). I felt a lot of pain in the knee. I was taking a bath when my hand suddenly touched a very tiny small lump. The small lump was ... [pause]. I was in too much pain and my mother took me to hospital (Paloma).

I was wondering about myself, walking with two crutches and an amputated leg. And... [silence] (Macarrão).

I felt sad (Karen). What came to your head [researcher]? First, hair loss [grimacing]; and then all the rest, the treatment (Karen).

Living and suffering throughout treatment – the need for immediate treatment intensifies uncertainty. The adolescent enters the realm of hospital procedures, revealed when the hospital equipment is used in the session; it evokes memories of pain, fear, grief, anxiety and stress from various diagnostic and therapeutic interventions not part of their world before the illness.

She looks scared at the nursing assistant with the syringe in her hand, coming toward her to saline totally implanted central venous catheter (Karen). How old is your brother [researcher]? Two (Karen). Do you play a lot with him [researcher]? She nods, staring at the nursing assistant trying to disconnect the unit from its access.

Although a central venous catheter is used to give chemotherapy, peripheral intravenous puncturing – for constant blood tests – is part of their routine. Thus, besides dramatizing the puncturing, they exposed their feelings and concerns about it and its effect on their body image.

Grabbing the scalp and staring at it: – This one doesn't hurt that much! It is like this ... showing the bruises on his right arm (Bidu).

I do not like this (the scalp) ... – whispers, eyes wide open – because I've been punctured a lot here (Paloma).

Today, I had surgery; they put on a prosthetic leg that replaces the bone that the tumour... it sort of weakens the bone and if I tried to tread too hard, it could break (Macarrão).

When they talked about the therapy, the adolescents expressed suffering because of the changes on their daily lives, such as the need to change festive days and go back to the oncology unit to control the progress of the disease, even after treatment,

It changed Christmas as well! I was leaving just before Christmas and New Year! Only this year I couldn't. I had to stay behind because I had a shot. Then I had to stay home (Paloma).

And at the end of the year ... December, we go to São Luís ... I think I'm back every six months for check-ups (Romulus).

I spent my birthday in hospital. It was not a very happy one! [With a wry smile] because I was there at hospital (Macarrão)

The adolescents emphasize the difficulties of chemotherapy and express a range of feelings and reactions, such as non-adherence to treatment, regret for the alopecia, sickness due to chemotherapy and even food restrictions.

I had a thrombosis and when I was hospitalized the doctor found out that I had cancer. She came and said that next week I would have to do chemotherapy. I said that I was not going to. I would not do. I would not do! (Paloma)

Yeah ... I still have it ... I throw out a lot. Next day, I'm usually a little sick. I want something sweet, because I can't eat salty things (Romulus).

Do salty things make you sick [researcher]? I just did chemotherapy and salty things taste very bitter. Taste changes. (Macarrão).

It is difficult when hair falls out. It is very difficult to see yourself losing your hair. I got out of bed and it was full of hair. And I used to like pulling it off ... and my mother would say: "Rosa, don't do that. I'll have you cut it". To have it cut was worse. They told us that when we were about to start the chemo. I cried. I cried a lot! (Rosa).

The effects of chemotherapy are so intense that the teenagers even think about quitting the treatment they have to follow.

I will be honest with you; I'd rather not be here! That's for sure ... But if I am, what can I do?! You must get on with it ... But I often thought about quitting and stop coming to hospital ... to drop everything! But my mother and my grandmother wouldn't allow it [laughs]. But I know that if I give up, it ... can spread. Then I can die. What can I do? What motivates you to think about quitting [researcher]? I find it is.... the chemotherapy. It's very hard to do that! (Paloma)

Seeing how cancer changes the course of life – being a chronic disease, cancer inflicts many changes in the adolescent's life; it claims readjustments and the development of strategies to face new situations, such as the change of home.

Looking at that cow, do you know what came into my mind? [laughs] my grandfather's farm, in Maranhão. There're cows just like that one (Rosa).

I'm leaving, goodbye to you all! You have to fix this stuff here! Where is he going to [researcher]? To Lorena (Bidu).

Taking the dog and the doll, he says: here in São Paulo ... we left a dog there in São Luis. I used to live in São Luis, in my city. There I was ...it's very different from here. I was more, let's say ...more free (Rômulo).

From the moment cancer is diagnosed, the adolescent's life turns upside down. Many ties are broken, whether with family, school, friends and even with the pet. Restrictions become part of their everyday life. Feelings of rage and anger generated from such restrictions are symbolically manifested.

The mother talks about the changes in her son's life after knowing about the cancer and asks him: Wasn't that so? (Victor's mother)? He doesn't answer; keeps piling colourful cubes and places the snowman beside it (Victor). Do you enjoy hearing your mother tell stories [researcher]? Hits the snowman, silently overturns the pile of cubes (Victor).

Benefits from a support network – despite the changes and difficulties, adolescents benefit from a support network – family, pets, friends and health care institution, where they find the strength to endure all difficulties.

People here are very affectionate. Then I study here at hospital with the teachers here because I can't go to school and I always study here (Macarrão).

In my house there's always a lot of people and I don't suffer from prejudice. That's good! My mother and my grandmother won't let me give up the treatment (Paloma).

Chemotherapy makes me sick. I'm a little sick on the second day, and she [the dog] amuses me so much that I forget to throw up. Once I didn't throw up, but she did it in my stead [smiling]. Then she helps me a little. She's always my good friend here (Rômulo).

Living in a world of hopes – encouraged by the support network, the teenager finds the strength to overcome the hardships of cancer, building a world of hopes, trusting in the treatment and believing in beating the disease.

I'm walking in crutches; then I'll take them off and walk with both legs. Then I'm going to do everything I did before: sports, I used to play Taekwondo ... a sport that uses 70% of legs and 30% of hands (Macarrão).

Despite the difficulty of the treatment, young people recognized the need for the procedures and the prog-

ress made. The cure, the feelings of comfort, safety and the strength found in God's grace are present in the adolescents and their families.

We pray a lot. My whole family is praying for me. And I'm here, and all is well! God willing, I'll get even better (Rosa). The treatment is at an end ... in July already. There's a girl whose treatment is ending together with mine. I think she is called Soraya (Bidu).

The completion of treatment makes the adolescents wish to return to their homeland and to their old habits, such as swimming in the sea, in the river and to meet the whole family.

What is it that you most wish to do when treatment is over [researcher]? To go back to São Luís. Back as it was before. To go to the swimming pool, here I can't; in the sea, in the river; to dive once again (Rômulo).

The participants praised their victories, telling about the obstacles they overcame from diagnosis to treatment.

So I kept going to school, studying there, taking all the examinations. Only on Mondays, Tuesdays and Wednesdays; not on Thursdays and Fridays because I'm at hospital. And I also miss a lot of the school stuff; but then I catch up later and study. I miss exams, most of them; so I have to take them later on. But ... I manage to catch up with everything, all the contents (Rômulo).

Play therapy is key to understanding the world of an adolescent with cancer – during play sessions the teenager demonstrated, verbally and symbolically, the importance of play, especially with hospital supplies even when in pain. The activity brought them satisfaction; it allowed them to ease tensions and reproduce experiences (catharsis). The performance of procedures that make part of the world of an adolescent with cancer was so important that the activity could only be closed after its manifestation.

He introduces the scalp in the puppet's arm; breaks into a big smile. He removes the left hand glove with bright eyes (Yan).

He gets the scalp, opens it; asks for help to strip the needle and looks about for something to stick it to. Picks up a doll and introduces the needle in the centre of its chest. Takes the scalp out and keeps watching. He puts the needle cover back on. Ready! Game is over! (Macarrão).

And this girl, what does she have [researcher]? Osteosarcoma as I. And where is hers [researcher]? In the arm, in both arms. [placing the syringe needle on the baby doll's arm]. Now I'll give saline for them to take. Shall we put together a story of a teenager who comes to know that he has cancer?" [researcher]? Yes! [smiling] (Bidu).

What do you think of the game [researcher]? It's cool! (Rosa).

DISCUSSION

The study results revealed how the adolescents' world changes course after a cancer diagnosis: it is full of suffering and uncertainty, despite them being sustained by a support group, faith in God and hope for the future.

The results also emphasized that feelings of uncertainty are triggered the moment doctors suspect the adolescent may have the disease and go beyond cancer diagnosis. During play therapy their performances showed that they waited too long for the appropriate treatment, and that they had been hospitalized several times for tests before final diagnosis was confirmed.

Suffering brought about by all the hospital procedures corroborates studies that say that the treatment for cancer is not simple and that its success depends on painful and invasive procedures that cause discomfort and distress.^{4,5,11,15}

Even with technological advances, such as long-term catheters that help to relieve the discomfort, they still suffer from the puncture and its physical restrictions. A study carried out with children and adolescents with cancer carrying these catheters reports the painfulness of punctures and the discomfort and fear caused by it, as well as emphasizes the restrictions and concerns about life-threatening infections.¹⁵

Cancer treatment is a sad and difficult experience. The pain, the limitations, the need for frequent hospitalizations and outpatient visits, numerous intrusive and painful procedures added to the awareness of having a chronic disease whose treatment does not guarantee its cure, not even its prevention, make it that way. The same context has been chronicled in other studies on cancer.^{11,16}

The disease treatment becomes part of the young people's life, and they come to recognize the importance of therapy, which is initially perceived as very difficult. As times go by, it becomes more bearable. Such assertion reiterates the findings of another study that concluded that children with cancer become accustomed to hospital routine, to treatment,¹⁷ and start to recognise chemotherapy as a chance of cure. Therefore, they prepare themselves psychologically to handle the changes they might face.¹⁸

In general, the adolescent with cancer gets silent because, according to the literature, diagnosis and treatment compli-

ance produce psychological disorders resulting from its symptoms, as well as from the perception patients and their families have of the disease and its stigma.¹⁹ This occurs because the adolescent who longs for freedom and autonomy is forced to undergo an extremely aggressive treatment that changes his routine having to get adapted to a new one.²⁰

Hospital stay, from the adolescents' point of view, means losing many things which triggers a grieving process. Most often, this process is aggressive due to the stress caused by the disease itself, life routine changes, the limitations of activities and "unforeseen" circumstances, such as the need for tests, medical check-ups, painful procedures and unpleasant medications.^{20,21}

Chemotherapy proved to be a major cause of distress given the changes it brings. At this stage they are aware of alopecia and sometimes refuse treatment because of it. Loss of hair is the most striking body change and therefore closely linked to their self-esteem. The change in their looks means that they do not fit in the "normal" beauty standards since alopecia projects an unhealthy image. The others' perceptions of them and their prejudices are emotionally damaging.⁵

Feeding difficulties, nausea and vomiting (even antiemetic medication) make them want to give up chemotherapy. Another research focusing on the metabolic and psychological damage and the fear of death experienced by adolescents in chemotherapy validates such results.^{3,5}

During dramatizations, adolescents explained how cancer changed their life, drawing them away from their homeland, family and pets. It changed their daily routine; it made them go through the difficulties to adapt to a new life which led to irritability and to be angry about the disease.

This fact is also highlighted in another study that demonstrates that the daily struggle with disease is source of great suffering not only for the family but also for the child; plans are postponed and all its members need to adapt to denial.¹¹ Not knowing how to deal with these feelings, adolescents often relocate them to health care professionals through an aggressive behaviour,²¹ which was shown here by puncturing the puppet that represents the health professional.

Faced to so many difficulties, the adolescents pointed out the importance of the support network to fight the disease. This network may be represented by the family, friends, and the health institution and even by a pet. This context is consistent with another study according to which when your world changes you need to reorganize it for it to exist in a new context. As future prospects are always uncertain, hope and trust in the health care team and family anchor encourage children to cope with enthusiasm this arduous path.¹¹

The pet dog, the support of friends, the help of health institution and family are essential coping resources. The role of the family is to stay with the teenagers, trying to ease their anx-

ieties and the negative feelings generated by the hospital, assisting them in their hour of need. This will help them accept treatment, as the study subjects mention here.²⁰

The disease, therefore, disrupts everyday interpersonal relationships and reshuffles others in order to provide support to the patients. They would rather have this support than any other thing such as intimacy, companionship and confidence, often identified as central to engage into friendship.²¹

School support within the institution was crucial for the teenager to carry on with his learning process. As demonstrated in other studies, the school routine is important and should be maintained.^{5,22} The school and the relationships promoted in its context should be present during the disease process for it encourages them not to give up.²³

Another study⁵, along with the present one, revealed that adolescents feel motivated to continue with previous activities. It gives them hope throughout the treatment. At the same time, side effects impart the notion that chemotherapy is eliminating what is bad; that the treatment is a step towards healing, encouraging them to continue. They speak enthusiastically about activities carried out with parents and seek to rescue those interests previous to the treatment.

Living together with other patients their same age helps them to overcome fear and then treatment becomes less daunting. It becomes resilient, its adaptation in the context of adversity and the ability to recover its normal functional patterns.²⁴ In yet another study faith appears as a valuable source of support for the adolescent and his family.²⁵

The role-play encouraged young people to talk about their illness; it fostered human relationships and allowed the establishment of a dialogue between those who care and those who are cared for. Playing enables patients to learn about their world, time and space; the individuals can express their world vision; it constructs and it deconstructs realities; it helps them to build a world that is meaningful to them and that meets the particular needs for their overall development; it provides them with an extensive knowledge of themselves and of the others and leads them to discover who they are.¹¹

FINAL CONSIDERATIONS

The study enabled the researchers to understand that the world of adolescents with cancer undergoes important changes resulting from hospitalization, illness and treatment. This calls for a support network represented by family, friends, health institution and even pets.

Based on acquired knowledge the authors would like health teams to realize that providing comprehensive and more human care to adolescents with cancer would alleviate suffering and contribute to a better acceptance of the disease

and therapeutic adherence. It would also meet not only their physical needs but those psychological and social ones as well, including the family's involvement.

Through the play therapy sessions teenagers revealed aspects of their world after the diagnosis and had the opportunity to vent their fears, worries, satisfactions and reactions respecting the treatment. This intervention should be used as a communication tool in nursing care to adolescents with cancer.

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