

EXPERIENCES OF FAMILIES WITH CHILDREN AND ADOLESCENTS AFTER COMPLETING A CANCER TREATMENT: SUPPORT FOR THE NURSING CARE¹

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Ortiz MCA, Lima RAG. Experiences of families with children and adolescents after completing a cancer treatment: support for the nursing care. Rev Latino-am Enfermagem 2007 maio-junho; 15(3):411-7.

The survival of children and adolescents with cancer has increased in recent years. Researchers and professionals in the health area have prioritized studies on the delayed effects of the treatment and quality of life of the survivors. This study aims to understand how parents and other family members of children and adolescents with cancer, experience the completion of the treatment. This descriptive and exploratory study adopted a qualitative methodological approach. A total of ten families whose children had completed the cancer treatment and were in follow-up in a hospital-school were selected for the study. The data were organized in two thematic axes: the memory % what was experienced and the present % what is being experienced. The study evidenced the participants' vitality to survive the treatment and fragility to live after it. The results allowed identifying aspects that need intervention, aiming at the improvement of quality of life of children, adolescents and the whole family after the end of the treatment.

DESCRIPTORS: neoplasms; child; adolescent; family; survivors; pediatric nursing

EXPERIENCIAS DE FAMILIARES CON NIÑOS Y ADOLESCENTES, POSTERIORES AL TÉRMINO DEL TRATAMIENTO DE CÁNCER: SUBSIDIOS PARA EL CUIDADO DE ENFERMERÍA

La sobrevivencia de niños y adolescentes con cáncer viene aumentando en los últimos años. Investigadores y profesionales del área de la salud han establecido como prioridad, estudios sobre los efectos tardíos del tratamiento y la calidad de vida de los pacientes. El objetivo de este estudio es comprender como las familias de niños y adolescentes con cáncer vivencian el término del tratamiento. El estudio es de naturaleza descriptivo- exploratoria con análisis cualitativo de los datos. Participaron diez familias de niños y adolescentes en la etapa final de su tratamiento seguido dentro de un hospital-escuela. Los resultados fueron organizados en dos ejes temáticos: la memoria- lo que fue vivido y el presente- lo que se vive. Con este estudio, se evidenció la vitalidad de los participantes para terminar el tratamiento y la fragilidad de vivir posterior al mismo. Los resultados permiten identificar aspectos que requieren de intervención, teniendo como objetivo una mejor calidad de vida para los niños, adolescentes y para su familia, posterior al tratamiento.

DESCRIPTORES: neoplasias; niño; adolescente; familia; sobreviviente; enfermería pediátrica

EXPERIÊNCIAS DE FAMILIARES DE CRIANÇAS E ADOLESCENTES, APÓS O TÉRMINO DO TRATAMENTO CONTRA CÂNCER: SUBSÍDIOS PARA O CUIDADO DE ENFERMAGEM

A sobrevivência de crianças e adolescentes com câncer tem aumentado nos últimos anos. Pesquisadores e profissionais da área de saúde têm estabelecido como prioridade estudos sobre os efeitos tardios do tratamento e qualidade de vida dos sobreviventes. O objetivo deste estudo é compreender como as famílias de crianças e adolescentes com câncer vivenciam a experiência do término do tratamento. O estudo é de natureza descritivo-exploratória com análise qualitativa dos dados. Participaram dez famílias de crianças e adolescentes na fase de término do tratamento que estavam em acompanhamento em um hospital-escola. Os dados foram organizados em dois eixos temáticos: a memória - o que foi vivido e o presente - o que se vive. Com esse estudo, evidenciou-se a vitalidade dos participantes de sobreviver ao tratamento e a tenacidade de viver após ele. Os resultados possibilitaram identificar aspectos que necessitam de intervenção, objetivando a melhoria da qualidade de vida de crianças, adolescentes e da própria família, após o término do tratamento.

DESCRIPTORES: neoplasias; criança; adolescente; família; sobreviventes; enfermagem pediátrica

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INTRODUCTION

In Brazil, the incidence of pediatric cancer is still unknown in its full extent, although national estimates from specialized services, affiliated with the Brazilian Society of Pediatric Oncology (SOBOPE) and registered at the Ministry of Health, indicate between 8,000 and 10,000 cases/year in Brazil⁽¹⁾. North American statistics estimate that one in every 900 persons between 16 and 44 years old will be a survivor of child cancer. This rate is expected to reach one in every 250 by 2010⁽²⁾. In Brazil, children and young people with acute lymphoid leukemia are cured in 80% of cases⁽³⁾.

Nowadays, being free from the disease from a medical perspective is a growing possibility for children and adolescents with cancer. However, the emotional and social dimensions of cure need to be taken into account. In this sense, if the experience of having a cancer affects all levels of the child's, the adolescent's and their relatives' lives, the same is true for the experience of surviving such a severe disease and aggressive treatment⁽⁴⁾. Children cured from cancer are ex-patients, who may suffer from more or less visible and disabling physical and mental sequela and preserve, for a long time, the marks of the threat that hit their body and put a burden on their lives⁽⁵⁾.

The term survivor emerged in the 1970's and there is no consensus in pediatric oncology literature about the definition of survivors. Some authors define the term as children and adolescents who are free from the disease for at least five years, while others use it to refer to patients who completed the therapy at least two years ago⁽⁶⁾. In this study, we adopt the definition that cancer survivors are people who were diagnosed with the disease and affected by the diagnosis. The latter situation also includes relatives, friends and caregivers⁽⁷⁾.

In interaction in the family sphere, each family member's health and disease state affects and is affected by the family. Children and adolescents, especially with severe diseases like cancer, affect the entire family and interactions among its members. In this perspective, becoming a patient and receiving health care covers a series of events that include the interaction among different people, among which the family, friends and health professionals. Each family's role in this process varies according to the type of health problem and the relatives' degree of involvement⁽⁸⁻⁹⁾.

The family represents an important source of support to its members in the health-disease process⁽⁸⁾. Consequently, it has assumed the daily care needed in the therapeutic process, in the home environment as well as during hospitalization episodes. As a result of the increasing emphasis on the family, the way it is perceived in the health context has changed, mainly surpassing the utilitarian definitions that used to be attributed to the family, when it was seen exclusively as a good for the patient and its presence was considered and sometimes tolerated, especially in health care environments, in view of its role in the affective sphere of the sick relative's recovery⁽⁹⁾.

Getting to know the family's experience in crises, the overload the disease provokes and the quality of life obtained in daily reality allows nurses, if aware of the strategies the families use, to offer support and discuss the best alternatives for coping with the disease situation⁽¹⁰⁾. Thus, this study aims to understand how parents and other relatives of children and adolescents with cancer experience the end of treatment, in order to support them to cope with this and future periods.

STUDY DESIGN

This is a descriptive-exploratory study with a qualitative methodological approach, given the nature of the study object and the proposed objective. We attempted to understand the meanings relatives of children and adolescents attribute to the experience of surviving cancer. These meanings are considered as being constructed in daily life, in the social relations with their peers.

The research was carried out at the Child Cancer Outpatient Clinic of the University of São Paulo at Ribeirão Preto Medical School *Hospital das Clínicas* (HCFMRP-USP). To comply with Decree 196/96 by the National Health Council, the research project was submitted to and approved by the institution's Research Ethics Committee. Study participants were ten families whose children finished cancer treatment. Nine mothers participated, as well as two fathers and two sisters.

Data were collected through semistructured interviews, observation and surveys of patient files. Semistructured interviews were used as the main data collection resource and were recorded, with the

participants' permission. We departed from the premise that the home context is a sphere the families master better and would thus grant security, freedom and greater privacy during the interview. It was observed that this actually occurred, as the participants demonstrated more tranquility at home than on the day they were addressed in the hospital sphere to present the project. The interviews at home allowed us to identify the situation the families lived in, offering resources for planning interventions that approached their realities.

RESULTS

Based on the data, two thematic axes were identified: the memory – what has been experienced, and the present – what is experienced. These will be presented below.

The memory – what has been experienced

Remembering the past, the path traveled until the correct diagnosis, the difficulties faced because the child's health status worsened, the fear and uncertainty entailed by the diagnosis and becoming familiar with the new routine, new people, new environments were part of the relatives' lives. The start of the disease, which is generally abrupt, without an unknown cause, was identified by small and random alterations that got worse suddenly and rapidly, surprising the family. The search for the correct diagnosis was part of the history of these parents and children. As cancer is a disease with non specific signs and symptoms, this can often make the diagnosis difficult, as observed in the report below.

I thought it was something typical of children, a silly pain. Sometimes we think that children complain too much... Then, in September, he started to get really bad, he started to have diarrhea and vomiting. I took him to the doctor who said he had worms, I gave medication and he didn't get better, I went back to the doctor with him, complaining of belly ache. This time they told me it was gas, I gave medication and the boy didn't get better, he started to lose weight... I ran from one doctor to another for four months, then, besides the abdomen, his belly started to hurt. He vomited and had diarrhea every day, I took him to the doctor who asked for a blood test and said it was hepatitis... I insisted, this is not hepatitis. When they were born, I took all of my children to one doctor because, if there's something wrong, it's easier to find it when they get ill (Fernanda, mother of Fábio).

Receiving the news of a cancer diagnosis triggers a waterfall of reactions, feelings and attitudes in the family and child, such as fear, revolt, guilt and the search for help.

... They found that he had a tumor. We got desperate. Our world ended (Ivana, mother of Iara).

... When we got there, the doctors from Ribeirão, they explained everything about the tumor, that it was treatable... that his hair would fall out. I got desperate, because everyone says that who has this disease [cancer] dies... Oh dear, I got... (Joana, mother of Junior).

The parents had to reorganize their activities in order to accompany their children. Their family was restructured in the social and financial sense, as mentioned below.

... Sometimes, he [child] said: dad, stay with me at the hospital to do the test. No! I can't stay... [lowers his head and remains silent]. Sometimes his mother got angry of course... and I.. I can't stay, I have to work because I'm the only one who works at home, if I start to be absent from work... I have to go there to do my job. It was no use, they fired me anyway... (Antônio, father of André).

... I used to go to mass with the girls every Sunday, but after treatment started I didn't go to church anymore, because she couldn't spend time in places with a lot of people... How could I leave her behind? Impossible! I stopped going to church... (Ivana, mother of Iara).

In this study, it was perceived that, when the organization for the child's care demands that one family member gives up his/her job, particularly when that member is financially responsible, this compromises family income.

... Until March 2004, I worked as a kitchen aid in a supermarket in the city and did some jobs here and there, as a maid... but after the girl got ill I had to stop to take care of my daughter. I divorced her father... it's just me... it's difficult... I'm still unemployed (Carla, mother of Cíntia).

Another situation the family may have to cope with is distancing among family members. Parents and healthy children go through separations due to the child's treatment, and healthy siblings are also affected by the treatment.

The sister had to go through the psychologist, during her [sick daughter] treatment, because her sister felt rejected... I only took care of her [sick daughter]... Her sister used to stay with her aunt or grandmother because, then, I used to live at the back of my mother-in-law's house (Carla, mother of Cíntia).

His brother suffered, he didn't understand it very well... He saw everyone crying and asked: mom, is Fábio gonna die? I said no... But I didn't hide anything, I said that Fábio's disease

was very serious, that he would have to stay in hospital to get better, he stayed with my mother-in-law (Fernanda, mother of Fábio).

The adverse effects, surgeries and the therapeutic plan led to moments of suffering and pain for the child, the adolescents and close persons. The possibilities of successful treatment, as well as the risks and sequelae of the therapy raised the parents' awareness as they went through the different phases of different protocols. The parents perceived that the disease, the treatment and the hospitalizations would entail not only biological, but also social repercussions. The possibilities of sequelae, due to the tumor resection or the news about the resection of one or more organs, caused moments of crises in the parents.

He was skinny, because of the chemo, the person's organism gets weak...because, at first, they have to give a very strong drug, he got skinny and soon his hair started to fall out, I just know that this period was very difficult... he used to vomit... [Father lowers the head and dries his tears] (Antônio, father of André).

She suffered a lot from the chemo, all of her hair fell out after a week, she got bald, really sick, that part caused great suffering... The surgery took almost 10 hours... I think it was Dr. Célio who arrived and said that it wasn't just the kidney they took out, no... it was the bladder, a piece of the pancreas... it was a shock... I even got sick at the hospital, I had a nervous crisis, my hand and mouth got twisted, everything... (Carla, mother of Cintia).

The reports show that the initial phase of the disease and the treatment caused changes in the parents and relatives' lives. All participants remembered the process of searching the diagnosis, the trajectory until they received the correct diagnosis, as well as the effect of the disease's confirmation in their lives. Thus, the parents started to obtain knowledge about cancer, the treatment and its consequences.

The present – what is experienced

The study participants mentioned joy at the end of the treatment but, at the same time, reported on their feelings and concerns related to the child's physical condition and adaptations to the sequelae.

When we got the news, it caused great joy for me and for him. But I'm very scared and I take great care of him. I don't let him play soccer, because imagine if a ball hits him on the site of the surgery. Because he's got that hole in his belly to pee. He's

not allowed to swim, because he may catch an infection. He's always got infections. Now he's taking antibiotics and got better. But you never know. He takes care of his catheters, every 4 hours. He doesn't sleep well, and neither do I, because I'm afraid that he won't wake up alone. He doesn't walk around without a shirt. He's always saying that he's different from others. Because I always call him, to use the catheter while he's playing, the others don't stop playing soccer to do that, he forgets. When you have to wake him up at night... oh dear! He wakes up angry... it's very tiresome, for him and for me. But we talk a lot, it's better like that than being dead (Helena, sister of Hugo).

The need for special care and follow-up of medical guidelines in the first months after the end of treatment were followed by the parents, including care that was no longer necessary, in order to prevent situations that could change the child's health state.

The doctor said that his life is normal now, that he's cured. Of course he can't have a normal life, because he can't drink tap water... But I maintain some care, I give him boiled water, I soak the fruit in water with bleach. That care is not difficult... It's even good... I buy bottle water, which seems to be good... But I boil the water nevertheless. Juice with boiled water only...he [son] takes boiled water to drink in school... it's never too much... I go to bed and think: does he have to take medication today? (Eva, mother of Eduardo).

Attention also focused on the sequelae deriving from the treatment. One mother's report revealed dissatisfaction and concern, acknowledging her daughter's need to take medication for the rest of her life.

Ah! I was happy when I got the news that treatment had ended. I was happy... Thanks God! I'm a bit annoyed because of the Benzectazil, because she has to take it for a long time... we get upset. Her bladder was removed, she'll have to take the Benzectazil for protection against contaminations. The doctor told me that it's quite risky, that, if she doesn't take it, she may catch a sever virus that causes death. Her bladder was removed because the tumor was rooted in, it had already affected and they also removed a piece of the pancreas. We get upset.... it's hard. I haven't been interested in asking yet... what it's going to be like from now on. I know there's the tomography, tests every six month. I think my head is really like... and we don't ask (Carla, mother of Cintia).

The sequelae interfere in the survivors' quality of life. The main concern seems to be with the self-image, specifically with the hair loss, perhaps because this makes the child or adolescent different from others.

Today, she's got some defects in her head, some holes, her head is not smooth like ours... Her head won't grow, it's full of

defects, she's ashamed, I feel sorry for her... [starts to cry] she doesn't like to go out, is concerned... I tell her it will grow, but it won't. I have to think that the hair is the least of all concerns. I hope I'll never have to go through this again. Sometimes I'm confident, but other times... Sometimes I cry a lot... She couldn't bear the disease again physically, nor emotionally. Neither could I... (Ivana, mother of Lara).

The period after treatment is also marked by conflicting feelings. The parents express that, after they got over the crisis of the disease and treatment, they survive, still feeling affected by different feelings and personal and emotional changes. Any severe disease confronts the child and his/her family with suffering and expectations, provoking profound and distinctive changes in their lives⁽¹¹⁾. The study participants also reported this situation, as highlighted below.

Oh dear, when I received the news that the treatment was over... [lowers her head and remains silent] that's when I started a difficult phase in my life, which I am in until today, I don't know what's gonna happen. I don't manage to deal with it, it's hard. Now, for me, something has changed, I feel it. I talked with his psychologist, I'm not the same person... I'm insecure, without patience, I need to learn how to deal with this problem. Sometimes I have sleepless nights. I walk around the house and remember the things that happened. I can see the day of the surgery exactly...my heart feels heavy.

Like what it was before. It's over... I know, but I can't cope with it. Why do I keep on remembering? Can you understand... It's complicated. It's complicated to deal with it. Some days I wake up feeling well. I sit her on my own and start to remember. It wasn't meant to be like this... it's over! It's over! I should be feeling calmer now but I don't... I keep on living that, I feel scared, I cry, suffer. I think it's difficult... That's not good.. (Fernanda, mother of Fábio).

The parents try to overcome their difficulties by restarting activities they used to do and which were interrupted by the treatment.

Now we try to go to the countryside, go out, have fun to try and forget. But you can't put it off, the thought always comes up... We go to mass every Sunday... Maybe we'll go to the beach... travel... we couldn't do that before. I want to do things, occupy my head (Eva, mother of Eduardo).

The parents experience the distancing from the health team that took care of the child during treatment in a dual way, that is, they mention that, at the same time as they celebrate the discharge, they feel threatened by the absence of the hospital and

the team, which was ready to deliver care in case of problems. They indicate that they lose the ground beneath their feet when the child is discharged and question their capacity to cope with the child's health state when the treatment ends.

I take him to hospital every 3 weeks and he'll have to do a resonance every 3 months... I don't know very well now... if he gets a fever his resistance decreases... he did not explain it well [physician] I'm gonna have to take him there [hospital] see that mess again.... Test, medication... he had a cough these days, I took him to the health station here and they gave him serum, but it's hard because nobody knows him here, they don't know what happened... I'm in doubt, he can only eat strong things... (Débora, mother of Daniel).

The parents acknowledge that the new routine of their children's time and care marks a new phase, a period after the disease. They recognize the families that are starting the treatment and show their availability to help them, as presented below.

I look at the outpatient clinic of cured patients... I saw many people who have been cured for a long time and did not have anything anymore... it's good... staff is needed to help the mothers... When I go back there I see more families going through what I've been through... Perhaps it would be good if we met... (Débora, mother of Daniel).

Now, it's the outpatient clinic of cured patients. The first year, he goes there every six weeks for a check-up, then, in the second year, he goes every two months and the intervals get larger. He'll never lose contact with the hospital (Antônio, father of André).

To move beyond the physical, social and emotional barriers left by the disease, the parents look for support from the family, friends, the health team and religion, as shown by the reports below.

The people from church help a lot, because I'm unemployed. They help with basic maintenance packages, they're even building a house for me and the children, then we'll move out of here, because it's not possible... The social worker there from the hospital also helps a lot, whenever I need it, she helps ... (Débora, mother of Daniel).

My sister helped me a lot, my mother too because treatment is not easy... and now we don't know very well... (Carla, mother of Cíntia).

If God cured him he won't let it come back, I have faith... Today, I believe that my son is cured, God cured the boy. Once I discussed with the doctor, because it wasn't the doctor who cured him, but God who made the doctor cure him... (Débora, mother of Daniel).

Paying attention to the quality of the cure, how the family reacts and perceives the sequelae of

cancer implies paying attention to quality of life after the therapy, in the short, medium and long term. The need for continuous follow-up of the survivors by the health team is evidenced by the possibility of detecting situations that demand intervention.

DISCUSSION

Surviving cancer contains distinct dimensions, there is the physical and the mental cure, in which the physical corresponds to the cure verified and announced by the health team, while the mental refers to the cure obtained when family members find or find back their identity⁽⁵⁾. In most cases, the way the patient and the family experience the disease is a unique event, a personal experience, resulting from each human being's history, way of life, being and relating, which can only be understood within that person's own history⁽¹²⁾. For people who have a child with a cancer diagnosis, it seems to be difficult to incorporate the disease into the family routine, although they organize themselves for daily visits to the outpatient clinic, deal with the complications of the disease or the treatment itself which maintain the family alert, and cope with the hospitalization periods⁽¹³⁾. The treatment period can entail positive and negative effects for the family members, like for the healthy siblings for example. They can present feelings of concern, protection, or also anger, anxiety and guilt with respect to the treatment of their sick sibling. The siblings need attention, encouraging parents to dedicate more time to their healthy children and mainly explanations about the disease and treatment⁽¹⁴⁾.

Families with experiences of living with and surviving cancer go through periods of transformations, with moments of greater disequilibrium in the family system during certain phases, which can be connected with the disease phases or with landmarks in child development. These periods demand care planning from nursing, with specificities and individualities⁽¹⁵⁾.

The constant threat of relapse and the possibility of restarting a new treatment reveal the feeling of insecurity in relatives of cancer survivors. In view of the complexity and aggressiveness of the disease and treatment, cancer survivors start to fight in the attempt to positively conquer the coping with memories of the past, seeking a new moment of life,

a life without the disease, or better, life after the disease⁽¹⁶⁾. They are concerned with their children's course, if they will overcome the limits that life itself imposes, if they will face difficulties due to the sequelae. As to the quality of survival, it should not only be based on biomedical measures, but also on criteria related to the existential dimension. Therefore, better knowledge is needed about this dimension and, more specifically, about the implications for children and adolescents who experience the changes deriving from the disease and treatment process⁽¹⁷⁾. In order to continue the survivors' follow-up, there is a need to establish a long-term relation between health professionals and patients. Continuity is defined⁽¹⁸⁾ as a word used instead of longitudinality, which is defined as "individuals' or groups' dealing with growth and changes during a number of years". This longitudinal relation between the team and the survivor allows for a greater probability of recognizing the patients' problems, by a team who is familiar with them. Nurses should integrally participate in this continuous care process for the children and their families, in order to stimulate and help to create the capacity in parents and relatives to face the diagnosis, treatment, cure and survival process.

CONCLUSION

We consider that surviving cancer represents the ground families covered with their children and adolescents who finished cancer treatment. Surviving also refers to a health state that may be accompanied by sequelae from the treatment, which can emerge early or in the long term, but in one way or another possess a distinctive meaning for the relatives, children and adolescents. In order to plan nursing interventions that involve the family, there is a need to understand the experience of the families whose children and adolescents finished the treatment in order to, during a later stage, help during the process of coping with and adapting to this new period.

Surviving the treatment is complex and depends on the families' objective and subjective aspects. The experience of ending the treatment is related with coping and with the adaptation in the way the relatives lived with the disease and the treatment, in the way they attempted to recover their routine and planned the future. We indicate some intervention strategies here to contribute to the families of children

and adolescents who finished cancer treatment: training and preparation of health professionals – specialization courses, permanent education and undergraduate programs themselves should include contents about the functional and psychosocial consequences of cancer and its treatment, emphasizing prevention and care for late effects; constitution of a multiprofessional team for care delivery to children, adolescents and relatives who survived cancer treatment; constitution of parent groups for orientation and experience exchange – promoting moments of meeting with family members

to talk about their doubts and difficulties; closing partnerships with companies and the community with a view to the survivors' training and inclusion in the job market; getting to know each family's reality. Therefore, home visits should be made to get to know the reality the relatives live. The specialized oncology service should get involved with the primary health care sector – by providing a counter-referral letter with each child's or adolescent's history, highlighting the possible signs and symptoms of relapse and late effects, involving the survivors in the decision making and treatment planning process.

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