

From Diagnosis to Terminal Illness: the Multiprofessional Team Endeavor in Pediatric Oncology

Do Diagnóstico a Terminalidade: Enfrentamento da Equipe Multiprofissional na Oncologia Pediátrica

Del Diagnostico a Terminabilidad: Afrontamiento del Equipo Multiprofesional en Oncología Pediátrica

Maira Scaratti^{1*}; Daniela Ramos Oliveira²; Ana Cláudia Roman Rós³; Raquel Debon⁴; Camila Baldissera⁵;

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ABSTRACT

Objective: The study's purpose has been to identify the perceptions and feelings that permeate the multiprofessional team assistance in childhood cancer. **Methods:** This is a both prospective and descriptive study with a qualitative approach, which was carried out with 32 professionals working in pediatric oncology at a referral hospital in the North region of the *Rio Grande do Sul* State. **Results:** The research reveals the role of pediatric oncology showing the bonds between professionals, patients and families, in which the multiprofessional team end up being involved in the network of interpersonal relationships. The multiprofessional team deals with daily expectations, fears and anguish in the face of uncertainty of both healing and death with regards to the child, then directly affecting the worker's psychic health. **Conclusion:** The study conveys the fragility of the training institutions in enabling the professional to properly perform in this challenging field.

Descriptors: Oncology, Health Professionals, Psychic Distress.

¹ Nursing Graduate by the *Universidade do Estado de Santa Catarina (UDESC)* with Exchange Program for Undergraduate student in *Università Degli Studi di Modena e Reggio Emilia, Modena, Italy*; Specialist's Degree in Cancer Care by the Multiprofessional Residency Program by the *UPF. Universidade de Passo Fundo (UPF)*, Brazil.

² Nursing Graduate by the *UPF*, MSc in Human Aging by the *UPF*, Supervisor of the Multiprofessional Residency Program in Elderly Health and Cancer Care at *UPF. Universidade de Passo Fundo (UPF)*, Brazil.

³ Nursing Graduate by the *UPF*, Specialist's Degree in Elderly Health by the Multiprofessional Residency Program in Elderly Health and Cancer Care at *UPF. Universidade de Passo Fundo (UPF)*, Brazil.

⁴ Nursing Graduate by the *Universidade Regional Integrada do Alto Uruguai e das Missões (Erechim Campus)*, Specialist's Degree in Elderly Health by the Multiprofessional Residency Program in Elderly Health and Cancer Care at *UPF. Universidade de Passo Fundo (UPF)*, Brazil.

⁵ Physiotherapy Graduate by the *Universidade Federal de Santa Maria (UFSM)*, Specialist's Degree in Cancer Care by the Multiprofessional Residency Program in Elderly Health and Cancer Care at *UPF. Universidade de Passo Fundo (UPF)*, Brazil.

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RESUMO

Objetivo: Identificar as percepções e sentimentos que permeiam a assistência da equipe multiprofissional no câncer infantil. **Métodos:** Trata-se de uma pesquisa qualitativa, prospectiva e descritiva, realizada com 32 profissionais atuantes na oncologia pediátrica de um hospital referência no norte do estado do Rio Grande do Sul. **Resultados:** A pesquisa revela a atuação na oncologia pediátrica cercada de vínculos entre profissionais, pacientes e famílias, na qual a equipe multiprofissional acaba envolvida na rede de relações interpessoais, defrontando-se diariamente com expectativas, medos e angústias frente à incerteza de cura e a morte na criança, afetando diretamente a saúde psíquica do trabalhador. **Conclusão:** O estudo expressa a fragilidade das instituições formadoras e empregadoras em capacitar o profissional para atuar nesta área desafiadora.

Descritores: Oncologia, Profissionais de Saúde, Sofrimento Psíquico.

RESUMEN

Objetivo: Identificar las percepciones y sentimientos que permean la asistencia del equipo multiprofesional en el cáncer infantil. **Métodos:** Se trata de una investigación cualitativa, prospectiva y descriptiva, realizada con 32 profesionales actuantes en la oncología pediátrica de un hospital referencia en el norte del estado de Rio Grande do Sul. **Resultados:** La investigación revela la actuación en la oncología pediátrica rodeada de vínculos entre profesionales, pacientes y familias, en la cual el equipo multiprofesional termina involucrado en la red de relaciones interpersonales, enfrentándose diariamente con expectativas, miedos y angustias frente a la incertidumbre de curación y la muerte en la vida del niño, afectando directamente la salud psíquica del trabajador. **Conclusión:** El estudio expresa la fragilidad de las instituciones formadoras y empleadoras en capacitar al profesional para actuar en esta área desafiante.

Descritores: Oncología, Profesionales de la Salud, Sufrimiento Psíquico.

INTRODUCTION

In Brazil, it is estimated that for the years 2016 and 2017 will occur about 12,600 new cases of cancer in children and adolescents from 1 to 19 years old. The therapeutic advances in the diagnosis and treatment of childhood and juvenile cancer have progressed in the last decades contributing to the increase of survival and cure; nonetheless, it is still the leading cause of death, accounting for 7% of the total.¹

The care provided to the child affected by cancer should be comprehensive and humanized, and a multidisciplinary approach is essential since the illness reaches biopsychosocial and spiritual dimensions. Thus, working in pediatric oncology represents a challenge to the professional's competences, since it demands technical-scientific knowledge, sensitivity and interaction capacity during the diagnosis and treatment process.²⁻³

Prolonged treatment, with several hospitalizations and outpatient visits, imposes coexistence between professionals, children, and family, promoting the approximation and the formation of a bond. Nevertheless, working often becomes stressful because the illness is potentially lethal,

the professional being susceptible to situations of strong emotional load and occupational stress.⁴⁻⁵

Once the professionals of the multiprofessional team become involved in the network of interpersonal relationships and are confronted with diverse feelings in front of the established situations, a question is imposed to the reflection: what are the perceptions and feelings of the multiprofessional team concerning the care of the cancer-bearing child.

Given the aforementioned, this study was implemented in order to answer the following research questions: How do you (professional) face the disease in the cancer-bearing child? What are your main doubts, anxieties, and fears about the assistance you provide? How do you face death in the oncologic child?

METHODS

This is a both prospective and descriptive study with a qualitative approach. The study was carried out from May to November 2016, in two pediatric oncology inpatient units and at the Infant-Juvenile Oncology Center (ambulatory) of the *Hospital São Vicente de Paulo, Passo Fundo city, Rio Grande do Sul State*. As inclusion criteria, it was established that the participants were health professionals, over 18 years old, active in pediatric oncology, who accepted to participate in the research and answered the questionnaire. This study included 32 professionals, among them nurses, nursing technicians, nutritionists, physiotherapists, and psychologists.

Data collection was performed through a semi-structured interview, composed of three guiding questions to stimulate the professional to reflect and talk about their feelings, understandings, and experiences regarding the childhood cancer. The research was carried out by the researchers in space reserved for this purpose. The average duration of each interview was 10 minutes, individually, recorded on a mobile device and later transcribed for data analysis. The information was interpreted following the thematic content analysis as proposed by Minayo, consisting of three stages as follows: pre-analysis, material exploration, and results handling.⁶

The pre-analysis consisted of reading and choosing the materials used, followed by transcription of interviews and transformation of the oral code into writing. In the second stage, the material exploration, identification of the expressions, and organization of the information was accomplished. Subsequently, in the third stage, the data was processed by grouping the content according to the themes, then being classified and categorized. Participants were identified by the letter "P" followed by the number corresponding to their interview.

The research was approved on June 3rd, 2016, under the Legal Opinion No. 1.572.974, and evaluated through the

Brazil Platform by the Research Ethics Committee from the Universidade de Passo Fundo/Vice-Reitoria de Pesquisa e Pós-Graduação, under the *Certificado de Apresentação para Apreciação Ética (CAAE)* [Certificate of Presentation for Ethical Appraisal] No. 56030216.8.0000.5342. Participants signed the Free and Informed Consent Term, fulfilling the Research Ethics Criteria with Human Beings according to the Resolution No. 466/2012 from the National Health Council.

RESULTS AND DISCUSSION

All participants were female, within the age group from 21 to 61 years old. The working time in the pediatric oncology field ranged from 4 months to 23 years. Based on the analysis of the interviews and aiming to answer the research goals, the following four categories of analysis were composed:

Coping against children's cancer

Caring in pediatric oncology is challenging as health professionals daily coexist with the disease and develop unique ways of facing such a threat. When questioned about how they face cancer in children, professionals express a sense of sadness about the diagnosis, and at the same time, they assume important aspects in caring; they seek equality in care, they are empathic, and by using good communication they are able to comfort and relieve the pain of the patient and their relatives.

I try to think a lot about the parents of these children, the suffering they spend. After I became mother, we put ourselves in their place and we have a sense of the suffering and the fear they must have in losing their child [...]. (P7)

I face it as if it were any disease, precisely so as not to treat them differently [...] as if they were not carriers of a disease, often terminal. (P8)

In the first moment the [professional] people become very sad, we know that it is a serious illness, which depends on an aggressive treatment and is not sure of the cure. (P16)

In this sense, when medicine fails and healing is no longer part of the prognosis, then the professionals feel powerlessness, depression, and denial. Then arise philosophical-existential questions facing the prospect of early life ending, therefore, aggravating the suffering of all people involved.⁵

The interviewees demonstrate in their speech that cancer is considered a disease strongly linked to the concept of death, in which professionals ask themselves about the meaning of life, the reasons why cancer affects the child and why they need to experience the process of illness and treatment so early.

We have the impression that they lived a short time and we wonder why it happens? (P3)

I leave here [hospital] with few questions in my head, why could not it have been different, why a child? (P11)

We wonder why a child, adult has lived the life, the child does not, it is just beginning and will not get that chance. (P14)

With the child, it is more difficult to understand, because we think that this child did not live enough. (P18)

I have a great difficulty accepting; I think this could not exist with such a little human being. (P19)

Ultimately, even though the occurrence of cancer in children is considered to be a good prognosis, in most cases it is still a disease that carries with it the stigma of death and suffering.

The professionals' feelings when facing the diagnosis and death of the cancer-bearing child

Faced with childhood cancer, professionals face situations of pain, finitude, death, physical and emotional effects, intense feelings and denunciations of human fragility.⁷

This can be understood by the fact that society places responsibility on the professionals for the maintenance of life and when this failure obligation arises anxiety and frustration. The participants elucidated that the feelings aroused in the multiprofessional team working in oncology often are summarized in depressive symptoms, anguish, fear, denial, and guilt.

It gives anguish, certain despair, fear, generates various feelings. (P1)

I cry a lot, it hurts a lot; the pain is with the family. (P2)

I would come home at night and dream about them, I had insomnia, I cried, I suffered a lot; I could not get rid of it. (P14)

The feeling is of outburst and hopelessness. (P22)

Faced with this, the wear and tear of professionals are significant factors in the appearance of diseases, making defense mechanisms necessary, so that the illness and suffering of the other do not interfere with the psychic and physical health of the worker. Nevertheless, such mechanisms are not always efficient to cope with loss and death situations, and the worker may present depressive symptoms.⁸

Another factor to be taken into account is the relationship established between professional, patient and

family. When the worker is faced with the loss of those who have established more intense ties, he experiences internal conflicts, revealing their fragility, vulnerability, fears and uncertainties.⁹

I get very sad, if you kill a lot, you create a bond of love, that's the word. (P2)

Thus, it is evident that the professionals create solid bonds with those involved in the treatment of the child, for the time of coexistence they were exposed to, and in this way, the greater the conviviality with professionals and the family, the more difficult is the confrontation of the loss.

There are some patients who get involved more, creating a greater bond, and in this case, the suffering is also greater... we also suffer from the loss. (P16)

The inability of not being able to interrupt the process sends the professional the idea that he is not able to do more to prevent the death of the other. The following statements reflect the fear of the professional regarding the possibility of negative evolution of the disease and the final result is death, demonstrating the impotence caused by the limits of personal and scientific resources, and the pain shared with the parents when there are no more options of cure.

It is sad, not very pleasant, but it is the reality of many people. Things will not always turn out the way you expect them to be. (P1)

My reaction is first to try to control myself in front of the parents, which is not always easy, and then at home I vent, I cry a lot and then relieves. (P9)

The great fear is that you do not find a positive response in the treatment of the cancer child, in which you are participating [...], I think this generates an anguish, a sense of impotence, often of revolt that you share with the parents. (P22)

The treatment of childhood cancer corresponds to a long period in which the coexistence with the children and their families makes the professionals live the expectations of the treatment, and they truly suffer when there is no possibility to cure.

Life ending of the cancer-bearing child

Specifically in the area of childhood cancer, death is present in the daily care, and there is no way to ignore it. When the patient experiences death, the team may have difficulty dealing with it, causing psychic distress in professionals in their practices.¹⁰ When death happens, the professional faces contradictory feelings, including denial,

suffering, and grief. Respondents describe in their speech such reactions:

It impresses me; I get very sad, I do not admit to losing a child. I shut up, and I feel a deep anguish. (P8)

I always say that our mourning as a professional is very different, we will spend a few days thinking about that child, thinking about that family, be sad and crying. (P16)

The team is often frustrated at the death of the patient because their training is focused on saving lives and not being able to avoid death or alleviate the suffering of the other brings to the professional the experience of his own death and finitude.¹¹

When there is no possibility of being cured, it becomes apparent that it is difficult for healthcare professionals to accept the loss and react to it, since the death of the child is seen as an unimaginable absurdity.¹⁰ This perception seems to have also been shared by the participants of this study:

You get destroyed, destroyed when it happens. Days of mourning, I go home choked, I want to be quiet. (P5)

I think that for death we are never prepared, so the loss is faced with suffering. (P20)

This is not a very easy thing to face; I cannot explain the feeling I have in the face of a child's death. (P22)

Given the constant expectation of death, it can be said that disbelief in relation to therapeutic measures, guilt, and denial, they all are a kind of barrier to reality. The speech below shows the lack of preparedness to deal with the losses, the perception that the efforts made were not enough, to the point that the professional feels guilty for the situation:

There was a situation that I had to seek help from psychiatrist, priest, sister, because I did not accept that the child had gone to death in a few hours. He did not accept that he had nothing more to do... a sense of guilt. (P7)

The death process, although present in the hospital environment, is silenced and avoided. When the child's finite moment arrives, the team that was previously committed to achieving healing faces the terminality and pain of the family.¹² This fact requires the emotional preparation of the professionals in order to face this moment of existence, however, many participants say that it does not always happen this way:

Anxiety at seeing parents when they [children] are in the terminal stage; you do not know how to handle the situation. (P10)

I have already participated in the process of terminal illness, we know that it will happen as it happens in the adult, but, certainly, it hurts more to participate in this moment. One observes the anguish of the parents and the heart feels in losing a child, even being professional, cannot separate this in these moments. (P8)

The phenomenon of death institutes much more than the termination of a biological process, death is the destruction of interpersonal relationships. Expressing pain and reflecting on it helps the practitioner to give meaning to his suffering, for the fear of death is directly connected to his existence. It is worth emphasizing that death in childhood is still a taboo in society, because it goes against the natural order of life, in which the child is seen as a being full of vitality.^{5,13}

There is no justification, they are beginning a phase of life and they are already beginning towards the end. (P11)

When we are faced with the death of a child it seems that this is kind of running over, this is not the moment; we do not expect the child to die. (P16)

Conclusively, when professionals face this determinant, they are constantly confronting reality, their own fears and anxieties, and activating their defense mechanisms.

Training towards the care of the cancer-bearing child

Health institutions should provide support and measures to assist pediatric oncology professionals to overcome their suffering, providing life quality, so that it can be able to offer a humanized and integral care.¹⁴

Faced with this, there is still the lack of capacity to deal with the subjective aspects that involve care. Regardless of the outcome, evolving to death or to cure, the child with cancer needs specialized care, which lasts for months or even years, and for this the professionals need to find ways to alleviate the suffering experienced.³ Participants focus on the need for psychological monitoring, as well as actions that help manage the loss of the patient:

With intense psychological work, with people from outside the team, who do not have this bond with the patient so they could do a good work along with us. (P8)

We should have more psychological support and training aimed at that; more engagement to talk about the loss. (P9)

Given the aforesaid, it is necessary to create spaces in the routine of the institution, so that professionals can speak, listen and be heard in them. It is important that you exchange experiences, share your feelings and difficulties, think about your actions, and continually assess the possibilities and limits of yourself and the context in which you are inserted.

More support, listening to the experience of other professionals, and [formulating] an escape and strategies for not suffering so much. (P18)

There should be psychologists supporting [...] a more open conversation, having a team prepared to work with those who work with the oncology child. (P13)

The health professional has difficulty in dealing with death, since its function is focused on prevention, diagnosis, treatment, and cure of diseases.¹⁵ Based on this, the lack of preparation during the graduation course of the future professional and training by the employment intuition with regards to oncologic child care, are both also seen as factors that impair the care services. In the speech of the participant P19, it is possible to verify that the professional feels insecure and unprepared to deal with the situations inherent to the cancer-bearing child:

[...] No one prepares us for this, and this is the greatest difficulty, situations that we never imagine we face, such as seeing such a small child suffering or dying. (P19)

Hence, it is necessary that there be institutional initiatives to carry out training and updates in an integrated way with the professionals who deal with the care of the child with cancer, becoming a character of continuous education, in which the professionals are participative in proposing changes to problems arising from practice.¹⁶

CONCLUSIONS

Through this study was possible show that the performance in pediatric oncology is surrounded by expectations, fears, anxieties and bonds between professionals, patients and families. It is also noteworthy that the professionals step back when facing the possibility of child's death, and when it is imminent they suffer for not knowing how to deal with this reality. Oftentimes, such a situation is not only within the institution's demographic limits, and in turn, directly affects the professional's psychic health.

It was also evidenced the lack of training with regards to the life termination issue, and all the process that surrounds it. Therefore, both training and hospital institutions should offer training on the subject, since child death is considered a complex process and also difficult to accept.

Conclusively, the results of this research suggest the need for continuing education and psychological support, in which strategies may be created aiming to allow the professional to express their feelings and experiences. Through this approach, the team will face its own taboos about the termination of life, without either suffering too much or falling ill for trying to practice its profession as best as possible, since the psychic distress impacts in both the worker's health and the service provision quality.

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***Corresponding Author:**

Maira Scaratti

Rua Vicente Burin, 36

Centro, Severiano de Almeida, Rio Grande do Sul, Brazil

E-mail address: mairascaratty@gmail.com

Telephone number: +55 54 99168-2563

Zip Code: 99.810-000

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