



Revista de Pesquisa Cuidado é
Fundamental Online

E-ISSN: 2175-5361

rev.fundamental@gmail.com

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de Janeiro
Brasil

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Revista de Pesquisa Cuidado é Fundamental Online, vol. 5, núm. 3, julio-septiembre,
2013, pp. 354-363

Universidade Federal do Estado do Rio de Janeiro
Rio de Janeiro, Brasil

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RESEARCH

FEELINGS, RECEPTION AND HUMANIZATION IN PALLIATIVE CARE TO CHILDREN WITH LEUKEMIA

SENTIMENTOS, ACOLHIMENTO E HUMANIZAÇÃO EM CUIDADOS PALIATIVOS ÀS CRIANÇAS PORTADORAS DE LEUCEMIA

LOS SENTIMIENTOS, RECEPCIÓN Y LA HUMANIZACIÓN DE LOS CUIDADOS PALIATIVOS A LOS NIÑOS CON LEUCEMIA

Mayara Rosário Soares¹, Thaisa Gino Rodrigues², Danielle Moreira Nascimento³, Marina Lira Santos Rosa⁴, Selma Maria da Fonseca Viegas⁵, Patrícia de Oliveira Salgado⁶

ABSTRACT

Objective: To realize the vision of a multidisciplinary team before the child with leukemia in palliative care. **Methods:** This study is a qualitative approach, outlined by the case study method. The study subjects were 17 health professionals who provided direct assistance to children with leukemia in palliative care. **Results:** The results showed that, for practitioners, palliative care involves suffering by the family and the professional, arouses many emotions in the team. And that humanized care should be done seeking the host of both the patient and family comfort, relief of pain and symptoms, support and assistance to the family. **Conclusion:** It is concluded that the health professional creates bond with the child in palliative care, and also with his family, which is beneficial for the treatment of the child. **Descriptors:** Palliative care, Child health, Cancer, Leukemia, Emotions.

RESUMO

Objetivo: Compreender a visão da equipe multidisciplinar perante a criança portadora de leucemia, em cuidado paliativo. **Métodos:** O presente estudo é de abordagem qualitativa, delineado pelo método de estudo de caso. Os sujeitos da pesquisa foram 17 profissionais de saúde que prestaram assistência direta à criança portadora de leucemia em cuidado paliativo. **Resultados:** Os resultados mostraram que, para os profissionais, o cuidado paliativo envolve um sofrimento por parte da família e do profissional, desperta muitas emoções na equipe. E que o cuidado humanizado deve ser realizado buscando o acolhimento tanto do paciente como da família, o conforto, o alívio da dor e dos sintomas, o apoio e a assistência à família. **Conclusão:** Conclui-se que o profissional de saúde cria vínculo com a criança em cuidado paliativo e, também, com sua família, o que é benéfico para o tratamento da criança. **Descritores:** Cuidados paliativos, Saúde da criança, Neoplasias, Leucemia, Emoções.

RESUMEN

Objetivo: Hacer realidad la visión de un equipo multidisciplinario antes que el niño con leucemia en los cuidados paliativos. **Métodos:** Este estudio es una aproximación cualitativa, se indica mediante el método de estudio de caso. Los sujetos del estudio fueron 17 profesionales de la salud que proporcionan asistencia directa a los niños con leucemia en los cuidados paliativos. **Resultados:** Los resultados mostraron que, para los médicos, los cuidados paliativos implica sufrimiento por la familia y el profesional, despierta muchas emociones en el equipo. Y que el cuidado humanizado debe hacerse buscando el anfitrión de ambos, el paciente y la comodidad de la familia, el alivio del dolor y los síntomas, apoyo y asistencia a la familia. **Conclusión:** Se concluye que el profesional de la salud crea un vínculo con el niño en cuidados paliativos, así como con su familia, lo cual es beneficioso para el tratamiento del niño. **Descriptores:** Cuidados paliativos, Salud infantil, El cáncer, La leucemia, Las emociones.

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INTRODUCTION

Currently the discussion on the topic cancer is gaining great impact, because it is a disease that needs to be diagnosed early and diagnosed sooner, the greater the chances of a cure.

Cancer in children is not very common, but over the years the number of children affected by cancer grows gradually. According to the World Health Organization (WHO),¹ in Brazil, the incidence of malignancy in children stands out as the third cause of death in the age group below 14 years, excluding accidents and internal causes.

Among children, the most common types of cancer are leukemias, central nervous system tumors and lymphomas. Leukemia is the most common among children under 15 years, mainly acute lymphocytic leukemia (ALL).²

When exhaust the possibilities of curing a child with poor prognosis, we adopt palliative care aimed at relieving symptoms without curative intent providing quality of life.

Palliative care is defined as conduct that improves the quality of life of patients and their families. Decrease the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early assessment, impeccable treatment of pain and other problems, physical, psychosocial and spiritual.¹

Palliative care is developed through multidisciplinary care, with inter-actions support and comfort for the child and his family. The support is from the relief of suffering by controlling pain and symptoms, as well as the psychosocial and spiritual.²

Palliative care is a subject that requires a daily reflection, especially when you think that technology advances can increase the life J. res.: fundam. care. online 2013. jul./set. 5(3):354-363

expectancy of patients without therapeutic management, which may not be synonymous with quality of life. This care is aimed at the development of a natural death, showing the importance of a comprehensive care when it comes to children with leukemia.

A child with a poor prognosis causes disruption and sadness for everyone around her. Leaves of common activities for their age, like going to school, playing, playing ball. Becomes part of the sphere with routine hospital examinations, consultations, medication, among others. These are tough times for a family, this being a period of remarkable and difficult to overcome.³

A child with chronic establishes a bond and a familiarity with hospital admissions due to recurrent and long. This makes the professionals who work in services and develop linkages know characteristics of both the family and the child, learning to identify their needs for, thus providing a quality care.⁴

Given this situation, it occurs to us concern about "what the feeling developed by health professionals who deal with death in their lives?"

The health professional involved in the care process is focused palliative as support for the patient and family face this difficult time of grief and even the sense of loss brought by death. Thus, the trader should be well on their interpersonal relationships and with yourself so you can offer security to those who are most vulnerable. The myths and fears that still surround cancer, particularly when it occurs in the early stages of life, the applicant association of the disease with death, even with the great possibilities of healing the LLA, the trajectory of these families become health services even more dramatic.⁴

The process of care is not necessarily recognized by the cure or treatment of a given

disease, but also by the comfort, the support and the attempt to reduce the suffering of patients and their families.

The daily advances in medicine and technology resulted in changes in the modes of preservation of life and emphasis of care for children with leukemia diagnosed with poor prognosis. Previously, the care was developed starting from the needs of children with terminal illness, the emotional effects of the bereaved family and the importance given to the preparation of the family facing a possible death of the child. Today, issues of survival and living with poor prognosis are larger.

In the literature, there are several studies on the preparation of the family, stating the need and importance of the multidisciplinary team that context. Noting the need for studies aimed at the vision of health professionals towards the development of palliative care to children with leukemia, ask: "What is the vision of a multidisciplinary team before children with leukemia included in the process of palliative care in a hospital in Belo Horizonte, Minas Gerais? "

This study aims to understand the vision of a multidisciplinary team before the child with leukemia in palliative care.

METHODOLOGY

This study is a qualitative approach, suited to the issues raised with regard to the views of practitioners faced with a child with leukemia. Therefore, as the meaning and the meanings created by these professionals are the focus of this research, the qualitative method stands out as a possibility for production and processing of data, since: a qualitative study is defined as one that favors the analysis of micro-processes through studies of individual and group social activities, with intensive examination of the data, and characterized by heterodoxy in the analysis.⁷
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Qualitative methodology provides the understanding of assignments meanings of a group, giving priority to the how, why, when feeling that develops in each given situation.

Among the possibilities raised by qualitative methodology, it is a choice here for the case study, which is a way of organizing social data, while preserving the unitary character of the social object studied. The case study is an empirical inquiry that seeks to understand a phenomenon in depth in this, especially when the matters discussed are unclear and evident.⁹

The study setting was a hospital of Minas Gerais (MG). It is a philanthropic, nonprofit organization that has a differential for public health in MG benchmark in the study and treatment of many diseases for the mining population.

The research subjects were the professionals who agreed to participate voluntarily in the study, among them nurses, practical nurses, psychologist, physiotherapist who met the following inclusion criteria: provide direct assistance to children with leukemia included in the process of palliative care work in the institution, study setting. Exclusion criteria we adopt the decision regarding the participant's manifest desire not to participate at any stage of their development and also the end of the study.

The study is evidence for the production of data, individual interviews based on a basic script with open questions. The confidentiality of the identity of respondents was respected by adopting pseudomonas chosen by them.

Data analysis followed the stages of content analysis proposed by Bardin. Thus, transcription of the interviews was conducted in full floating reading and globalized them. It was conducted by the encoding of the enumeration and aggregation of data, allowing to achieve a representation of its content or expression. Following the coding, were categorized by

semantic criteria. Data were organized into thematic categories, discussed and reasoned as literature and the study objective.

Note that the data collection started after the project was approved by the Ethics in Research of PUC Minas, Opinion CAEE 0154.0.213.000-11, and the Ethics Committee of the Institution Hospital - study setting, Opinion CAEE 102 / 2011. The research was conducted according to the guidelines and rules for research involving humans, according to Resolution 196/96. This Resolution has references of bioethics: autonomy, beneficence, non-maleficence and justice always look on the individual and the collective, ensuring the rights and duties of the scientific population, the research subjects and the state.¹¹

RESULTS AND DISCUSSION

Palliative care was approached by informants with expressions that qualify toward their feelings, the reception and humane care and vision as a professional and a human being in the context of assistance to children with leukemia included in this process.

The relationship with the other builds communication skills to give and receive verbal and nonverbal. Communication is a key element in human relationship, being a fundamental element for care. The everyday with healthcare professionals allows the patient, share fears, doubts and sufferings which contributes significantly to the decrease in stress, guaranteeing autonomy.¹²

We end up living for a very long time and as much as we try to separate the professional's emotional, being a child, being a mother for us also, to see the pain of another mother, we end up sticking a bit, right? Not to mention that we do not cling and does not share the pain or we're used to it, because we're not used to it. We have

a certain strength to cope with the situation, but get used to something bad, do not get used, but we take great care because it is too long to contact us (Alfazema).

The context of palliative care professionals do remember that he has family and is a being who gets emotional in front of the child and their family.

The human suffering needs to be understood because, in addition to physical pain, living some conflicts and needs drugs or technology cannot solve. Therefore, in addition to sharing their fears and anxieties relating with peers, he needs to feel care, supported and comforted.¹² This double track brings certainty, sense of protection and comfort. Thus, the link happens:

Because a child is a long term, you want to or not, you end up creating bond, because you know them and spend more time here than at home. You have to learn to deal with the situation, because in fact you also end up losing your partner. Because just being a companion, because goes and back several times, you know? So is doing is dealing with the same side of feeling, because if not we end up suffering too ... (Azaleia Vermelha)

The long stay in the hospital's proximity promotes a professional / child / family favoring a daily coexistence respectful and construction bonding. Even though this work presents sadness, helplessness and frustration, always seeking a force to support the family and try to ease the pain.¹³

Professionals who work in these services develop links because admissions are long and applicants, enabling them to ascertain characteristics of both the family and the child, learning to identify their needs to thus provide quality care.⁴

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This close relationship of partnership and trust develops a sense of friendship and cooperation among professionals that turns the work into something very enjoyable and makes the care of the child / family is more humanized.

Considering the particularities be careful, the informant expressed:

But with time we will get used to things, learns to care for and learn more about these children, also known pathology. It is because these children are long here, so just having a great bond. Then you know what the child likes, sometimes she does not like being punched in the arm, there is only the arm to punch you. So we try to meet this desire of that child, to the extent possible (**Cactus**).

Assistance in palliative care should consider the patient a unique, complex and multidimensional - biological, emotional, social and spiritual. This kind of careful, comprehensive and humane is only possible when the team makes use of various communication possibilities, to realize that, understand and employ the verbal and non-verbal.¹⁵

In addition to our special care of children with leukemia, has also the host that is important to me because we end up creating a special bond with these kids, even though it is in palliative care, because when the doctor will not invest in children they warn for us, but independent not invest, we do not cease to give affection, love, call them by name, asking how was the day, you know, put them on Orkut, send messages during the day. We create a bond of friendship with these children, especially when they go, we suffer, we cry when they go away, you know! So the main thing for a child with leukemia is welcoming, caring, is to see that even she admitted, here may be a legal living it (**Dormideira**).

The bond built was approached by most informants in this study, so these experiences and

possibilities of management have spoken to the tensions and joys, alternating always so caring. In this context, the host becomes more secure and reliable for a true bond.¹⁶

Host is a constitutive process of health promotion practices involving accountability of all involved, from the entrance to the exit door. It is important, in the process of hosting, hear the complaints of the people, taking into account their anxieties and concerns, developing a qualified auscultation, ensuring full attention, solving for continuity of care when necessary.

Informants show that, in this context of palliative care, those involved are natural carriers of the bond, "a fundamental aspect of comprehensive health care".^{18:382}

The issue of palliative care now reminds us that this idea is still: to bring comfort to children, we know that she will not survive, the possibility of cure by then it was canceled. We know that she will not have more life expectancy. Then you know is that palliative care is, we already have a certain zeal, right? Special care so ... You feel penalized with the child. So you want to bring more comfort, you want to bring a quality of life even. To say you do not know right?! When will be the time is not estimated and we have, I dunno, it's weird! But, alas ... we want to cuddle it, we want to protect, is complex! (**Alecrim**)

For professionals caring palliatively is challenging because the child could have a long life. Moreover, the fact that palliative care be named brings professionals require some trepidation by the concern not only with treatment as well as the comfort and humanization.

Thus, it is necessary to recognize the interactions that allow mutually establish a day to day the touch, listening, respect for human consolidate the commitment to maintain the right to health provided with senses, knowledge and

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actions for the "whole" and not for all, thus creating opportunities for the Services are suitable to receive work and human differences. This is the exercise of rearrangements to try new practices in health, the practice of comprehensive care.

It is the erroneous assumption that there is nothing else to be done by the patient without therapeutic possibilities. While there is life, there is a need of multidisciplinary team care. In this sense, the performance of the team is very important and essential to provide maximum comfort to the patient in palliative care, helping you to experience the process of dying with dignity, to use in the best way possible, as long as you remain.¹⁵

My experience is more comfort for the family, even more for the family than for child because the family suffers, the mother suffers a lot with this child and sickened [pause]. That does not have much else to do, quotation marks, possibility [...] has no more treatment, then we are the care. You avoid her suffer, to feel pain. Minimal invasive procedures, it is, pain medications. Our part is that (Gerbera).

"We care ..." expresses that subjects living in their daily actions "being in health attitudes that transcend the actions institutionalized, crossing the boundaries of objectivity in the context of Service".^{20:83} The pursuit of comfort for the child and zeal for his life building practices completeness. Thus, caring for others can be understood as "more than an act, caring is an attitude"^{21:33} that generates many other acts of humanization of care.

Then we start working first humanization, submitting work within the ward; here, look at this guy is that is coming to stay with us and that is the mother or father, most are women who are here with us. Here, we speak of rules and routines for initial information. The children, some have begun with the care of chemotherapy

and, in the meantime, is entering the social service, to act together, to see what the child likes, likes what this mother, the family (Azaleia Branca).

The good relationship between the patient, family and health professionals can bring more satisfaction and success in treatment, which allows those who currently are more fragile, become more secure about the process of palliative care.

The role of parents is very important in this delicate phase that weakens them. But therapeutic measures can contribute softening impacts. The multidisciplinary team has the mission to promote humanized therapeutic alliance between staff and families of terminally ill children.²²

Most important to work with you if your child is behaving in a safe manner in doing, you know? And welcome this child and family too, because when we get a job, along with the family, we get an integration of this child, because parents are afraid, so are children. Here are afraid of losing the vein, there is feeling pain, is that what you're doing're not overloading? The parents, when their children get sick, overprotect. And we want to take that comfort that okay, then when they realize that children will have improved, they are happier, then there is a very large proximity. So well, pediatrics is not an area where we meet only the child, we meet the family and much has to be open heart to welcome, to reassure (Flores do Campo).

Humanize is to recognize each other as legitimate national rights, always valuing the different subjects involved in the production process of health.¹⁷

Humanizing the hospital where the child is inserted is paramount, and one of the most effective and humane ways of doing this is by introducing the family in caring for the child. Note that the family member at this time provides a better acceptance, decreasing anxiety. It is very important to listen to your family care giving

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issues, emphasizing their needs so that they can be laid possible solutions.

When the professional provides affection, attention, respect, dignity, love of customer-binomial family, everyone feels safe, confident and realize the benefits of differential treatment, humane treatment.²⁴

Look [pause, sigh] is sad, huh! Because you know, we goes watching the day to day life and there comes a time that is as if he lost everything, you're going with their parents, with all that hope, every day they renew hope, hope to leave and does not go away, so so very sad (**Acacia**).

The healthcare provider realizes that parents are renewed in the hope of curing the child and that, often, the healing does not occur. Although, most of the time, knowing that there is no solution more parents are not without hope in the treatment and cure, as this helps them to move forward and reduce the anxiety they feel.

At no time, despite the stigma of death that is associated with cancer, parents lose the will to fight and win, never think of giving up. Even when the individual experiences the stage of "acceptance of the disease", hope it works as a protection against despair, making the difficult periods of death are addressed more effectively.²⁴

It is very difficult even have to like what you do, because we get emotional, I'm turning myself and seen the shirt oncology. Because I put myself in the place of everyone who're going through, the patient's mother. Mainly the companions, the greatest caution is still sometimes the disease is higher in charge, a mother than the child himself. I work only with children, the adult I think I can also be the same. With the child is very difficult! (**Crisântemo Branco**)

The health professional is a direct participant in the suffering of others, while also undergoes unpredictable situations in everyday

life. Therefore, there is a need to control emotional coping of emergencies.

The professional can still feel emotion before the most difficult situations and before the patient in palliative care. The care and attention improves client framework assisted humanely.

Customers develop a greater connection with that professional who always looks in their eyes, that shows interest to what the patient has to say, contributing positively to the treatment, developing a comprehensive and humane care.¹⁵

You keep fighting to keep the child well and when you have a relapse, it is like a little disappointed, you know? Because you want to see it well, want it to go away, that it is good! But it is frustrating you see and know that it may not have more time to do things she wants to do and the more difficult it is to deal with it, is you look at the mother's face, look at his father's face and see that suffering so even ... (**Azaleia Vermelha**)

Ten children died in one year, there is too sad! We suffer together, I think it is much suffering, I'm like, I cannot not get involved, I get involved with strength, I suffer along with the mother (sad face expression), but I think it is part of life, then do what?! I think we in this world are fleeting, life is on the other side, but I still think it hurts too much (**Azaleia Rosa**).

They are two sides, the team did not want to let the child stay well and loving family suffers for the child and not want something bad to happen to him.

It is a harrowing experience, experienced in daily by parents of child cancer, moments of insecurity, suffering and emotional instability.²⁴

They always re-hospitalized here, they know where is the playroom, we sit, play with them, so thus the special I think, for your search, so is love, know, learn love, host and learn to listen, often, they just want you to sit

down and listen. I think it is interesting to learn to love ... (Dormideira)

need too much [emphasis] of the people, need too! (Girassol)

Everyone needs some occupation, the play is the child's work because, through play, children learn about their world, over time and space, expresses reality, clutter and orders, build your own world in a meaningful way and that matches their intrinsic need for global development.

Thus, the playroom is important in the treatment of children in palliative care, because it becomes a meeting place for patients. It is an environment that provides the child forget momentarily their disease, their pain, their suffering throughout. It is a space that encourages the child to play within a play environment, and aims to rescue the spontaneous play, assist in development of the child rescue and socialization.

Moreover, the therapy with toys is seen by parents as a way to reduce the suffering of children, constituting a communication tool that reveals fears, dreams and desires. The child forgets the pain and / or when the disease is in the playroom.

The treatment of children with cancer occurs most often with prolonged hospitalization, multiple invasive procedures, various stress situations. So the play has contributed to adherence to treatment.

Everyone needs some occupation, the play is the work of creativity; I just think how we have to do what you love and I think I do what I like (Azaleia Rosa).

It ... (Silence) I do not know, I think that beyond the psychology service, should have another type of service, you know, that met more [pause] are not all hospitals have the whole structure equal here. It has a playroom. I think it distracts a little child. Because the truth is not only the child, the mother has, I think it should have nursing care beyond, beyond psychology, another type of care more closely with the children, because they

On a daily basis, health professionals are several situations, deal with the rising and dying that are distinct moments that mark deeply human. However, the balance must occur for that suffering does not influence the professional activities performed.

The interaction between professionals and the healthcare team provides the humanizing therefore the work done with enthusiasm, love and humor is the ability to relieve pain and tension and promoting the dignity of customers redeeming values in the terminal phase.

The interaction between the multidisciplinary team contributes positively to dignified care to patients without therapeutic possibility because thus care happens holistically, enabling the comfort and protection for patients undergoing palliative care.

CONCLUSION

This study allowed us to understand that healthcare professionals interact directly during treatment provided to children with leukemia in palliative care. Show feel, really, in every situation worsening or loss of a patient.

The professional creates bond with the patient, knows best their singularities. Thus, due to the involvement purchased in providing care, professionals often do not get used to the pain of loss.

It was observed that the professional receives and pays humanized to children with leukemia in palliative care, providing you with maximum comfort and decreased pain. It was found that the palliative performed encompasses not only the patient but also attains its family. The professional supports, welcomes and comforts

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the entire family of the client during the process of palliative care.

The professional in your daily work, you should always try to understand the feeling and the trajectory of the patient and their family. You should always support them, welcome them, help them overcome this difficult time, giving them a period of stay safe and comfortable in hospital.

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Received on: 13/08/2012

Required for review: 25/08/2012

Approved on: 27/02/2013

Published on: 01/07/2013