Perceptions of the interdisciplinary team regarding palliative care in pediatric oncology

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Abstract

This exploratory and descriptive study aims to understand the perceptions of the interdisciplinary team of the Porto Alegre Clinical Hospital Pediatric Oncology Unit, Rio Grande do Sul, Brazil, regarding palliative care in the context of childhood cancer. The sample consisted of one representative from each of the 12 professions that make up the interdisciplinary team. Individual semi-structured interviews were carried out and the material was analyzed by content analysis. There has been confusion, starting at diagnosis, between the concepts of palliative care and exclusive palliative care, generating feelings of frustration, impotence and guilt. The results point to the need to create spaces for theoretical discussions about death and palliative care, as well as systematic meetings to address the perceptions related to the care of these patients.

Keywords: Palliative care. Medical oncology. Oncology service, hospital. Patient care team.

Resumo

Percepções da equipe interdisciplinar sobre cuidados paliativos em oncologia pediátrica

Este estudo exploratório e descritivo tem como objetivo compreender as percepções da equipe interdisciplinar da Unidade de Oncologia Pediátrica do Hospital de Clínicas de Porto Alegre, Rio Grande do Sul, Brasil, sobre cuidados paliativos no contexto do câncer infantil. A amostra incluiu um representante de cada uma das 12 profissões que compõem a equipe interdisciplinar. Foram realizadas entrevistas individuais semiestruturadas, e o exame do material se deu por análise de conteúdo. Verificou-se confusão entre os conceitos de cuidados paliativos exclusivos e cuidados paliativos desde o diagnóstico, gerando sentimentos de frustração, impotência e culpa. Os resultados apontam a necessidade de criar espaços de discussões teóricas sobre morte e cuidados paliativos, bem como de encontros sistemáticos para abordar as percepções relacionadas ao cuidado desses pacientes.

Palavras-chave: Cuidados paliativos. Oncologia. Serviço hospitalar de oncologia. Equipe de assistência ao paciente.

Resumen

Percepciones del equipo interdisciplinario sobre cuidados paliativos en oncología pediátrica

Este estudio exploratorio y descriptivo tiene como objetivo comprender las percepciones del equipo interdisciplinario de la Unidad de Oncología Pediátrica del Hospital de Clínicas de Porto Alegre, Rio Grande do Sul, Brasil, sobre los cuidados paliativos en el contexto del cáncer infantil. La muestra incluyó un representante de cada una de las 12 profesiones que componen el equipo interdisciplinario. Se realizaron entrevistas individuales semiestructuradas, y el examen del material estuvo dado por el análisis de contenido. Se verificó una confusión entre los conceptos de cuidados paliativos exclusivos y cuidados paliativos desde el diagnóstico, generando sentimientos de frustración, impotencia y culpa. Los resultados señalan la necesidad de crear espacios de discusión teórica sobre la muerte y los cuidados paliativos, así como de generar encuentros sistemáticos para abordar las percepciones relacionados con el cuidado de estos pacientes.

Palabras clave: Cuidados paliativos. Oncología médica. Servicio de oncología en hospital. Grupo de atención al paciente.

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Declaram não haver conflito de interesse.

Cancer is one of the main causes of morbidity and mortality in the world population, with approximately 14 million new cases and 8 million deaths in 2012¹. In the field of pediatric oncology, an estimated 12,600 new cases of cancer were estimated for 2016, which corresponds to 3% of the total in the same year in Brazil². The progress of studies and treatments allows the percentage of cure to reach 70% in children. However, this diagnosis still represents the primary cause of death due to illness in children and adolescents above 1 year of age³.

The World Health Organization (WHO), by means of the document entitled "Cancer pain relief and palliative care: report of a WHO Expert Committee"⁴, elaborated the first concept of palliative care for cancer patients. According to the 1990 text, it is the active and total care of patients with diseases that no longer respond to curative treatment. The focus was on pain control and other physical, psychological, social and spiritual symptoms with the aim of improving the quality of life of patients and their families.

The concept was redefined in 2002, and it is now considered that palliative care should start from the diagnosis of a life-threatening disease, with a focus on preventing and alleviating suffering related to disease- and treatment, as well as promoting quality of life⁵. Thus, it is not recommended to speak about palliative care associating the diagnosis to the notion of terminality. Likewise, the idea of the impossibility of a cure is now replaced by the concept of treatments that modify the disease, thus removing the mistaken notion of "having nothing more to be done"⁶.

In this context, it is important to address *exclusive palliative care*⁷, which refers to the first WHO definition and refers to the last phase of palliative care, that is, for patients whose disease no longer responds to curative therapy. The treatment will then be directed towards the management of the symptoms of disease progression, with no pretense of cure. Another relevant aspect is the prognosis of life span. With a prognosis of 6 months or less, the indication of exclusive palliative care is adequate, and other therapeutic resources that seek only to prolong the life of the patient are discarded⁸.

Currently the WHO classifies palliative care as a set of therapeutic approaches aimed at alleviating the symptoms caused by illness. These approaches are considered urgent for people with cancer and other chronic diseases, and are estimated to provide relief of physical, psychosocial, and spiritual symptoms in more than 90% of cancer patients⁹.

Palliative care in pediatric oncology should include three levels of intervention: physical,

referring to symptoms such as pain and nausea; psychosocial, as identification of fears and concerns; and spiritual¹⁰. In this sense, the integrated work of an interdisciplinary/interprofessional team¹¹, including physicians, nurses, pharmacists, nutritionists, social workers and psychologists^{12,13}, among other professionals, is fundamental for the best approach when dealing with patients and their families.

This study aims to understand the perceptions of the interdisciplinary team of the Pediatric Oncology Unit at the Porto Alegre Clinical Hospital (*Hospital de Clínicas de Porto Alegre* - HCPA) regarding palliative care in the context of childhood cancer. As a possible development, it proposes the reflection on knowledge, feelings, values and attitudes of health professionals in relation to the subject.

Methodology

This is an exploratory and descriptive study ¹⁴, with a qualitative approach ¹⁵, carried out at the Porto Alegre Clinical Hospital Pediatric Oncology Unit. The sample consisted of a representative from each of the 12 professions that comprise the interdisciplinary team: social worker, nutrition assistant, hygiene assistant, physical education professional, nurse, pharmacist, physician, nutritionist, educator, psychologist, secretary and nursing technician. The choice of professionals was for convenience. With the saturation of data, it was not necessary to include other participants besides those anticipated.

One of the investigators conducted the individual semi-structured interviews, after the informed consent forms (ICF) were signed. The interviews were conducted without the presence of other people, in the environment of the pediatric unit itself. Data collection took place between July and August 2017, and the results were examined based on content analysis¹⁶. The study followed the ethical guidelines for research with humans, as per Resolution 466/2012¹⁷ from the Brazilian National Health Council (*Conselho Nacional de Saúde* - CNS), and meets the criteria established by the "*Consolidated criteria for reporting qualitative research (Coreq)*"¹⁸.

Results

The examination of the interviews generated four categories of analysis: 1) knowledge and understanding; 2) feelings and values; 3) team; 4) attitudes.

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Knowledge and understanding

Some terms appeared more frequently in the interviews about palliative care, such as "quality of life", "relief from suffering", "protection", "comfort", "dignity", and "security". With the exception of one interviewee, everyone sees palliative care as a therapeutic resource only when healing is no longer possible. One of the participants based their practice on the idea that palliative care starts with the diagnosis of a chronic and/or severe disease and accompanies the course of the disease:

"Before palliative care always referred to terminal diseases, right? So it used to refer to patients who were already dying and had to be cared for to die. Now I think we can do palliative care starting from diagnosis. So that's the difference, we can work from the start on all things that can be associated with protecting the patient who has a serious chronic illness or who has a serious illness like cancer but can be cured" (E7).

However, analysis of the other interviews showed that the team tends to understand palliative care as an indicated treatment when the curative possibilities have already been exhausted, focusing on the control of the disease and the management of the symptoms associated with its progression. Thus, they are more linked to the end of life:

"Palliative care, for me, is that the patient ... who is provided care only to relieve pain and to have a better quality of life, for whom healing is no longer ... there is no more cure, isn't it?" (E3);

"Palliative, I understand, is when the patient has no way back, it would be the end, the end of life" (E2).

Among professionals who associate palliative care with the impossibility of cure, some show knowledge of the current definition. Despite this, they do not understand its application in pediatric oncology, pointing out, as a justification, the difficulty of thinking about palliative approaches to disease with a high probability of cure. According to the interviewees:

"The investment in a cure until it becomes exclusively palliative is a characteristic of the treatment of childhood cancer" (E10);

"If you think about the basic concepts of palliative care, at last, there are many lines of thought that say that palliative care begins with diagnosis, but, knowing the cure rate of childhood cancer, specifically in pediatric oncology, I personally cannot see it starting from the diagnosis" (E8). This misleading notion that palliative care refers only to the end of life has also made it possible to verify the tendency to link it to the patient's transfer to the Pediatric Intensive Care Unit (PICU), since this sector reinforces the idea of the clinical status becoming worse and the need for intensive care:

"I think that when it is palliative is when they are there in PICU (...) when they go there, it is because there is no way" (E11).

Despite the misunderstanding, in practice the team is concerned with providing the best care to patients in this situation. The interviewees understand that, although there are no possible cures, the care alternatives are multiple, and depend on the professional being present in the day-to-day of these patients and listening to their real demands. In addition, the team is very invested to ensure that the patient is discharged, if this is the patient's desire and that of his/her family:

"If you know how to direct your gaze, you know there is a lot to do. You have to have a closer relationship with this family, you have to be willing to interact, to be present, to want to solve things with them" (E5);

"From now on what we have to cherish is that he feels good, and that I can keep him well and that he can go home ... So that he can go to his home. The graciousness of palliative care is to be able to leave the patient in a good situation, and that he can enjoy his home and his family" (E8).

Feelings and values

During the interviews, emotional fluctuations were noted in all participants. On the one hand, feelings of pride, pleasure and gratification for the service provided to patients in palliative care; on the other hand, tendencies of rationalization, understood as a defensive mechanism, and an inclination to avoid the mourning process.

The interviewees also expressed anxiety about not being able to attend oncological patients in the analyzed context. It was verified that sadness and great frustration due to the impossibility of healing are associated with a certain affective detachment from patients to avoid suffering. The care provided to pediatric oncology patients, at all stages of the treatment, is permeated by an intense emotional burden, often causing suffering to the team members.

In addition to the disease, the perspective of integrality in the care offered to children, in order to

minimize the suffering associated with difficult and painful treatment, arouses feelings of well-being and gratification in some professionals:

"I feel good, because I can make the patient not feel pain, not be in discomfort, I can leave it wide open for them to ask and to answer ... There is no suffering, I cannot think of doing anything else"(E7);

"It's very good for me, I do not see working with these families as a bad thing (...) Are we going to be sad? Yes. Are we going to cry? Yes. But it is a feeling of sadness, not depression. There are days when we leave here very sad, there are days we do not" (E5).

However, most interviewees reported difficulty and suffering in assisting pediatric oncology patients in palliative care and their families, describing feelings of frustration, sadness and impotence, among others. In an attempt to avoid personal suffering, some professionals tend to affectively distance themselves from patients, as is clear from the following excerpts:

"But I'll tell you that when I started here I always had a lot of expectations for healing, so I was very frustrated when the children did not recover and the suffering was much greater"(E4);

"It's always harder for me [to work with no possibility of a cure], it's not a very easy thing (...) this question of not having more hope for healing, for me, is a harder feeling to deal with" (E6);

"I became hypertensive as soon as I came here and I take some medications, so... because I need to. We suffer too much, too much indeed, for sure" (E12);

"So, I don't get too involved, right? I try to get involved as little as possible (...) I think the more you know the story, the worse it is, right?" (E2).

In addition, the intense emotional load of some interviews made it possible to perceive the difficulty on the part of the professionals in dealing with death in general. They use defensive mechanisms to protect themselves from realities as daunting as caring for these patients:

"I think that in the last moments they do not stay here, they stay in PICU, and that part I think is less bad, because I do not see them suffer, I do not see their last moments, and in a way I become more tranquil, because I wouldn't know how to deal with it (...) so that's what I use: while they are here they are still being treated, even if the relatives say that it is palliative and such (...) I really prefer that they are at the PICU, so that I do not see. What is not seen is not remembered" (E11);

"And then I focus my strength on those who are arriving, and I try to keep those who left with memories, and not many memories either ... I also do not like to talk a lot about those who left (...) our role here is to help, so I have to help those who are fighting. Those who have already lost the fight will be remembered, lovingly, kept in a distant place for me, distant" (E8).

Team

The main finding in this category concerns the impact generated by professionals who do not participate in the information and decision-making spheres. In addition, issues such as the type of personality required for professionals working in pediatric oncology and the investment required by the team for the best palliative care to patients also appeared in the interviews, as well as, critiques regarding the care provided to adults at the institution.

Regarding the institutional understanding of palliative care, some non-medical professionals, associated with operational tasks, related their responses to the medical team's performance. These professionals, who do not participate in the spheres of information and decision-making regarding the patients, confuse the performance of the medical team with the position of the hospital. This is aggravated when other professionals, directly linked to care, have a more critical view of the palliative care offered, since they perceive that the concerns regarding the patient are geared more to physical demands than to non-medical issues:

"I do not know the positioning of the hospital, but the physicians themselves are very solicitous, they are very sensitive in this regard, of palliative patients"(E11);

"It seems to me that sometimes, when talking about palliative care, it is very restricted to the medical team. It's pain control, right? Exams to verify the level of evolution and what is going to be done, the type of conduct that will be done in the face of a more serious status ... I think it is very restricted to the medical team, and the multi [professional] team is forgotten" (E1).

Alien to the information and decision-making activities, professionals not directly involved in care are often unaware of the processes and people involved in the definition of conduct. Therefore, they do not know who participates in the decision-making and in what form the communication with the family occurs:

"I also do not know, also do not know [when questioned whether or not families know when the patient goes into palliative care and what does that mean]. But I think they do, right? Because ... no one ever told me if they do or not, but I think they should, right?" (E2).

Some interviewees stated that the professionals from the Pediatric Oncology Unit have certain characteristics that give them greater tolerance to suffering and frustration:

"Actually we already have a selection thing, so, pediatric oncology is either love it or leave it, right? There is no middle ground. Many people come here and do not adapt, others come and do not want to leave, so ... Why? Because it is a matter of profile, of the things that you do here, and that's it, we are not going to save everybody, but we'll take care of everyone until the end" (E5);

"It's obvious that you learn to cope, but I think you must have a prior ego structure that allows you to deal with death, deal with the suffering of others without falling apart. So I do not think (...) that it is anyone who can work in a pediatric oncology unit and not fall apart due to the things that are seen there, due to the level of suffering of families and children" (E10).

In addition, some interviewees questioned the effectiveness of adult palliative care in specialized units focused only on this type of care:

"When they say there is no treatment anymore, instead of getting them into a normal unit they send them to that [palliative care] unit. Then the patient already enters that unit knowing that he/she is entering there to die. It's a cruel feeling, I think, and reinforces the idea that palliative care is that, right?" (E7).

In any case, respondents consider that the interdisciplinary team of the Pediatric Oncology Unit is prepared to deal with patients' pain and the physical symptoms associated with the progression of the disease. In addition, professionals also invest in the well-being of patients so that they can return home, see family members, do activities that they enjoy, that is, that they have the best quality of life possible. From this perspective, some interviewees described the role of the team in preparing the families and providing conditions for them to take care of patients at home.

Attitudes

In this category of analysis are the findings regarding the ways of coping, attitudes and strategies used by the interdisciplinary team of the Pediatric Oncology Unit to deal with the realities that often evoke suffering, as in the case of palliative care. Some interviewees emphasized the practice of physical exercise as a kind of release valve:

"I think we often need to practice a physical activity, something through which you have a kind of catharsis, when you stop and do not think much, right?"(E10)

Frequently, the professional who works with someone else's illness and the possibility of death does not feel entitled to share their experiences and feelings with family and friends. In this scenario, personal treatment (psychotherapy) was identified as a place for listening and self-knowledge. The perception of one's limits, the possibility of speaking about one's own death and dealing with personal grief were pointed out as essential:

"Why is it often intolerable for our relatives, boyfriends and friends to speak first of death, second of oncology, and pediatric oncology then?! People don't tolerate hearing about it. It's scary (...) so I think one way to mitigate this is to undergo personal therapy" (E10);

"And to know that everyone has a limit as to what they can do (...) so I know what I do is what I can do at that moment" (E6);

"One has to want to make this internal journey and search, right? Not everyone is available, sometimes you have to deal with things of your own, sometimes do therapy, try to develop spirituality in some way (...) if you are afraid to see the issues of death, whenever a patient dies you will not be dealing with the issues of his/her death, you're going to be dealing with your own issues" (E5).

Another fundamental point mentioned by some of the participants was the possibility of improving our perception regarding patients' worsening conditions, adjusting our expectations according to the evolution of the clinical status and dealing with the anticipated mourning in the face of the threat of death:

"We keep seeing those who stay hospitalized longer, those who keep battling through the treatment. I always comment to the trainees: 'Look, the patient is not responding well, the prognosis may not be very good' (...) And we already start trying to deal with these issues in advance, so that when it becomes palliative it's not a surprise" (E4).

Finally, the professional's investment in their contact with these patients, the creation and strengthening of the bond, as well as the feeling of well-being when giving the best care possible were considered of extreme importance when facing the difficulties of the work processes:

"If there is a child in any doorway who is in need, and it is a palliative case, you have to go, you have to give support, not deny it and pretend they do not exist" (E12);

"I try to look at it this way, to bring life while the person is alive (...) I try to focus [on the idea] that I'm offering something good for him/her. That I am a good moment, like an island that takes him/her out of that situation"(E9).

Discussion

From the analysis of the interviews and the dialogue relating to the literature on the subject, this article proposed to draw parallels between the four categories that emerged during the research, in an attempt to explain some phenomena pointed out in the results.

In 1990, the WHO developed the first concept of palliative care, defining it as the appropriate approach for patients with incurable diseases, in order to improve their quality of life⁴. The concept update in 2002 indicates a new perspective for palliative care, considering that the problems faced by patients at the end of life originate at the beginning and during the course of the disease and, if left untreated from the beginning, their management will be hampered. Thus, the current concept establishes that palliative care should start from the diagnosis of the life threatening disease⁵.

In this sense, the idea of treating end-of-life patients and/or diseases that no longer respond to curative approaches refers to the concept of exclusive palliative care. It is important to note that the results of this study were discussed based on the interviewees' understanding of palliative care.

As for the first category of analysis, the team's misconception about the concept is directly related to feelings of failure, frustration and impotence, which is corroborated by the literature ¹⁹.

Regarding feelings and values, it was found that considering palliative care starting from diagnosis, as a set of practices to reduce suffering associated with painful treatments, the professional works from the perspective of health, protection and promotion of quality of life, which is rewarding and generates wellbeing. On the other hand, seeing it as the final care in the face of curative impossibility and, above all, of terminality, accentuates the feeling of failure in the face of illness.

The total investment in cure, coupled with the understanding of palliative care only in terminal situations, reinforces the idea that such care is provided when there is "nothing more to be done". In this context, it is probable that the professional abandon the patient, since the patient is no longer "investable".

Centralizing palliative care in a specific unit also reinforces this perception, as some interviewees pointed out. When patients "enters palliative care" and are transferred to the unit responsible for this care, they may experience, in addition to mourning for their own health, mourning for the breakdown of the bond with the team they used to refer to, and for moving away from the known unit²⁰.

Faced with the search for cure at any cost and the culture of avoiding death²¹, it is increasingly difficult to deal with the illness of children, which is further aggravated when they begin to receive palliative care. Some professionals, when reporting experiences of patients and relatives, projected their own anguish and personal difficulties, showing great difficulty in facing feelings related to the finitude of life and one's own death. The projection consists of *attributing one's own feelings and desires to another person, because these inner feelings are intolerable and painful²²*.

In relation to the team, it is emphasized that the fact that some professionals do not participate in informative and decision-making spheres interferes in their adequate understanding of palliative care, of the processes involved in the definition of behaviors, and of the way in which communication with patients and their families happens. The testimonials indicated that these professionals tend to deny palliative care at the Pediatric Oncology Unit, even though some patients in the sector are at this stage of treatment.

The role of defense mechanisms, used unconsciously by individuals to avoid or reduce suffering caused by threatening scenarios, is highlighted. In this case, the diagnosis and treatment of childhood cancer can be considered realities that raise varying levels of anguish and anxiety in health professionals. In the interviews, the main defense mechanisms identified were denial, projection and rationalization. With regard to attitudes, denying palliative care and the possibility of death of patients hospitalized at the Pediatric Oncology Unit, *the perception of some painful aspects of reality are avoided, denying sensory data and abolishing external reality*²². On the other hand, based on rationalization, the subject *offers rational explanations in an attempt to justify attitudes, beliefs or behaviors that may otherwise be unacceptable*²². These mechanisms came to the fore when professionals were questioned about their views on palliative care, and avoided expressing feelings, directing the answers to practical aspects and theoretical explanations.

Regarding the last category of analysis, the professional's investment in contact, in creating bonds and offering the best assistance to patients in palliative care, is linked to feelings of gratification, pride and well-being. In addition, the literature indicates that the established bond between team and patient/family contributes to less painful and traumatic treatment¹². Therefore, affective distancing of patients, mentioned as a means of avoiding professional suffering, may, on the contrary, heighten it, because *without a bond it is not possible to perform good care*, as some interviewees say.

Several studies confirm that health professionals distance themselves from patients and their families when dealing with critical illness situations, in an attempt not to get involved with the suffering of others^{23,24}. Faced with the emotional burden experienced in the reality of providing palliative care to pediatric oncology patients, it can be thought that suffering and stress permeate the work routine, leading to professionals becoming ill.

In this sense, the interviewees raised some possible areas to work on, both personal and as a team. Among them, the importance of developing spirituality and adopting an empathic and restrained manner with patients and teammates is evident. The professionals also pointed out the need to give meaning to the experience of death and to feel supported, highlighting enhancing the capacity to listen and personal treatment (psychotherapy) as a form of self-knowledge and thinking about one's own end. Investing in physical and leisure activities is also very important to stimulate self-care and improve quality of life. Regarding team interventions, as pointed out in an earlier study²⁵, it is proposed that spaces for theoretical discussion about death and palliative care be created, aiming to work on understanding this type of care and demystifying the subject of death. In addition, the importance of investing in effective communication between the team is evident, so that all collaborate to define plans to provide care. Finally, it is fundamental to promote systematic meetings between the interdisciplinary team to address feelings related to professional practice and to deal with the grief associated with the daily care of patients.

Final considerations

The information collected in the study allowed the identification of the participants' understanding of the subject, verifying that there is confusion between the concepts of exclusive palliative care and palliative care starting from diagnosis. The misconception that this type of care refers to end-of-life situations or curative impossibility generates intense suffering in most professionals, who experience frustration, impotence and guilt, among other feelings.

In an attempt to deal with such suffering, professionals often use defense mechanisms, which can be considered adaptive because they allow the professional to get in touch with the suffering of the other (patient/family) without falling apart emotionally. However, when used in a recurring and inflexible way, they can lead to psychological suffering and illness.

Among the attitudes that help to face this reality, professionals emphasize the regular practice of physical exercise and personal treatment through psychotherapy. In addition, they pointed out the need to be trained to provide palliative care, as well as the need to have spaces to stimulate the exchange of experiences between the team.

It reiterates the importance of future work on the habitual understanding of palliative care in order to institute the culture that this assistance should be implemented from the diagnosis of a chronic and/or severe illness and be part of all stages of treatment.

Referências

- 1. Stewart BW, Wild CP, editores. World cancer report 2014. Lyon: International Agency for Research on Cancer; 2014.
- 2. Instituto Nacional de Câncer. Estimativa 2016: incidência de câncer no Brasil. Rio de Janeiro: Inca; 2015.
- Instituto Nacional de Câncer. Câncer na criança e no adolescente no Brasil: dados dos registros de base populacional e de mortalidade. Rio de Janeiro: Inca; 2008.

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- 4. World Health Organization. Cancer pain relief and palliative care: report of a WHO Expert Committee. Geneva: WHO; 1990. p. 11.
- 5. World Health Organization. National cancer control programmes: policies and managerial guidelines. 2ª ed. Geneva: WHO; 2002. p. 84.
- Matsumoto DY. Cuidados paliativos: conceito, fundamentos e princípios. In: Carvalho RT, Parsons HA, organizadores. Manual de cuidados paliativos ANCP. 2ª ed. São Paulo: Academia Nacional de Cuidados Paliativos; 2012. p. 23-30.
- Mudigonda T, Mudigonda P. Palliative cancer care ethics: principles and challenges in the Indian setting. Indian J Palliat Care [Internet]. 2010 [acesso 1º nov 2017];16(3):107-10. Disponível: https://bit.ly/2AjRcwX
- Arantes ACLQ. Indicações de cuidados paliativos. In: Carvalho RT, Parsons HA, organizadores. Op. cit. p. 56-74.
- World Health Organization. Cancer: fact sheet [Internet]. 2017 [acesso 1º nov 2017]. Disponível: https://bit.ly/1qsngX6
- Barbosa SMM. Cuidado paliativo em pediatria. In: Carvalho RT, Parsons HA, organizadores. Op. cit. p. 461-73.
- Barr H. Interprofessional education: the genesis of a global movement [Internet]. London: Centre for Advancement of Interprofessional Education; 2015 [acesso 30 jul 2018]. Disponível: https://bit.ly/2r3O3gK
- 12. American Academy of Pediatrics. Committee on Bioethics, Committee on Hospital Care. Palliative care for children. Pediatrics [Internet]. 2000 [acesso 1º out 2016];106(2):351-7. Disponível: https://bit.ly/2zxhKLZ
- Instituto Nacional de Câncer, Instituto Ronald McDonald. Diagnóstico precoce do câncer na criança e no adolescente. 2ª ed. Rio de Janeiro: Inca; 2011.
- 14. Gil AC. Métodos e técnicas de pesquisa social. 2ª ed. São Paulo: Atlas; 1989.
- Minayo MCS. Análise qualitativa: teoria, passos e fidedignidade. Ciênc Saúde Coletiva [Internet]. 2012 [acesso 8 out 2016];17(3):621-6. Disponível: https://bit.ly/2FfryQ1
- 16. Bardin L. Análise de conteúdo. Lisboa: Edições 70; 1977.
- 17. Conselho Nacional de Saúde. Resolução CNS nº 466, de 12 de dezembro de 2012. Aprova diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos [Internet]. Diário Oficial da União. Brasília, nº 12, p. 59, 13 jun 2013 [acesso 8 out 2016]. Disponível: https://bit.ly/20ZpTyq
- Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care [Internet]. 2007 [acesso 8 out 2016];19(6):349-57. Disponível: https://bit.ly/2Sapie7
- Cardoso DH, Muniz RM, Schwartz E, Arrieira ICO. Cuidados paliativos na assistência hospitalar: a vivência de uma equipe multiprofissional. Texto Contexto Enferm [Internet]. 2013 [acesso 1º out 2016];22(4):1134-41. Disponível: https://bit.ly/2yIrsvT
- 20. Maciel MGS. Organização de serviços de cuidados paliativos. In: Carvalho RT, Parsons HA, organizadores. Op. cit. p. 94-110.
- 21. Ariès P. História da morte no ocidente: da idade média aos nossos dias. Rio de Janeiro: Ediouro; 2003.
- Eizirik CL, Bassols AMS, Gastaud MB, Goi J. Noções básicas sobre o funcionamento psíquico. In: Eizirik CL, Bassols AMS, organizadores. O ciclo da vida humana: uma perspectiva psicodinâmica. 2ª ed. Porto Alegre: Artmed; 2013. p. 15-30. p. 28.
- 23. Martins JT, Robazzi MLCC. O trabalho do enfermeiro em unidade de terapia intensiva: sentimentos de sofrimento. Rev Latinoam Enferm [Internet]. 2009 [acesso 7 nov 2017];17(1):52-8. Disponível: https://bit.ly/2OYE5XC
- Viero V, Beck CLC, Coelho APF, Pai DD, Freitas PH, Fernandes MNS. Trabalhadores de enfermagem em oncologia pediátrica: o uso de estratégias defensivas no trabalho. Esc Anna Nery [Internet]. 2017 [acesso 7 nov 2017];21(4):e20170058. Disponível: https://bit.ly/2BupsaS
- 25. Silva AF, Issi HB, Motta MGC, Botene DZA. Cuidados paliativos em oncologia pediátrica: percepções, saberes e práticas na perspectiva da equipe multiprofissional. Rev Gaúcha Enferm [Internet]. 2015 [acesso 1º out 2016];36(2):56-62. Disponível: https://bit.ly/2S7JsWk

Participation of the authors

Cássia Linhares Pacheco collected the data. Both authors conceived the project, analyzed the data and wrote the article.

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Appendix

Interview script

Profession: _____ Date: ___/___/____

- 1. What do you understand by "palliative care" (from the perspective of the interviewee, patient, family, and hospital)?
- 2. How do you feel when there is a change in perspective from curative treatment to exclusive palliative care? That is, how do you feel when there is no longer a curative treatment to offer, it being possible to only control the disease and manage symptoms? Have you had any practical experience in this regard? How was it?
- 3. When it is determined that a patient has entered palliative care, how do you feel? What coping strategies do you use to deal with this reality? Do you have any suggestions?