

# Oncological homecare: family and caregiver perception of palliative care

*Atendimento domiciliar oncológico: percepção de familiares/cuidadores sobre cuidados paliativos*

*Atención oncológica domiciliaria: percepción de la familia/cuidadores sobre cuidados paliativos*

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## ABSTRACT

**Objective:** To identify family and caregiver perception of palliative care for patients diagnosed with terminal cancer receiving in-home health services. **Methods:** A descriptive study with a qualitative approach was conducted with six family members and caregivers of patients receiving in-home palliative care services exclusively provided by the Palliative Care Unit of a referral hospital. Data were collected through semi-structured interviews conducted between September and October 2015, analyzed in the light of Bardin's Content Analysis. **Results:** The following themes arose: Family members/caregivers' routine when providing palliative care; Palliative care team; Support for family members/caregivers; Family members/caregivers' understanding of palliative care; Family members/caregivers' feelings about palliative care; Family members/caregivers' experience with in-home palliative care. **Conclusion:** It was possible to identify the importance of in-home palliative care as it enables the reduction in the impact of suffering caused by cancer and guarantees dignity in the death process.

**Keywords:** Palliative care; In-home health services; Family; Oncology.

## RESUMO

**Objetivo:** Conhecer a percepção do familiar/cuidador de pacientes com diagnóstico de câncer terminal em atendimento domiciliar sobre cuidados paliativos. **Métodos:** Pesquisa descritiva, abordagem qualitativa realizada junto a seis cuidadores familiares de pacientes que recebem atendimento domiciliar em cuidados paliativos exclusivos prestados pela Unidade de Cuidados Paliativos de um hospital de referência. Os dados foram coletados no período de setembro a outubro de 2015, por meio de entrevista semiestruturada analisada a luz da Análise de Conteúdo de Bardin. **Resultados:** Emergiram-se as seguintes temáticas: Rotina do familiar/cuidador diante dos cuidados paliativos; Equipe de cuidados paliativos: Apoio ao familiar/cuidador; Entendimento do familiar/cuidador sobre cuidados paliativos; Sentimentos do familiar/cuidador em cuidados paliativos; Vivência do familiar/cuidador acerca dos cuidados paliativos em domicílio. **Conclusão:** Foi possível resgatar a importância dos cuidados paliativos no domicílio como possibilidade de minimizar o impacto do sofrimento com a doença e assegurar a dignidade no processo de morrer.

**Palavras-chave:** Cuidados paliativos; Atendimento domiciliares; Família; Oncologia.

## RESUMEN

**Objetivo:** Conocer la percepción de la familia/cuidador de enfermos con diagnóstico de cáncer terminal en atención domiciliar sobre cuidados paliativos. **Métodos:** Investigación descriptiva, cualitativa, realizada con seis cuidadores familiares de pacientes que reciben atendimento domiciliar en cuidados paliativos exclusivos, prestados por la Unidad de Cuidados Paliativos de un hospital de referencia. Los datos fueron recolectados en el periodo de septiembre a octubre de 2015, através de entrevista semiestruturada que utilizó el Análisis de Contenido de Bardin. **Resultados:** Emergieron las siguientes temáticas: Rutina del familiar/cuidador frente a los cuidados paliativos; Equipo de cuidados paliativos: Apoyo al familiar/cuidador; Conciencia del familiar/cuidador sobre cuidados paliativos; Sentimientos del familiar/cuidador en cuidados paliativos; Vivencia del familiar/cuidador sobre cuidados paliativos en el hogar. **Conclusión:** Se posibilitó rescatar la importancia de los cuidados paliativos en el hogar como posibilidad de minimizar el impacto del sufrimiento con la enfermedad y asegurar la dignidad en el morir.

**Palabras clave:** Cuidados Paliativos; Atención Domiciliaria; Familia; Oncología.

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## INTRODUCTION

According to the World Health Organization (WHO), cancer will become a greater problem in the next decades; the estimated number of new cases will increase from ten million in 2000 to 27 million in 2030, in addition to 17 million deaths and 75 million individuals living with malignant neoplasms, the majority of which in low-income countries. In Brazil, 600,000 new cases are estimated for 2016/2017.<sup>1</sup>

When cancer is at an advanced stage or developing towards this condition, the palliative approach must be followed when dealing with symptoms that cannot be easily controlled, provided that it is associated with psychosocial aspects of this disease. In the terminal stage, when patients have a short time of life, palliative care is emphasized to guarantee dignity and quality of life.<sup>2</sup> According to the Palliative Care Alliance Worldwide (WPCA), six million individuals with cancer require palliative care worldwide, the majority of which are adults aged more than 60 years.<sup>3,4</sup>

According to the World Health Organization (WHO), in a concept updated in 2002, palliative care consists in health services provided by a multi-disciplinary team that aim to improve the quality of life of patients and their family members, when coping with a disease that threatens their life, through prevention and reduction in suffering, early identification, effective assessment and treatment of pain and other physical, social, psychological and spiritual symptoms.<sup>5</sup>

Among these symptoms, pain is an unpleasant sensation that ranges from mild discomfort to excruciating pain, associated with a current or potential destructive process of tissues which takes place through an organic and/or emotional reaction, considered as the fifth vital sign. Data indicate that pain affects 60% to 80% of cancer patients, 25 to 30% of which at the time of diagnosis, while 70% to 90% of those with advanced-stage cancer categorized their pain from moderate to severe.<sup>6</sup>

In view of these facts, the WHO declared that the pain associated with cancer is a worldwide medical emergency and, in 1986, it published treatment guidelines aimed at alleviating pain among 90% of patients.<sup>6</sup> Thus, the role of palliative care has been defended, which should be provided as early in the course of the disease as possible, rather than in its final stages. Additionally, it is recommended that there should be integration of services on all health care levels, with an emphasis on primary care. This integration of palliative care in the health system is considered to be an important aspect for the quality of care at the end of an individual's life.<sup>7</sup>

According to the Global Atlas of Palliative Care, family and caregiver support for patients requiring palliative care is very important and frequent, especially in a community. The implementation of palliative care services must include interventions to support caregivers, aiming to enable better assessment and provision of health care.<sup>7</sup>

In this context, the family as a key aspect in palliative care for cancer patients has been discussed in several areas and social contexts. In the health sector, this is not different and the work

with family members is one of the most significant strategies. In addition to being a space which enables protection, where its members feel that they belong to a group united by bonds of love and affection, it has also been defined as a health system for its members.<sup>8</sup>

Nonetheless, it could be observed that coping with this disease in the family context depends on factors that are closely associated with the following: the stage of life in which a family finds itself; the role played by its sick member; the implications that the impact of a certain disease, in this case cancer, has on each of them; and the way in which it organizes itself during the disease period.<sup>9</sup>

Health care becomes essential when the greater perspective of care for patients in palliative care is taken into consideration. This individual can be from the family itself and/or community, with adequate support and guidance from health professionals, whose role surpasses the simple follow-up of daily activities of individuals. They must be prepared to experience the death process of their loved one, especially inside their homes, as many of them have not had this experience and are afraid to go through this.<sup>9-11</sup>

Any individual who approaches the final stage of a debilitating health condition requires more palliative care. In this process, family members/caregivers and health professionals need to work together as a team to provide comprehensive care. This is because, at such moment, it is important to guarantee quality care.<sup>12,13</sup>

In view of the context described, the following guiding question arose: What is the family members'/caregivers' perspective of palliative care for patients diagnosed with terminal cancer who receive in-home services exclusively provided by the Palliative Care Unit (PCU) of a referral state university hospital for cancer treatment?

Thus, the present study aimed to identify the family members'/caregivers' perspective of palliative care for patients diagnosed with terminal cancer who receive in-home health services for palliative care exclusively provided by the PCU of a university hospital in the city of Recife, Northeastern Brazil.

## METHODS

A descriptive exploratory study with a qualitative approach was conducted, using the Content Analysis technique. The content analysis technique proposed by French author Laurence Bardin is characterized by a set of communication analysis techniques that use descriptive exploratory studies, systematic procedures and objectives of message content description.<sup>14</sup>

The setting was the PCU of a university hospital included in the 1<sup>st</sup>, 2<sup>nd</sup>, 3<sup>rd</sup>, 4<sup>th</sup> and 5<sup>th</sup> health districts of the city of Recife, in Pernambuco state, Northeastern Brazil. This unit provides services for 16 families on average and it is comprised of a multi-disciplinary team. This team includes a physician, nurse, occupational therapist, psychologist, nutritionist and nursing technician, who have been responsible to provide in-home care for patients with chronic and severe diseases since 2000.

Research participants were six family members/caregivers of patients diagnosed with cancer and followed by the PCU team between September and October 2015. The inclusion criteria were as follows: to be a family member/caregiver; to be aged 18 years and more; to be responsible for the patient diagnosed with cancer; to be receiving in-home care from the PCU of the HUOC during data collection. Thus, data collection began after the research project was approved by the Research Ethics Committee (CEP/HUOC/PROCAPE), under CAAE number 46601815.0.0000.5192.

Semi-structured interviews based on guidelines developed by the authors of this study were the technique used. The guiding question was as follows: What is the family members'/caregivers' perspective of palliative care for patients diagnosed with terminal cancer who receive in-home health services exclusively provided by the Palliative Care Unit (PCU)? Visits had been previously set up with family members/caregivers. Interviews were performed individually at home, recorded to guarantee reliability and transcribed by the researcher. Additionally, they will be destroyed after five years.

These interviews were analyzed, data were grouped according to linguistic and content characteristics that take into consideration the totality of the text shown, following the stages of pre-analysis, material exploration and treatment of results.<sup>14</sup>

All research participants signed an Informed Consent Form and the dignity, respect for autonomy and defense of vulnerability of research participants were guaranteed, in accordance with Resolution CNS 466/12 issued by the Brazilian Ministry of Health/National Health Council (CNS/MS). Aiming to guarantee the confidentiality and anonymity of participants, the names of caregivers were replaced by words expressing the feelings that each patient represented for them: Love, Companionship, Joy, Friendship, Hope and Gratitude.

Based on the understanding of the reports given by caregivers, the following thematic categories arose: Family members/caregivers' routine when providing palliative care; Palliative care team; Support for family members/caregivers; Family members/caregivers' understanding of palliative care; Family members/caregivers' feelings about palliative care; Family members/caregivers' experience with in-home palliative care.

## RESULTS AND DISCUSSION

The characterization of the family members/caregivers of patients who receive palliative care was as follows: four women and two men, aged between 32 and 51 years; regarding level of education: one participant had incomplete primary education, three had complete secondary education. One had complete higher education, and one had a postgraduate degree; regarding employment status: one was unemployed, two were housewives, one was retired, one was a nursing technician, and one was a sales executive; and regarding family relationship: there were two granddaughters, one niece, one son, one daughter and one husband.

### Palliative care team: support for the family member/caregiver

The guidance and support provided by the PCU palliative care team were briefly recorded through the reports given by each caregiver:

*There's the guidance on what palliative care is. Then we can begin to understand this. There's also support with guidance on medication, diet and even patient management. (Love)*

*They recommend how we should act if she feels a little pain, care for her bath, if something comes up, I can call the team. Everything is prescribed by the physician, there's also follow-up with a psychologist, nutritionist and nurse, everything is under control. (Friendship)*

*The best one possible, so that, thank God, the whole team gives me support, it's easy to communicate and approach them, look them in the eye, which is essential in this final stage of the disease. (Hope)*

Family members/caregivers begin to perform functions that most of them are often unfamiliar with, such as: wound dressing, hygiene, drug management, probe and drain management, in addition to dealing with the development of the disease and possibility of death. This reality takes into consideration the fact that in-home palliative care is unique, especially in the advanced state of the disease. Soon, these activities can have emotional, physical, social and economic effects that can even lead to depression, affecting their quality of life.<sup>9</sup>

For this reason, it is important that the palliative care team is well aware of family members/caregivers and families involved with care, so that all the support required can be provided in a way that negative reactions generated during the provision of such care can be minimized.<sup>15</sup>

Palliative care founded on enabling efficient communication and dialogues about the prognosis are key characteristics. To understand this, it is essential to identify approaches that promote the decision of treatment which is primarily in accordance with the patient and family and in the hope of an improvement in quality of life. Care centered on patients considers the fact that the experience of a disease must be shared with and founded upon the clinical perspective.<sup>10,16</sup>

These programs essentially aim to offer an integrated and multi-disciplinary approach to prevent and alleviate pain, suffering and other physical, psychosocial and spiritual problems associated with the disease. Palliative care is part of a philosophy that promotes life and deals with death as a natural process, without influence of its time of occurrence; support systems are available for patients to live as actively as possible until their death and for families to cope with the disease of this patient and their own mourning.<sup>17</sup>

### Family members/caregivers' routine when providing palliative care

When focusing on the routine of caregivers, the negative change in the personal life of one of the family members stood out, although the majority had a positive experience. This negative change was associated with the loss of a job, when this caregiver neglected his life or part of it for fear of letting his wife alone and losing her during his absence while at work, as reported below:

*Our routine is like this, you know, I leave home, but I come back soon, because I'm afraid that she'll have a crisis, die and then our girl will be the only one here for the baby. Before, it was just me and her. I worked, then I had to quit to take care of her, but I preferred it that way. (Companionship)*

In contrast, positive changes in life also stood out:

*She's feeling more peaceful, both the family and the team are taking better care of her. We thought it'd be better to bring her home, you know? (Friendship)*

*Much better, more organized and safer, because we receive support and feel safe to go on giving care at home. (Love)*

*Then, day by day, however exhausting this disease can be, the fact that there is palliative care gives support to the family, you know. It gives emotional support, it doesn't only heal the pain, it doesn't only bring quality of life to her, but to everyone at home. (Hope)*

*I'm fine, I feel very supported, things I'd never imagine to have something to do with me were provided. Because it supports patients, including their family members in their environment. This is why my day is more peaceful. (Gratitude)*

Caregivers re-dimension their life to cope with the disease and its complications. However, personal wishes were ignored, as they began to live exclusively for the fulfillment of the desires of the patients cared for. "The thin line between the patient's life and that of the caregiver disappears, as the latter starts to experience the life of their sick family member intensely so that nothing is missing".<sup>18</sup>

This occurs because one has to assume the responsibilities of care alone, as the presence of other members of the family is sporadic and fragmented. This caregiver loses energy, feels tired and emotionally exhausted. Additionally, this situation compromises the quality of care provided.<sup>9</sup> Therefore, it is important to focus on the importance of the development of the palliative care team, aiming to promote and follow this caregiver and family through guidance when in-home services are provided. This information enables caregivers/family members to feel safe and independent, both for patient care and for themselves.<sup>19</sup>

### Family members/caregivers' understanding of palliative care

It is essential to combine palliative care with the proposal of more humanized care as an act of respect and solidarity. Based on this premise, family members' understanding of palliative care was important to clarify how the interaction among patients, family members/caregivers and the team occur. This fact can be observed in the following reports:

*Palliative care is a complement to that which we can improve, in terms of better care, special care, affection, attention, dedication and love. It's a complement. (Friendship)*

*To give the required support for sick people and to comfort the family at the time of death. (Love)*

*I think that, based on what has been explained, they are measures that must be taken for patients to have psychological and physical comfort and for pain to be alleviated whenever possible. They're also instructions given to family members and caregivers so they can stay calm and comfortable during this period. (Gratitude)*

*Palliative care is different, it's more humanized. It's looking in the eye, telling the truth, following someone and being there with them. In this sense, it brings much comfort. (Hope)*

Family members/caregivers of patients diagnosed with cancer in palliative care must overcome the difficulties of dealing with a member with an advanced-stage disease, i.e. without the possibility of therapy. Thus, it should be emphasized that the communication between caregivers and the team is invaluable, as each caregiver and patient are unique and their needs must be met in the most adequate and objective way possible.<sup>10</sup>

However, the palliative care team's role is to make them understand the purpose of such care, valuing world social questions present in the life of family members who care for a sick member in palliative care, apart from the meaning that they attribute to this experience and their actions or interactions. This is because it is possible to seek more authentic care through the understanding of this health care model.<sup>20</sup>

Family members/caregivers need a spiritual, emotional and physical boost and information for them to feel safe and prepared for this new reality.<sup>21</sup> This can minimize questions, anxiety and concerns and enable the promotion of quality of life for caregivers and patients in palliative care.

There is great stigma associated with palliative care, which can persist even after positive experiences in the first interventions. Moreover, the ongoing definition of palliative care for patients and their caregivers is care provided at the end of life, although a worldwide change in this definition was made over a decade ago.<sup>22</sup>

A name change can be taken into consideration, although it is essential that such change involves the way palliative care is

portrayed. Thus, it is clear that wide basic education is required to guarantee a greater understanding of what palliative care represents and involves.<sup>22</sup>

### Family members/caregivers' feelings about palliative care

To know that one's family member is receiving palliative care can generate a number of feelings,<sup>23</sup> ranging from negative ones such as greater fear to others of comfort, due to the fact that this member is at home with their family. Such feelings are frequently expressed by the patients themselves and some of the family members who are aware of the follow-up of the palliative care team. The following reports describe this:

*I'm afraid that she'll start to feel sick here and the children will be at home. Like I was talking to her (our daughter) yesterday. Look, be patient, the doctor has already explained everything. She can pass away at any moment. (Companionship)*

*Sad, as there's no investment, but at the same time comfortable and satisfied, as there's a team giving the support I need now, you know? Palliative care goes way beyond what I thought it was. There's a multi-disciplinary team. We have support and guidance for our family. We feel safer, so we can wait for this moment of loss. (Love)*

At this moment, the importance of professionals' support and communication with the families of patients who will begin to receive palliative care should be emphasized, as this contact is essential to provide high quality services.<sup>24</sup> Based on this fact, the importance of establishing connections between the team and caregiver/family member stands out, as it promotes trust among those involved.<sup>25</sup>

*I felt very happy and privileged and so did my family. Especially my dad, who is the privileged patient receiving such excellent service. All professionals are part of a multi-disciplinary team and they're all very committed. (Gratitude)*

*I felt happy, because it's hard, it's been seven years, countless hospitalizations and surgeries, you know? So, when you know someone is receiving palliative care, it's hard, you know? But at the same time you see that it's a different type of care. Patients are with their families and receive support from the team. I'm very satisfied, because the whole team makes me feel safe and comforted, you know? Peace for her and for me, as I'm an only child and alone. So, when we say we're receiving palliative care at Oswaldo Cruz, people say: "At Oswaldo Cruz? Do they have it there?". People don't have any idea of the dimension of your work. I think that this stage with terminal patients is very important. Because it's a passage and family members don't usually know how to deal with*

*this. So, help those who don't know and improve the perspective of those who know something. (Hope)*

The fact that they feel like they have company and are not alone enables most caregivers to express their feelings more easily. As a result, the new definition of palliative care established by the World Health Organization (WHO) recommends searching for quality of life of family members of patients with an advanced-stage disease, support during the period of coping with this disease and even the mourning period.<sup>1</sup>

With these reports, the satisfaction of family members/caregivers with the work of the palliative care team is emphasized. They were expressed in a positive and satisfying way, attributed to enthusiastic statements and compliments. The team reached the caregivers' expectations, meeting the needs that arose due to suffering and terminal stage. In view of this context, families expect such team to have the abilities, competences, reliability and safety in their care and even friendship. Thus, it is possible to affirm that the satisfaction with health professionals' actions is considered to be positive in the dimensions of professionalism.<sup>15</sup>

## FINAL CONSIDERATIONS

The present study identified the emphasis on the importance of in-home palliative care as a possibility to minimize the impact of suffering with this disease and guaranteeing the dignity in the death process.

Family members/caregivers of patients diagnosed with cancer are also responsible for the in-home care process and perceive the palliative care team as an essential ally when coping with the terminal disease. Thus, the present study is expected to have contributed to the construction of such knowledge and, especially, to drawing the attention of managers and professionals to the need for in-home palliative care.

One of the limitations of this study was associated with the number of individuals and setting, as only one unit was included, thus preventing the generalization of findings. However, these findings are considered to be valid, as they reflect similar conditions observed in larger studies. The need for complementary studies on this theme should be emphasized. There is a lack of studies on in-home palliative care practices, while this type of care has been more analyzed in the hospital environment.

## REFERENCES

1. Ministério da Saúde (BR). Instituto Nacional de Câncer José Alencar Gomes da Silva. Coordenação de Prevenção e Vigilância. Estimativa 2016: incidência de câncer no Brasil. Rio de Janeiro (RJ): INCA [internet]; 2015. Available from: <http://www.inca.gov.br/estimativa/2016/sintese-de-resultados-comentarios.asp>
2. Souza LF, Misko MD, Silva L, Poles K, Santos MR, Bousso RS. Dignified death for children: perceptions of nurses from an oncology unit. *Rev Esc Enferm USP*. [Internet] 2013; [cited 2016 Mar 02]; 47(1): 30-37. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0080-62342013000100004&lng=en&nrm=iso&tIng=en](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0080-62342013000100004&lng=en&nrm=iso&tIng=en). <http://dx.doi.org/10.1590/S0080-62342013000100004>

3. Connor SR, Sepulveda-Bermedo MC. Global Atlas of Palliative Care at the End of Life. Worldwide Palliative Care Alliance, World Health Organization [internet], 2014 [cited 2016 Mar 02]. Available from: [http://www.who.int/nmh/Global\\_Atlas\\_of\\_Palliative\\_Care.pdf](http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf)
4. WHA67.19. Fortalecimiento de los cuidados paliativos como parte del tratamiento integral a lo largo de la vida. Resolución WHA; 67a Asamblea Mundial de la Salud [internet], 2014 [cited 2016 Mar 02]. Available from: [http://apps.who.int/gb/ebwha/pdf\\_files/WHA67/A67\\_R19-sp.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-sp.pdf)
5. Ministério da Saúde (BR). Instituto Nacional de Câncer. Cuidados Paliativos Oncológicos: Controle da dor. Rio de Janeiro: INCA, 2002 [cited 2016 Mar 02]. Available from: [http://www1.inca.gov.br/publicacoes/manual\\_dor.pdf](http://www1.inca.gov.br/publicacoes/manual_dor.pdf)
6. Rangel O, Telles S. Tratamento da dor oncológica em cuidados paliativos. *Revista Hospital Universitário Pedro Ernesto*. [Internet] 2012; [cited 2016 Mar 02]; 11(2): 32-37. Available from: [http://revista.hupe.uerj.br/detalhe\\_artigo.asp?id=324](http://revista.hupe.uerj.br/detalhe_artigo.asp?id=324)
7. Marcucci FCI, Cabrera MAS, Perilla AB, Brun MM, Barros EML, Martins VM, Rosenberg JP, Yates P. Identification and characteristics of patients with palliative care needs in Brazilian primary care. *BMC Palliative Care*. [Internet] 2016; [cited 2016 Mar 02]; 15(1): 1. Available from: <https://bmc.palliativecare.biomedcentral.com/articles/10.1186/s12904-016-0125-4>. DOI: 10.1186/s12904-016-0125-4.
8. Sanches MVP, Nascimento LC, Lima RAG. Crianças e adolescentes com câncer em cuidados paliativos: experiência de familiares. *Rev Bras Enferm*. [Internet] 2014; [cited 2016 Mar 02]; 67(1): 28-35. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0034-71672014000100028](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0034-71672014000100028). <http://dx.doi.org/10.5935/0034-7167.20140003>
9. Nietzsche EA, Vedoin SC, Bertolino KCO, Lima MGR, Terra LG, Bortoluzzi CRL. Healthcare team and family caregivers: care for the terminally ill at home. *Revista de Enfermagem Referência*. [Internet] 2013; [cited 2016 Mar 06]; 10: 55-62. Available from: <http://www.scielo.mec.pt/pdf/ref/vserlln10/serlln10a07.pdf>. <http://dx.doi.org/10.12707/R1112137>
10. Gramling et al. Design of, and enrollment in, the palliative care communication research initiative: a direct-observation cohort study. *BMC Palliative Care*. [Internet] 2015; [cited 2016 Mar 02]; 14(1): 1. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/26286538>. DOI: 10.1186/s12904-015-0037-8.
11. Ministério da Saúde (BR). Secretaria de Atenção à Saúde. Secretaria de Gestão do Trabalho e da Educação na Saúde. Guia prático do cuidador. Brasília: Ministério da Saúde, 2008. 64 p.: il. - (Série A. Normas e Manuais Técnicos). Available from: [http://dab.saude.gov.br/portaldab/biblioteca.php?conteudo=publicacoes/guia\\_pratico\\_cuidador](http://dab.saude.gov.br/portaldab/biblioteca.php?conteudo=publicacoes/guia_pratico_cuidador)
12. Vasconcelos EV, Santana ME, Silva SED. Desafios de enfermagem nos cuidados paliativos: revisão integrativa. *Enfermagem em Foco*. [Internet] 2012; [cited 2016 Mar 06]; 3(3): 127-30. Available from: <http://revista.portalcofen.gov.br/index.php/enfermagem/article/view/296/158>
13. Araújo MMT, Silva MJP. O conhecimento de estratégias de comunicação no atendimento à dimensão emocional em cuidados paliativos. *Texto & Contexto Enferm*. [Internet] 2012; [cited 2016 Mar 06]; 21(1): 121-29. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0104-07072012000100014](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-07072012000100014). DOI: <http://dx.doi.org/10.1590/S0104-07072012000100014>
14. Bardin L. Análise de Conteúdo. Tradução de Luís Antero Reto e Augusto Pinheiro. São Paulo: Edições 70, 2011. p.95-103.
15. Silva AF, Issi HB, Motta MGC. A família da criança oncológica em cuidados paliativos: o olhar da equipe de enfermagem. *Cienc Cuid Saude*. [Internet] 2011; [cited 2016 Mar 06]; 10(4): 820-27. Available from: <http://ojs.uem.br/ojs/index.php/CiencCuidSaude/article/view/18328>. DOI: 10.4025/cienccuidsaude.v10i4.18328.
16. Alfaya GMM, Bueno PMJ, Hueso MC, Guardia MP, Montoya JR, Garcia CMP. Palliative care team visits. Qualitative study through participant observation. *Colomb Med*. [Internet] 2016; [cited 2016 Mar 06]; 47(1): 38-44. Available from: <http://colombiamedica.univalle.edu.co/index.php/comedica/article/view/2022>
17. Allende PS, Verástegui AE, Mohar BA, Meneses GA, Herrera GA. Oncología integrada y cuidados paliativos: experiencia de cinco años en el Instituto Nacional de Cancerología en México. *Salud pública de México*. [Internet] 2016; [cited 2016 Mar 06]; 58(2): 317-24. Available from: <http://www.scielosp.org/pdf/spm/v58n2/0036-3634-spm-58-02-00317.pdf>
18. Oliveira SG, Quintana AM, Denardin-budó ML, Moraes NA, Lüdtke MF, Cassel PA. Internação domiciliar do paciente terminal: o olhar do cuidador familiar. *Rev Gaucha de Enferm*. [Internet] 2012; [cited 2016 Mar 06]; 33(3): 104-10. Available from: <http://www.scielo.br/pdf/rngen/v33n3/14.pdf>
19. Pires LCB, Vargas MAO, Vieira RW, Ramos FRS, Ferrazo S, Bitencourt JVOV. Relação entre equipe de enfermagem e família de pessoas em cuidados paliativos. *Enfermagem em Foco*. [Internet] 2013; [cited 2016 Mar 06]; 4(1): 54-57. Available from: <http://revista.portalcofen.gov.br/index.php/enfermagem/article/view/504/194>
20. Nunes MDGS, Rodrigues BMRD. Tratamento paliativo: perspectiva da família. *Rev. Enfem. UERJ* [Internet] 2012; [cited 2016 Mar 06]; 20(3): 338-43. Available from: <http://bases.bireme.br/cgi-bin/wxislind.exe/iah/online/?IsisScript=iah/iah.xis&src=google&base=LILACS&lang=p&nextAction=lnk&exprSearch=661968&indexSearch=ID>
21. Fonseca JVC, Rebelo T. Necessidades de cuidados de enfermagem do cuidador da pessoa sob cuidados paliativos. *Rev Bras Enferm*. [Internet] 2011; [cited 2016 Mar 06]; 64(1): 180-84. Available from: <http://www.scielo.br/pdf/reben/v64n1/v64n1a26.pdf>. <http://dx.doi.org/10.1590/S0034-71672011000100026>
22. Zimmermann C, Swami N, Krzyzanowska M, Leigh N, Rydall A, Rodin G, Tannock I, Hannon B. Perceptions of palliative care among patients with advanced cancer and their caregivers. *CMAJ*. [Internet] 2016; [cited 2016 Mar 06]; 188(10). Available from: <http://www.cmaj.ca/content/early/2016/04/18/cmaj.151171>. DOI: 10.1503/cmaj.151171.
23. Cardoso DH, Muniz RM, Schwartz E, Arriera ICO. Hospice care in a hospital setting: the experience of a multidisciplinary team. *Texto contexto - enferm*. [Internet]. 2013 Dec; [cited 2016 Mar 06]; 22(4): 1134-41. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0104-07072013000400032](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-07072013000400032). <http://dx.doi.org/10.1590/S0104-07072013000400032>
24. Correia FR, Carlo MMRP. Evaluation of quality of life in a palliative care context: an integrative literature review. *Rev. Latino-Am. Enfermagem* [Internet]. 2012 Apr; [cited 2016 Mar 06]; 20(2): 401-10. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0104-11692012000200025](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-11692012000200025). <http://dx.doi.org/10.1590/S0104-11692012000200025>
25. Capello EMCDS, Velosa MVM, Salotti SRA, Guimarães HCQCP. Enfrentamento do paciente oncológico e do familiar/cuidador frente à terminalidade de vida. *J. Health Sci. Inst*. [Internet] 2012; [cited 2016 Mar 06]; 30(3): 235-40. Available from: [https://www.unip.br/comunicacao/publicacoes/ics/edicoes/2012/03\\_jul-set/V30\\_n3\\_2012\\_p235a240.pdf](https://www.unip.br/comunicacao/publicacoes/ics/edicoes/2012/03_jul-set/V30_n3_2012_p235a240.pdf)