PERCEPTION OF PATIENTS ABOUT PALLIATIVE CARE
PERCEPÇÃO DOS PACIENTES SOBRE OS CUIDADOS PALIATIVOS
PERCEPCIÓN DE LOS PACIENTES SOBRE LOS CUIDADOS PALIATIVOS

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ABSTRACT

Objective: to identify, in scientific production, how palliative care is offered under the perception of patients who need this therapy. **Method:** this is a descriptive, descriptive, integrative review, of studies published between 2006 and 2016 in the MEDLINE, BDENF, IBICS and LILACS databases. Controlled descriptors were used, in DeCS, and results presented in the form of tables and figures, discussed with the literature. **Results:** 27 publications were identified, which comprised the final sample. Two thematic categories were elaborated: Patients' perception of palliative care offered by specialized teams and non-specialized teams; and Differences in palliative care according to the environment: home care versus hospital care. **Conclusion:** it is evident that the palliative care offered, according to the patients' perception, should cover the totality of the subject. It was identified that specialized teams are able to better serve patients in palliative care. It should be emphasized that this study will contribute to the lack of publications on the subject, taking into account the rise of palliative care, and it is necessary to understand the patient's perception about the provision of this care. **Descriptors:** Palliative Care; Perception; Patients; Hospital Assistance; Home assistance; Palliative Medicine.

RESUMO

Objetivo: identificar, na produção científica, como os cuidados paliativos são ofertados sob a percepção dos pacientes que necessitam dessa terapia. **Método:** trata-se de estudo bibliográfico, descritivo, tipo revisão integrativa, de estudos publicados entre 2006 e 2016, nas bases de dados MEDLINE, BDENF, IBICS e LILACS. Utilizaram-se descritores controlados contemplados no DeCS, e resultados apresentados em forma de tabelas e figuras, discutidos com a literatura. **Resultados:** identificaram-se 27 publicações, as quais compuseram a amostra final. Elaboraram-se duas categorias temáticas: A percepção dos pacientes quanto aos cuidados paliativos ofertados por equipes especializadas e pelas equipes não especializadas e, As diferenças dos cuidados paliativos segundo o ambiente: atenção domiciliar *versus* atenção hospitalar. **Conclusão:** evidencia-se que os cuidados paliativos ofertados, segundo a percepção dos pacientes, devem abranger a totalidade do sujeito. Identificou-se que as equipes especializadas conseguem atender melhor os pacientes em cuidados paliativos. Ressalta-se que este estudo irá contribuir para a carência de publicações na temática, levando em consideração a ascensão dos cuidados paliativos, sendo necessário compreender a percepção do paciente sobre a oferta desse cuidado. **Descritores:** Cuidados Paliativos; Percepção; Pacientes; Assistência Hospitalar; Assistência domiciliar; Medicina Paliativa.

RESUMEN

Objetivo: identificar, en la producción científica, cómo los cuidados paliativos son ofrecidos bajo la percepción de los pacientes que necesitan esa terapia. **Método:** se trata de estudio bibliográfico, descriptivo, tipo revisión integrativa, de estudios publicados entre 2006 y 2016, en las bases de datos MEDLINE, BDENF, IBICS y LILACS. Se utilizaron descriptores controlados contemplados en el DeCS, y resultados presentados en forma de tablas y figuras, discutidos con la literatura. **Resultados:** se identificaron 27 publicaciones, las cuales compusieron la muestra final. Se elaboraron dos categorías temáticas: La percepción de los pacientes en cuanto a los cuidados paliativos ofrecidos por equipos especializados y por los equipos no especializados y, Las diferencias de los cuidados paliativos según el ambiente: atención domiciliar frente a la atención hospitalaria. **Conclusión:** se evidencia que los cuidados paliativos ofrecidos, según la percepción de los pacientes, deben abarcar la totalidad del sujeto. Se identificó que los equipos especializados logran atender mejor a los pacientes en cuidados paliativos. Se resalta que este estudio contribuirá a la carencia de publicaciones en la temática, teniendo en cuenta la ascensión de los cuidados paliativos, siendo necesario comprender la percepción del paciente sobre la oferta de ese cuidado. **Descritores:** Cuidados Paliativos; Percepción; Pacientes; Atención Hospitalaria; Atención Domiciliar de Salud; Medicina Paliativa.

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INTRODUCTION

There is a progressive population aging, with the decline of mortality in the 1960s and fertility in the 1980s, as well as increases in cases of cancer and other chronic non-communicable diseases (CNCDs). CNCDs are one of the greatest public health problems in the contemporary world, as they generate loss of quality of life due to the limitations caused by the disease, as well as a great economic impact for families and society.¹

Nursing and Social and Public Administration, at the time, met Cicely Saunders, a patient suffering from an advanced and incurable disease, who began to think about palliative care in the middle of 1948. It follows from this relationship Cicely Saunders's determination to learn more about the care of those who have advanced and incurable diseases. He graduated in Medicine and inaugurated in London in 1967, St. Christopher's Hospice, in search of humanization in the process of dying, initiating the Modern Hospice Movement.²

They are based on this new population profile and its needs, and palliative care is in evidence and recognized by the World Health Organization (WHO) in 1990, being conceptualized in 2002 and revised in 2017. Care is conceptualized palliative care as an approach that improves the quality of life of patients and their families when faced with problems inherent in a life threatening illness.³⁻⁴

Palliative care was implemented in Brazil in 1983 at the Clinical Hospital in Porto Alegre. Other initiatives emerged during the period after that date, and it is important to highlight the creation of palliative care services in 1986 at the National Cancer Institute (NCI) in Rio de Janeiro, the Brazilian unit that is closest to the St model Christopher's. From the 2000s onwards, palliative care presents significant growth.²⁻³

There were only 40 specialized palliative care services in Brazil in 2013, evidencing the need for professional training and insertion of this modality in the current health model. This is confirmed by the World Wide Palliative Care Alliance, which released in 2012 statistics showing that 18 million people died on the planet, suffering unnecessarily due to inadequate access to pain treatment.⁶

It is understood that the participation and the perception of the patients are fundamental in the therapeutic relation, since it presupposes a qualitative idea of the pathological phenomenon from the experience

of the subject.⁷ It is believed that this study may contribute to the improvement of the repercussions identified as negative by the patients in palliative care and, with this, improvements can be made in the hospital and home practice within UHS and in the private initiative, besides providing a basis bibliography for the development of other research that contextualizes and explores this theme.

It is stated that, in this direction, this study started from the following guiding question: "In patients of the home and hospital care network, submitted to palliative care, what is the patients' perception of palliative care?".

OBJECTIVE

- To identify, in scientific production, how palliative care is offered under the perception of the patients who need this therapy.

METHOD

It is a bibliographical study, type integrative review, research method that aims to gather, synthesize and analyze results of previous studies referring to a certain subject, seeking to identify knowledge gaps and reveal the central issues in relation to the phenomenon in study.⁸

The PIO format was adopted, so that it was possible to establish an efficient structure for the search of data. It means the initials PIO: (P) participants; (I) intervention; (O) results / effects to be achieved.⁹ The following guiding question was elaborated: "In patients of the home and hospital care network (P), undergoing palliative care (I), what is the patients' perception of to the palliative care offered (O)?".

A search strategy was developed that identified the research object, through the following Descriptors in Health Sciences (DeCS) and Medical Subject Headings (MeSH) for the selection of studies: palliative care, perception and patients.

The articles were identified by the bibliographic search, carried out from November 2016 to December 2016, in the Medical Literature Analysis and Retrieval System Online (MEDLINE) databases, accessed through PubMed; Nursing Specific Database (BDENF); Spanish Health Sciences Index (IBECS) and Latin American and Caribbean Literature in Health Sciences (LILACS), consulted by the Virtual Health Library (VHL). Two search strategies were developed: one for each database, through the assistance of a librarian.

The following inclusion criteria were used for the study: publications of the last ten years (2006-2016); in Portuguese, English or Spanish; consist of articles available in full. The searches were carried out with the inclusion of these criteria, and 1,044 articles were obtained, being 836 in MEDLINE; 96 in LILACS; 62 at IBICS and 50 at BDENF. From these publications, repeated items were excluded, resulting in 53 duplicates. After reading the titles of the articles, we defined the exclusion of 612, with 379 articles remaining for the reading of the abstracts.

When the abstracts were read, those who did not approached the patient's perception of the palliative care offered (326) were removed from the sample, which resulted in 53 publications, of which 49 were from MEDLINE; three from LILACS; one from IBICS and none from BDENF. Seven publications of the sample were excluded because they were not available in full.

For the final selection, the entire publications were carefully read by two external researchers (peer review), resulting in seven articles that did not coincide among the reviewers regarding their inclusion in the sample. A third researcher was chosen, who read the material to define the inclusion or exclusion of the divergent articles in the final sample.

It was determined, after reading the publications, the rejection of 19 articles, and 27 composed the final sample of the review. The qualitative results were analyzed using the Content Analysis technique proposed by Bardin.¹⁰ The studies were organized by database, titles, year, language, authors, journal, type of study, objectives, theoretical methodological reference, limitations, synthesis and evaluation in pairs. Follow-up steps were taken for the composition of the final sample, and these are demonstrated in figure 1. Relevance tests were performed to define the inclusion of the articles, with test I being the reading of the abstract and title, and the relevance test II corresponded to the reading in full.

The selected articles were selected based on the level of evidence of each scientific production for quality evaluation, with 1 being the best classification and 6 being the lowest.⁸ It was identified during the classification that 26 articles were considered level 4 of evidence and an article, level 5, justified by the majority of the selected studies were of qualitative methodology.

Figure 1. Scheme of selection of publications. Belo Horizonte (MG), Brazil, 2017.

RESULTS

Twenty-seven publications, which composed the final sample, were identified and listed in table 1, characterized by authorship, year of publication, type of study, language and classification by Qualis CAPES (Qualis is the set of procedures used, by the Coordination of Improvement of Higher Level Personnel - CAPES, for the stratification of the quality of the intellectual production of the graduate programs) in the Nursing area. For the articles that did not have Qualis for Nursing, the Qualis of related area (Medicine).

Author	Year	Type of study	Language	Qualis
Sparla, Flach-Vorgang, Villalobos, Krug, Kamradt Coulibaly, et al. ¹²	2016	Qualitative	English	B1 (related areas)
Hannon, Swami, Rodin, Pope, Zimmermann C . ¹⁸	2016	Qualitative	English	A1
Klarare, Rasmussen, Fossum, Fürst, Hansson, Hagelin.	2016	Qualitative	English	A1
Kohler, Cerchiaro, Levites. ³⁷	2016	Cross-sectional	Portuguese	B5 (related areas)
Sandsdalen, Grondahl, Hov, Høye, Rystedt, Wilde-Larsson. ³²	2016	Cross-sectional	English	B1 (related areas)
Nagington, Walshe, Luker. ²²	2016	Qualitative	English	A1
Coelho, Parola, Escobar-Bravo, Apóstolo. ³⁰	2016	Qualitative	English	B1 (related areas)
Lakew, Musema, Shimeles, Challinor. ³⁴	2015	Cross-sectional	English	B1
Robinson, Gott, Gardiner, Ingleton. ³³	2015	Qualitative	English	–
Sandsdalen, Rystedt, Grondahl, Hov, Høye, Wilde-Larsson. ¹⁵	2015	Cross-sectional	English	B1 (related areas)
O'Quinn, Giambra. ²⁶	2014	Systematic review	English	A1
Milberg, Friedrichsen, Jakobsson, Nilsson, Niskala, Olsson, et al. ¹⁶	2014	Cross-sectional	English	B1
Sampson, Finlay, Byrne Snow, Nelson. ¹¹	2014	Qualitative	English	–
Meeker, Waldrop, Schneider, Case. ¹⁴	2014	Qualitative	English	A1
Abu-Saad Huijjer, Sagherian, Tamim, Naifeh Khoury, Abboud. ²⁵	2013	Cross-sectional	English	–
Chand, Gabriel, Wallace, Nelson. ³⁹	2013	Qualitative	English	–
Metzger, Norton, Quinn, Gramling. ²³	2013	Qualitative	English	A1
Melo, Maia, Magalhães, Nogueira, Morano, Araújo, et al.. ²⁷	2013	Qualitative	Portuguese	B3
Bray, Goodyear-Smith. ¹³	2013	Qualitative	English	B4
Tallman, Greenwald, Reidenouer, Pantel. ¹⁹	2012	Qualitative	English	–
Milberg, Wahlberg, Jakobsson, Olsson, Olsson, Friedrichsen. ¹⁷	2012	Qualitative	English	A2
Claessen, Francke, Sixma, de Veer, Deliens. ³⁵	2012	Qualitative	English	–
Duggleby, Penz, Leipert, Wilson, Goodridge, Williams. ²⁴	2011	Qualitative	English	B1
Cawley, Waterman, Roberts, Caress. ²⁹	2011	Qualitative	English	A1
Bradley, Frizelle, Johnson. ³¹	2010	Qualitative	English	A1
Conner, Allport, Dixon, Somerville. ³⁶	2008	Qualitative	English	B3 (related areas)
Hordern, Street. ²¹	2007	Qualitative	English	A1

Figure 2. Characterization of the selected productions for the review. Belo Horizonte (MG), Brazil, 2017.

It is evident that most publications, 21 (77.7%), have more than three authors and only six authors (22.3%) have authored up to three authors. It should be noted that the studies begin in the year 2007, and in 2016, the largest number of articles on the subject was published, indicating a current discussion on this subject. It is observed, in relation to the language of the works, that 25 (92.5%) were in English and only two (7.5%), in Portuguese.

As far as the methodology of the included studies is concerned, 20 (74.1%) refer to qualitative research, six (22.2%) are quantitative surveys and one (3.7%) is literature review. It should be noted that the most prevalent data collection technique in this sample is the interview, and this is justified due to the research question, which seeks the patient's perception.

The characteristics of the study participants were identified: three (11.1%) studies were performed with the elderly; one (3.7%) with adults; 21 (77.8%), with adults and the elderly, and two (7.4%) with children. Parents' perceptions were considered in the studies in which children could not report their perception, 15 (55, 5%) performed in the hospital setting, four (14.8%) hospice; three (11.1%) studies were performed in the home environment; two (7.4%), in hospital environment, hospice and at home; two (7.4%), one in the hospital and one in the home, and one (3.7%) in hospice and at home.

Some recurrence was observed in subjects such as: control of pain and symptoms; accessibility to palliative care, fears and insecurity with care; comparison of specialized palliative care teams with non-specialized teams and home and hospital care environment.

The articles included in the sample were classified in the areas of Medicine and Nursing, with the following Qualis: nine (33.3%), in A1; one (3.7%) in A2; seven (25.9%) in B1; two (7.4%) in B3; one (3.7%) in B4 and one (3.7%) in B5, and the Qualis of three journals was not found in the Sucupira Platform, which made it impossible to detail six (22, 2%) articles.

DISCUSSION

The studies analyzed were discussed in two thematic categories: Patients' perception of palliative care offered by specialized teams and non-specialized teams; and Differences in palliative care according to the environment: home care versus hospital care, which led to discussion with the purpose of answering the research question.

♦ Patients' perception of palliative care offered by specialized teams and non-specialized teams

It was identified that the patients attended by specialized palliative care teams reported that the team paid a quick attention to the symptoms, especially the pain, and emphasized that symptom management was the area of greatest attention of professionals.¹¹⁻² It was pointed out that the support provided by the palliative care team was more than a focus on the physical symptoms, but it was carried out in order to cover the psychosocial concerns and thus try to provide the best care possible, alleviating the difficulties faced by the individual.^{11, 13-5}

It can be seen that the patients' reports from the studies allowed us to understand that specialized care contributed to the

reduction of patients' fears and insecurities, who report more easily in talking with professionals who attend to the unique and subjective issues of being.¹⁶⁻⁷

It was observed that the importance of the work of the multi-professional team, regarding the offered care, was identified for the adaptation of the patients to the environment in which they live, to maintain their life habits as close as practiced previously. It is emphasized that a highlight of the work of the specialized teams was the inclusion of the patients in the discussion of their care and in the decision making. It was also identified that professionals attend to the needs of family members.¹⁸⁻²⁰

A fragmentation of care is emphasized by non-specialist teams due to the large number of caregivers and the lack of communication between them, and this contributes to a care focused on the body and not on being.^{18,21-2} This condition should be applied to issues related to the work process of professionals not specialized in palliative care, such as the demand for work, the scale and difficulty in articulating a meeting with all professionals involved in the discussion of cases.

It is perceived, as a recurrent finding in the articles, the safety and trust that the palliative care team transmits to the patients, both at the hospital and at home. It is emphasized that the attention given by professionals and their sensitivity to changes soothe patients, making the sense of security comfort them.^{19, 21,23}

It was considered, as a negative issue of specialized teams, the turnover of professionals, as this creates insecurity in patients due to the presence of new members who do not know their case.^{18,21,24}

It is pointed out that professionals who do not have specialized training in palliative care have a look at the physical aspects, leaving, in a secondary way, the emotional and subjective aspects of the patients. It is identified that this understanding, in particular, has been reported in the proper management of pain.^{11,13,17,25} It is evidenced that this finding indicates a deficiency in the attention to the mental and spiritual health of the patients by these teams, with influence in the process of care, mainly palliatives.

In the studies, a fragmentation of care by non-specialist teams is emphasized, due to the large number of caregivers and the lack of communication between them, and this contributes to a care focused on the body and not on being.^{18,21-2} This condition should be applied to questions related to the work

process of professionals not specialized in palliative care, such as the high demand, scale and difficulty in articulating a meeting with all the professionals involved in the discussion of cases.

It was also possible to identify in the reports that non-specialized teams do not include patients and their families in decision-making.²⁵ It is therefore identified that professionals reinforce patients' fears, feelings of helplessness and anguish, and due to lack of communication and information.^{11,18,25}

It is pointed out that non-specialized teams may not understand the whole patient, leading to greater intensity in emotional suffering, contributing to their restriction, reducing their autonomy and threatening their identity. It is understood that these feelings arise from their experiences with illness and with the care.^{24,7} It can be impacted, with this, the care, in a determinant way, in the conditions and lifestyle that will be experienced by the patient.

It was identified in the analysis of the studies that the term palliative care was unknown by some patients, highlighting the communication deficit between them and the professionals.¹⁷ Another finding is found regarding the communication regarding the use of technical terms, which make it difficult to understand and discuss what is best for the patient.^{13,28} A criticism is then made of specialized and non-specialized professionals, who should be enlightening, allowing information in an accessible manner.

It is noticed that the nursing services in palliative care are appreciated by the patients due to their dedication, the ready accessibility and the management of situations to improve the comfort.^{12,18,29-30} In this condition, there are essential characteristics that must be developed by these professionals, such as listening, knowledge and attention to the patient's singularity, whether or not they make up specialized palliative care teams. It is also emphasized in the studies that patients consider it extremely important to receive support when depressed, stressing the professional category of Psychology as being of extreme significance for their mental well-being.^{18,20,29}

The subject of sexuality and its relation to palliative care were rarely discussed in the selected sample. This subject was portrayed in only one article, which addressed the impact of palliative care on patients' sexuality.²¹ It is specified in this article that sexuality and intimacy are most often set aside. It is evident from the findings that

patients place their undisputed trust in health professionals to correct their medical problems, regardless of the physical and psychological impact this may have on their condition in expressing sexuality and intimacy.^{21,31}

One of the selected studies refers to the rural context, which portrays the difficulty faced by patients living in this region, as it is a place of difficult access to palliative care.²⁴ It was identified that the lack of accessibility to palliative care was described as somewhat shocking due to the lack of continuity of care and insecurity in the event of intercurrents.^{12,22,24}

It was possible to state, after the analysis of the results, that the specialized palliative care teams seek to meet the patients' demands. However, it is noteworthy that this theme is still new in Brazil, with few training experiences in this field. It was observed that there is an insufficient number of specialized palliative care teams, which influences the reality of care provided to patients who need this type of care.

It was identified that the patients' perception of unspecialized palliative care teams is unfavorable, due to the factors that hinder palliative care in its totality. It should be emphasized, however, that the findings are not sufficient to conclude that all teams that do not have specialization in palliative care exercise fragmented care.

♦ Differences in palliative care according to the environment: home care versus hospital care

Results were higher than in the hospital setting, at the home palliative care service or at institutions such as Hospice.^{14,32-3}

It was shown that, in hospitals, patients reported being more comfortable being in palliative care units when compared to other treatment units, being an environment that facilitates interaction with their cultural and religious habits.^{13,15,17,34-5}

However, it was pointed out in one of the selected studies¹³ that patients viewed the clinic very positively, regardless of the care setting,²⁴ emphasizing the importance that patients attribute to the care provided by the health professionals' team.

It was identified that the limitation of the hospital environment can negatively impact the experience of the patients, considering that this environment has busy teams and is burdened with many tasks, which causes greater stress to the interneers, making them feel more distressed and restless.^{11,36-37}

It was described, in the findings, regarding home palliative care, that the patients expressed a sense of security during the visit of the team, noting the importance of the link with the professionals and their knowledge about the clinical case. In the patients' reports, it was observed that being able to call caregivers in the face of some intercurrents contributes to their sense of security and their families.^{11-2,21,23}

It can be identified, therefore, that the home environment has obtained better results in terms of palliative care. This affirmation is consolidated because the home environment is welcoming and individualized. It is perceived, therefore, that one should not only cultivate a posture contrary to curative, but question the methods employed and reflect on the conduct, seeking the necessary balance between the scientific, the spiritual and the emotional, so that one can give quality care.³⁸⁻⁴⁰

Hospice is one of the places of choice for patients, providing a sense of security, as an institution similar to asylum, which counts on the support of professionals for its operation.^{12,29,33} It should be noted that these institutions are already part of the Brazilian reality, however, challenges still remain for the implementation of hospice care in Brazil, and it is possible to mention the need to increase the number of centers specialized in this care.

CONCLUSION

Patients' perception of palliative care is presented as a novelty, based on a review, which made it possible to identify the central issues and what should be improved in the care.

It should be emphasized that specialized teams are able to better serve patients in palliative care; however, in Brazil, this is a reality of few hospitals and home care service, and this is due to the lack of a current policy that regulates this care. It is known that academics do not count this content in a mandatory way in their National Curricular Guidelines, contributing to the results elucidated in this study when dealing with non-specialized teams. It is sought, therefore, that the professionals, the educators and the patients try to advance and to gain new rights on the subject.

It is inferred, therefore, that the study may contribute to the improvement of care provided to patients who need this care in Brazil. It is also worth noting the importance

of new studies in the area to advance the discussions of this care so specific and unique.

The limitations of the study are the lack of access to seven articles in its entirety and the lack of Qualis CAPES classification of three journals (Lebanese Medical Journal, The Permanent Journal and Supportive & Palliative Care).

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