

PSYCHOLOGICAL ASSISTANCE FOR END-OF-LIFE PATIENTS UNDER PALLIATIVE CARE IN THE HOSPITAL ENVIRONMENT: AN INTEGRATIVE REVIEW

Cuidados paliativos na terminalidade: revisão integrativa no campo da psicologia hospitalar

Atención paliativa en terminalidad: revisión integrativa en el campo de la psicología hospitalaria

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ABSTRACT

Objective: This study sought to analyze scientific publications on the psychologists' role in providing assistance for terminal patients under PC. **Methods:** This integrative review was carried out from June to August 2019 by searching online databases. The following *Descritores da Ciência da Saúde* (DeCS) [Health Science Descriptors] were used: Psychology, terminal patient, palliative care, terminal care, and review. These descriptors were combined using the Boolean operator "AND" with the purpose of refining search results. **Results:** The analysis of 15 publications allowed the emergence of two categories: "Forms of psychological interventions targeting patients and their relatives from the perspective of terminality and "Benefits of the psychologist's action for the end-of-life patient under PC". **Conclusion:** The number of studies on the subject was scarce, which justifies the need for further research to extend the knowledge about psychological assistance for end-of-life patients under palliative care.

Descriptors: Psychology, Terminal patient, Palliative care, Terminal care, Review.

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RESUMO

Objetivo: Caracterizar o perfil epidemiológico das gestantes assistidas na consulta de enfermagem do pré-natal em uma Unidade de Saúde da Família do Rio de Janeiro. **Método:** estudo descritivo, exploratório, quantitativo do tipo documental, com emprego da técnica de observação indireta e análise estatística. **Resultados:** foram investigados 160 prontuários eletrônicos de gestantes atendidas em 2014. A maioria das mulheres tinha idades entre 20-34 anos (73,8%), cor parda (44,3%), mora com companheiro (46,3%), e ensino médio completo (26,9%). São primigestas (41,3%), sem história de aborto (54,4%), não planejaram a gravidez (66,9%) e tiveram primeira consulta no primeiro trimestre gestacional (61,2%). **Conclusão:** embora a maioria das gestantes investigadas tenha baixo risco obstétrico, o seguimento das mulheres na consulta de pré-natal torna-se primordial para uma gestação saudável.

Descritores: Estratégia saúde da família, Enfermagem obstétrica, Cuidado pré-natal.

RESUMEN

Objetivo: Caracterizar el perfil epidemiológico de las gestantes asistidas en la consulta de enfermería del prenatal en una Unidad de Salud de la Familia de Río de Janeiro. **Método:** estudio descriptivo, exploratorio, cuantitativo del tipo documental, con empleo de la técnica de observación indirecta y análisis estadístico. **Resultados:** se investigaron 160 prontuarios electrónicos de gestantes atendidas en 2014. La mayoría de las mujeres tenían edades entre 20-34 años (73,8%), color pardo (44,3%), vive con el compañero (46,3%), y la enseñanza media completa (26,9%). (41,3%), sin antecedentes de aborto (54,4%), no planificaron el embarazo (66,9%) y tuvieron primera consulta en el primer trimestre gestacional (61,2%). **Conclusión:** aunque la mayoría de las gestantes investigadas tienen bajo riesgo obstétrico, el seguimiento de las mujeres en la consulta de prenatal es primordial para una gestación sana. **Descriptor:** Estrategia de salud familiar, Enfermería obstétrica, Atención prenatal.

INTRODUCTION

It is estimated that approximately 36 million deaths from chronic non-communicable diseases (NCDs) will occur worldwide. Among these diseases, the following four groups are highlighted: cardiovascular diseases, chronic respiratory diseases, diabetes, and cancer.¹ According to the Brazilian Institute of Geography and Statistics, the Brazilians' life expectancy at birth, which is different for men and women, rose to 76 years in 2017. For men, it rose to 72.5 years, while for women it rose to 79.6 years.² Thus, longer lives are related to the increased incidence of chronic diseases.

In this context, palliative care (PC) emerges as a care philosophy that seeks to improve the quality of life of patients with incurable and terminal diseases. In 1990, the World Health Organization (WHO) recognized PC. In 2002, the WHO updated its definition, conceptualizing it as an approach to promote the quality of life of patients facing life-threatening diseases and their relatives through the prevention and relief of suffering. Such care requires early identification, evaluation, and treatment of pain and other problems of a physical, psychosocial, and spiritual nature.³

It is essential to deliver PC during the terminal phase, in which the patient has little time to live so that quality of life, comfort, and dignity can be ensured. Terminality is defined as the phase in which there is no possibility of a cure. Consequently, care actions targeting patients and their relatives are carried out to contemplate all terminal disease stages, providing relief from suffering, avoiding futile measures, emphasizing patients' interest and respecting their feelings and wishes of their relatives, and promoting adequate communication between patients, relatives, and health care teams.¹

Multiprofessional health teams deal with the possibility of death in the daily routine of PC workers, which involves patients, family members, and health care teams, requiring that specialized care be delivered in accordance with their psychological dimension. Considering the importance of the psychological aspects of the PC delivered to terminal patients and the need for studies that seek to broaden the understanding of the subject, the following guiding question emerged: "What is known in the scientific literature about the performance of psychologists assisting terminal patients under PC?"

Hence, this study sought to analyze scientific publications on the role of psychologists in providing assistance for terminal patients under PC.

METHODS

This is an integrative review of the literature. Literature search was conducted in the following databases: Scientific Electronic Library Online (SCIELO), Latin American and Caribbean Literature on Health Sciences (LILACS), PubMed/Medical Literature Analysis and Retrieval System Online (MEDLINE), Índice Bibliográfico Español en Ciencias de la Salud (IBECS) [Spanish Health Science Bibliographic Index], Base de Dados de Enfermagem (BDENF) [Nursing Database], Index Psychology and COLEC SUS Br. The following Descritores da Ciência da Saúde (DeCS) [Health Science Descriptors] were used: psychology, terminal patient, and palliative care. The Boolean operator "AND" was used to combine these DeCS in order to refine search results. Methodological rigor was ensured according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).⁴

The literature search was conducted from June to August 2019. Inclusion criteria were articles available in full and published in Portuguese from 2009 to July 2019. This period was chosen because of the need to highlight current knowledge on the subject.

RESULTS AND DISCUSSION

The results of the selected studies were extracted according to the PRISMA methodology (Figure 1), which

allowed the emergence of two thematic categories in order to analyze the data obtained from the articles and compare them with the literature.

Duplicate publications (theses, dissertations, editorials, and articles) were excluded, as well as those not addressing the study subject.

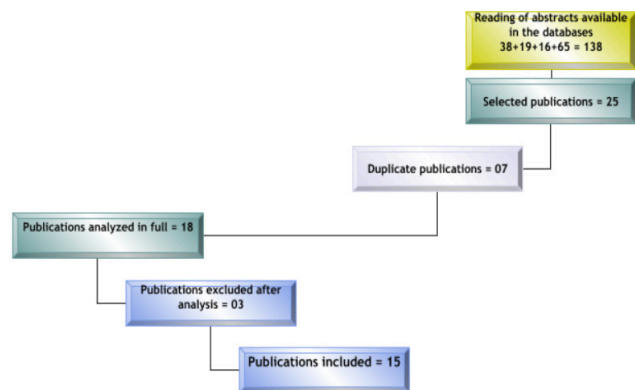


Figure 01. PRISMA flowchart illustrating the process of selecting the publications that composed the final sample.

A total of 138 articles were initially found. From them, 25 articles addressing the subject of this study were selected. Among these, 07 were duplicates and were excluded, leaving only 18. Among these, 03 were excluded after full analysis as they did not address the theme. Finally, 15 articles composed the final sample.

To extract data from the articles included in this review, an instrument with the following items was used: article modality, keywords/descriptors, article title, authors, language, objectives, study approach (qualitative or quantitative approach), group/population, research setting, results, and conclusions. The data obtained were organized into charts and tables and interpreted in accordance with the literature.

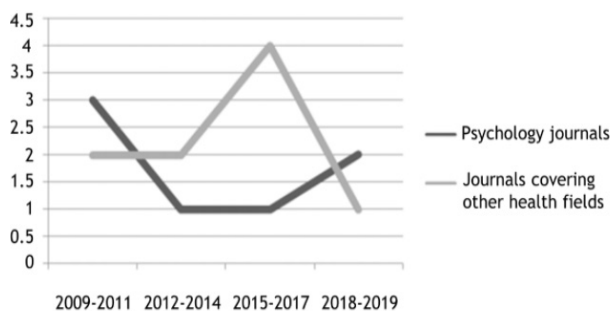


Figure 2. Distribution of the selected articles by year of publication and area of knowledge (n = 15).

As can be seen in **Figure 2**, articles published over a period of 11 years (2009-2019) were analyzed. The number of scientific publications in the health field was found to be high from 2015 to 2017. However, they were published in journals that were not specific to psychology.

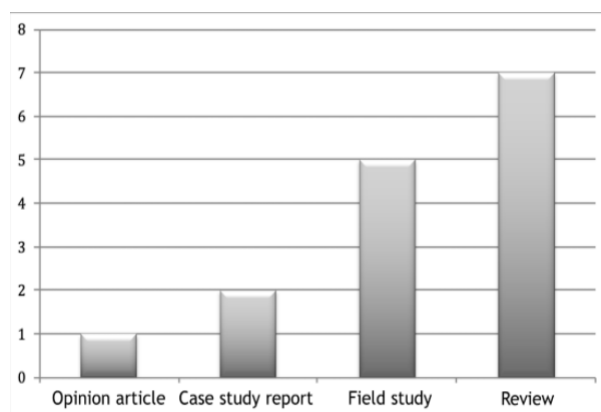


Figure 3. Distribution of the selected articles by type of study (n=15).

The selected publications were published in nursing and psychology journals. Regarding the type of study, there was a predominance of reviews and field studies (**Figure 3**).

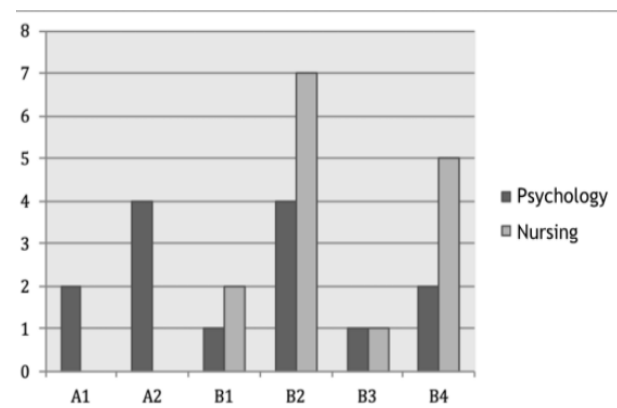


Figure 4. Distribution of the selected articles by Qualis journal classification (psychology/nursing).

Figure 4 shows the distribution of the selected studies by Qualis journal classification (psychology/nursing). Most of the articles published in nursing journals were from Qualis B2 journals, while the articles published in psychology journals were from Qualis A2 and B2 journals.

Variable	Category	Articles analyzed N = 15
Authors	Graduates	3
	Specialists	4
	Masters	1
	PhDs	6
	Former postdoctoral researchers	1
Database	Index Psychology	6
	BDEF	3
	LILACS	12
	MEDLINE	2
	COLEC. SUS	1
Keywords/descriptors	Terminal patient	2
	Palliative care	11
	Hospital psychologist	4
	Death	6
	Interdisciplinary team	2

Table 1. Distribution of the selected studies by first author's highest educational attainment, database, and main keywords/descriptors.

Regarding the first authors' highest educational attainment, it was observed that most of them obtained a

PhD according to their respective *Lattes* curricula. On the other hand, in respect of the databases, the study results showed that there were articles available in more than one database, most of them being found in LILACS, which is a Latin American database containing bibliographic information about health sciences. "Palliative care" was the keyword/descriptor most prevalent (11), followed by "Psychology", thus meeting the inclusion criteria.

This study provided an overview of the importance of psychology for the palliative care delivered to terminally ill patients. To analyze and discuss the selected articles, two categories were created: "Forms of psychological interventions targeting patients and their relatives from the perspective of terminality" and "Benefits of the psychologist's action for the end-of-life patient under PC".

Forms of psychological interventions targeting patients and their relatives from the perspective of terminality

The performance of psychologist's PC activities involves relationships formed since the diagnosis and evolution of the diseases affecting terminal patients. These activities are focused on the perception of patients and delivery of humanized care.⁵

The psychologists' duties involve providing psychological support in situations of stress, depression, and suffering. Also, they involve providing emotional support for family members and other professionals. It is mainly necessary to respect patients' autonomy in the final stage of life and allow family members to know and understand the disease during its different phases^{6,7}

Psychologists attempt to identify exchange interactions among patients, family members, and health care workers, aiming at promoting a good adherence to the proposed assistance. The role of the PC team is to provide a new meaning of quality, value, and life. In this context, psychologists' actions are of utmost importance since they work with on the subjective and, consequently, give patients conditions to deal with this situation and rediscover the meaning of life.⁸

Therefore, clinical investments are based on the interventions performed by psychologists as they can greatly influence treatment adherence and decision-making, favoring the mental and physical well-being of patients under PC.⁹ It is important to emphasize that clinical psychologists' duties can go beyond the assistance provided in the hospital environment. Psychological assistance can be provided in the communities or inside residences in accordance with the objectives of palliative care. Psychologists' actions within the context of primary care are aimed at the prevention and treatment of acute and chronic diseases, in addition to the promotion of healthy behaviors in order to improve patients' quality of life regardless of their prognosis.¹⁰

Psychological intervention enables the recognition of death, in which there may be an opportunity for the expression of feelings by patients, relatives, and professionals.¹¹ Also, qualified listening allows psychologists to act by deciphering the terminal patient's responses to family members and managing expectations. The objective of psychologists is to receive, welcome, and humanize patients. To this end, they employ methods based on listening and speaking in order to help patients and their relatives to experience new perceptions and sensations.¹²

In this framework, it is important to know the patients' real demands and have good verbal and non-verbal interpersonal communication to establish a relationship of trust with the patient at the end of life.⁶

Psychological treatment should be directed at providing a listening place and active support, witnessing the limits of existence, and following up patients while they psychologically elaborate upon their subjective issues. To provide psychological treatment is to construct the crystallization of the subject's history. In addition, psychological treatment involves mobilizing and strengthening patients' subjective resources with the aim of gaining knowledge to deal with the imminence of death.¹³

Thus, it is necessary not only to raise the consciousness of finitude and make it more integrated into the existential condition but also, from this closer look, allow patients to obtain a clearer understanding of the meaning of life. Thus, recognizing the spiritual dimension as an integral part of the needs of patients and their relatives is an important exercise of empathy by PC teams because it brings comfort and authorizes patients to share their understanding about disease and death.¹

Moreover, psychologists must perceive patients' religious foundation as an alternative to reinforce emotional support, providing them with an understanding of the meaning of life, suffering, and illness, which some authors consider as the psychology of religion.⁶

Psychological analysis must consider not only the spiritual dimension but also the historical and dynamic aspects of death. Objects are not stable or fixed; they develop and can transform themselves. For example, analyzing the meaning of death attributed by our current culture is sufficient for understanding this phenomenon. It is necessary to understand the different meanings attributed by modern Western culture throughout history and the determinations of these meanings.¹⁴

The process of dying not only involves clinical aspects but also a form of care that provides those who experience the process of finitude and those who need to continue living (bereaved relatives and the health care professionals who frequently deal with the process of dying) with dignity and comfort. The psychologists' work must be based on the adequate use of the guiding principles of PC: clear and careful communication, interdisciplinary action, relief of suffering, and support for family members during all stages

of the assistance, including bereavement.¹

The following actions should be performed during this phase of psychological care: teaching new pain and stress management skills, training family members to help the patient express their needs and thoughts, motivating family members to deliver progressive care that favors the bereavement process, conducting pleasant activities more frequently, improving community support that favor home care, and seeking to make the process of death as comfortable as possible.¹⁵

The role of psychologists in providing assistance for terminal patients under PC involves communicating with them and their relatives and valuing the spiritual dimension in order to allow the resignification of disease and death.

Benefits of the psychologist's action for the end-of-life patient under palliative care

Faced with human terminality psychologists seek to improve patient quality of life by minimizing suffering, anxiety, and depression in the face of death. Psychologists' work immediately after diagnosis and is important in the prevention of these conditions and throughout treatment.⁶

Contrary to common sense, which correlates life-threatening diseases to purely negative implications, a study has shown that patients can present a high degree of satisfaction and well-being even after diagnosis. From this perspective, the importance of viewing psychological assistance as a strategy capable of alleviating anguish and helping in coping with the disease is verified, especially among patients with advanced cancer receiving PC.^{16,17}

One of the characteristics of the psychologists working in the hospital environment was the care for users and their relatives, especially in cases of terminality and death. In this context, the purpose of psychologists is to favor the relationship among patients, family members, and multiprofessional teams as well as meet all of their demands in health facilities.¹⁸

Psychological care can help patients break the silence, talk more about the disease, and prove the information needed for treatment, which is often denied by family members. They often consider it best to keep the patient devoid of any information, which is called "conspiracy of silence". Psychologists can help patients and family members to talk about the problem, which in turn can help patients to face the disease. Consequently, events related to the disease, the process of death, and bereavement can be experienced.^{6,15}

Moreover, psychologists, by means of qualified listening, allow subjects to say and resignify their feelings in the face of death. These reflections become inevitable at the end of life.¹⁹

Psychosocial support at the moment of terminality is fundamental since the concept of death has been permeated by prejudices and stigmas involving a series of

threatening and persecutory elements that terrify people. Psychologists can provide assistance for terminal patients and this work has already produced widely recognized results, such as significant increases in survival rates, improved quality of life, and psychological strengthening to face terminality. Psychologists should also be attentive to the positive emotions and senses that provide well-being for individuals experiencing life-threatening situations since they can express gratitude, compassion, forgiveness, spiritual comfort, and post-traumatic growth.¹⁰

Bearing the aforesaid in mind, hospital psychology is understood as a necessary tool for allowing patients under PC to experience a humanized process of dying. It is worth highlighting the psychological assistance for patients under PC as a means to recover the humanism that is absent from modern health actions. Health care is full of technologies and healing effectiveness, but often meaningless in terms of empathy, love, affectivity, and human warmth. Therefore, it is incapable of providing complete and effective relief of peoples' suffering.⁸

Given the above, it becomes evident that psychologists are important in welcoming and paying attention to the physical, mental, spiritual, and social conditions of patients at the end of life, alleviating suffering, anxiety, and sadness. It is clear that their work facilitates the delivery of care. With the help of the multiprofessional PC teams, psychologists help to improve patients' quality of life, reduce their anguish, and cope with the disease in the imminence of death. Moreover, psychologists make it possible for patients and their relatives to express their needs.

CONCLUSIONS

Life-threatening diseases are accompanied by great changes. Therefore, it is important that psychologists understand these changes and hear what patients have to say, considering that care actions should be focused not only on diseases but also on people.

The analysis of the selected publications showed that hospital psychology was an important tool for the assistance of patients under PC. Hospital psychology made the process of dying more humanized and improved the quality of life of patients facing terminality. The actions of hospital psychologists working together with PC teams should be guided by empathy, love, and affection. Moreover, they should perform qualified listening and minimize the occurrence of the conspiracy of silence.

This study has limitations, the main being the lack of publications on PC applied to Psychology. Therefore, it is necessary to conduct further research in order to expand the knowledge about the work of psychologists as members of palliative care teams, as well as the benefits of this work for end-of-life patients.

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