

Aged patients in palliative care: the impact on their spouses

Idosos em cuidados paliativos: impacto em seus cônjuges

Pacientes mayores en cuidados paliativos: impacto en sus cónyuges

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ABSTRACT

Introduction: A constant growth in the number of elderlies in Brazil highlights the importance of dialogues about end of life. Brazil was 42th positioned in the *Death Quality Index* publicized in 2015, which reflects a need of improvements in quality of death associated to institution of strong and effective national politics of Palliative Care. **Objective:** To produce an integrative review about how the application of PC in elderly people help their partner/spouse in the terminality process when compared to patient that do not receive PC. **Methods:** It was produced an Integrative Review with articles of the databases PUBMED and BVS during the period of 2000 to August 2020. **Results:** The main results demonstrated that caregivers that utilized PC reported more discrete symptoms of post-death depression and anxiety, in comparison with did not used PC. The most important determinants of satisfaction with PC were the professional help available and holistic attendance, when including family and observing their physic, psychologic, spiritual and psychosocial determinants. **Conclusions:** As presented, frequently it is responsibility of the partner/spouse to assume a caregiver role. The isolation and exclusive dedication of the caregiver could initiate depressive feelings and overload, especially when there is a lack of support. In this scientific work it could be observed that the use of PC can provide a better understanding of the illness evolutive process, since the beginning of evolution until family grief.

Keywords: Pair bond. Palliative care. Aging. Marriage.

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RESUMO

Introdução: Diante do maior número de idosos no país, destaca-se a importância de diálogos voltados ao cenário de fim de vida. O Brasil foi o 42º no Death Quality Index de 2015, o que reflete a necessidade de melhorias na qualidade de morte associadas à instituição de política nacional de cuidados paliativos (CP) forte e efetiva. **Objetivo:** Realizar revisão integrativa sobre como a aplicação dos CP no idoso auxilia o parceiro/cônjuge no processo de terminalidade, em comparação aos de pacientes que não recebem CP. **Métodos:** Foi feita uma revisão integrativa com os artigos das bases de dados PubMed e Biblioteca Virtual em Saúde no período de 2000 a agosto de 2020. **Resultados:** Os principais resultados demonstraram que os cuidadores que utilizaram CP relataram sintomas mais baixos de depressão pós-morte e ansiedade em comparação com aqueles que não usaram CP. Os determinantes mais importantes da satisfação com o CP foram a ajuda profissional disponível e o atendimento de natureza holística, que englobou a família e observou os cuidados físicos, psicológicos, espirituais e psicossociais dos familiares. **Conclusões:** Conforme apresentado, muitas vezes, cabe ao parceiro/cônjuge realizar o papel de cuidador. Seu isolamento e dedicação exclusiva podem desencadear sentimentos depressivos e excesso de responsabilidades, sobretudo quando não há suporte. Nesta pesquisa, observou-se que o uso do CP pode propiciar melhor entendimento do processo evolutivo da doença, desde o início até o luto.

Palavras-chave: Vínculo do casal. Cuidados paliativos. Envelhecimento. União estável.

RESUMEN

Introducción: Delante del mayor número de adultos mayores en Brasil, se resalta la importancia de diálogos sobre el contexto de fin de vida. Brasil fue el 42º colocado en el *Death Quality Index* de 2015, lo que demuestra la necesidad de mejoras en la calidad de muerte asociado a la institución fuerte y efectiva de política nacional de Cuidados Paliativos. **Objetivo:** Realizar revisión integrativa sobre cómo la aplicación de los CP en el adulto mayor ayuda en el proceso de terminalidad a la pareja/cónyuge, cuando comparado a pacientes que no reciben CP. **Métodos:** Se desarrolló una Revisión Integrativa con artículos de las bases de datos PUBMED y BVS durante el periodo de 2000 a agosto de 2020. **Resultados:** Los principales resultados demostraron que los cuidadores que utilizaron CP relataron síntomas más bajos de depresión después de la muerte, en comparación a los que no utilizaron CP. Los determinantes más importantes de satisfacción con CP fueron la ayuda profesional disponible y el atención holística, al englobar la familia y al observar sus cuidados físicos, psicológicos, espirituales y psicossociales. **Conclusiones:** Como presentado, frecuentemente le cabe a la pareja/cónyuge realizar el papel de cuidados. El aislamiento y la dedicación exclusiva del cuidador puede desencadenar sentimientos depresivos y exceso de responsabilidades, sobre todo cuando no hay soporte. En este estudio, se observó que el uso de CP puede propiciar un mejor entendimiento del proceso evolutivo de la enfermedad, desde su inicio hasta el luto.

Palabras-clave: Apareamiento. Cuidados paliativos. Envejecimiento. Matrimonio.

INTRODUCTION

The Brazilian population is undergoing an aging process and an increase in life expectancy that brings new health challenges. The demographic and epidemiological transition to the predominance of chronic- degenerative diseases highlights the importance of dialogs that address the end-of-life scenario. The last census, carried out in 2010,¹ noted an increase in the relative participation of the population aged 65 and over, which was 5.9% in 2000 and reached 7.4% in 2010, illustrating the increasing aging process of the Brazilian population.

In this context, the quality of life and death of the elderly population is an important aspect of health care. In 2015, the Death Quality Index was published, a study by the British consultancy Economist Intelligence Unit,² in which 80 countries are evaluated based on indicators in the areas of health and palliative care (PC), human resources, quality of care, among others. Brazil ranked 42nd, reflecting the need for improvements in the implementation of public policies and skills of health teams for this scenario. In line with this need, Resolution No. 41, published in Brazil in 2018, aims to integrate PC into the health care network of the Unified Health System (*Sistema Único de Saúde – SUS*).³

The approach of PC refers to the promotion of the quality of life of patients and their families, especially in the face of life-threatening processes, through strategies to alleviate physical, social, psychological, and spiritual suffering.^{4,5} In this sense, PC encompasses diseases and chronic conditions associated with

aging, as well as the entire process that follows, composed of decreased functionality, management of comorbidities and the inevitable end of life.⁴

The family, as a system, along with its older members, faces important adjustment challenges in old age. Coping with the terminality process is perhaps the most difficult task for the family, as it involves a prolonged period of care and decisions about life and death.⁶ This context can evoke what is known as anticipatory grief for the family, especially for the caregiver who is involved throughout the entire process. This grief can lead to conversations about the issue, planning the way the person wants to die and redistribution of tasks, or, on the other hand, it can cause negative feelings such as depression, anger, and guilt.⁷

The multiprofessional team is essential to manage the process of finitude and grief.⁸ According to the Home Care Notebook of the Ministry of Health,⁹ the professionals of PC must work recognizing the values and functioning of the families served, communicating clearly and providing care that ensures quality of life and dignity.

In this regard, the importance of the family physician, general practitioner and other health professionals who make up the care network is emphasized. Effective communication with family members, caregivers and patients about expected clinical outcomes is essential. Through an individualized therapeutic plan, the team must also assist in building a social support network and engaging family members, neighbors, spiritual/religious support to reduce caregiver's burden.⁹

With this in mind, the present study conducted an integrative review based on the research question: —How does the use of PC in aged people help their partner or spouse in the process of terminality, compared to patients who do not receive PC?

METHOD

The integrative review method enables an organized search for data on current topics relevant to the scientific field. This research technique aims to analyze existing knowledge in research on a particular topic and allows for the collection of scientifically based information, allowing the generation of new knowledge through the synthesis of multiple studies in the field.¹⁰

For the elaboration of the research question, the PICO strategy was used, whose name is an acronym that stands for: P is population; I is intervention; C is control group; and O is outcome. Such a tool makes it possible to formulate an appropriate research question for the bibliographic search, focusing on the research scope and optimizing the search for evidence in the databases in accordance with the recommendations of the Evidence-Based Practice.¹¹

The four components of the PICO strategy were defined in this study as follows: P — partner or spouse of aged patients; I — partner or spouse use of PC in the process end-of-life care of aged patients; C — comparison between partners or spouses of patients who received PC *versus* those of patients who did not receive PC; O — partner or spouse support in end-of-life care of aged patients in PC.

The survey covered the period from 2000 to August 2020 and was conducted in two phases, the first between the months of April and June 2018 and the second in September 2020, with the aim of complementing the previous search and keeping the review as up-to-date as possible. Descriptors in Portuguese, Spanish, and English were used, found in the databases Descriptors in Health Sciences (*Descritores em Ciências da Saúde* – DeCS, in Portuguese and Spanish) and Medical Subject Headings (MeSH, in English) and related to the research question. The Portuguese descriptors used were — *vínculo do casall*, — *cuidados paliativosll*, — *envelhecimentoll* and — *união estávell*, in the combinations (*vínculo*

do casal AND cuidados paliativos OR envelhecimento) and (*cuidados paliativos AND união estável*). The Spanish descriptors used were — *unión estable*ll, — *apareamiento*ll, — *cuidados paliativos*ll and — *envejecimiento*ll, in the combinations (*unión estable AND apareamiento AND envejecimiento OR palliative care*). The English descriptors used were — *palliative care*ll, — *aging*ll, — *spouses*ll, — *death*ll, — *acceptance*ll, — *end-of-life care*ll and — *spouse's death*ll, in the combinations (*palliative care AND aging NOT spouses*), (*palliative care AND aging AND spouses*), (*palliative care AND aging NOT death*), (*acceptance AND end-of-life care AND spouse's death*), and (*acceptance AND end-of-life care NOT spouse's death*).

Inclusion criteria were: Articles related to the topic addressed, answering the guiding question and were available in the selected databases; studies written in Portuguese, Spanish, and English; and published in the delimited period from 2000 to August 2020. Exclusion criteria were: Papers that dealt with postmortem grief; studies on palliative care in non-elderly patients; and studies that addressed the dying process experienced by family members other than spouses.

Regarding the selection process, the articles whose abstract addressed the research question were selected first, the inclusion and exclusion criteria were applied, and duplicates were excluded. Then, after reading of the texts in full, only those that fully or partially answered the guiding question were selected, resulting in 11 articles. To minimize bias, the steps described were performed independently by two reviewers. There were no disagreements about paper inclusion because all reviewers agreed with the selected studies.

For the analysis and synthesis of articles that met the inclusion criteria, a table was created in Microsoft Office Word 2016, that included the following variables: Title of the article, authors, journal, study type/approach, aim/question of research, and results.

RESULTS

In the selection of articles, 4,064 articles were found from 2000 to August 2020. When applying the inclusion and exclusion criteria, only 11 works met the focus of this study.

The distribution of references obtained from PubMed and VHL databases from 2000 to August 2020 is shown in Figure 1. Of the selected articles, eight were from the United States, one from Spain, one from the United Kingdom, one from Norway, and none from Brazil. In terms of language, all articles are in English. Regarding publication, six appeared in journals/periodicals focused on PC, one for clinical practice, two for geriatrics, one for internal medicine, and one for oncology.

Chart 1 shows the characteristics of the 11 selected articles.¹²⁻²²

DISCUSSION

Summary of the main findings

Decreased mortality, anxiety, and depression

Clinical observations suggest that patients who die —good deathll may cause less stress on their spouses. Therefore, Christakis and Iwashyna¹³ investigated whether the use of PC by a deceased person is associated with a reduced risk of death in surviving and bereaved spouses. A retrospective

cohort study was carried out with a population sample of 195,553 aged couples in the United States. A total of 30,838 couples in which the deceased used PC were compared, with 30,838 couples in which the deceased did not use PC using the propensity score method. The main outcome of interest was the survival time of bereaved widows. After adjusting for other measured variables, 5.4% of bereaved wives died 18 months after the husband's death when the husband had not been on PC, and 4.9% died if the deceased husband had been on PC (adjusted *odds ratio* [OR] 0.92, confidence interval [95%CI] 0.84–0.99 in favor of hospice use). Similarly, while 13.7% of bereaved husbands died 18 months after the wife's death if she had not been on PC, 13.2% died when the deceased wife had been on PC (OR of 0.95, 95%CI 0.84–1.06 in favor of hospice).

In the study by Irwin et al.,¹⁵ 120 caregivers (spouses) of patients with Alzheimer Disease were interviewed. As a result, specifically, caregivers who used PC in particular reported lower symptoms of postmortem depression (2.2 ± 0.55 vs. 5.73 ± 1.18 ; $F(1,29) = 6.10$, $p < 0.05$) and anxiety (3.70 ± 1.16 vs. 6.14 ± 1.12 ; $F(1,29) = 5.71$, $p < 0.05$) compared to those who did not use PC. In turn, 1,016 spouses participated in the work of Ornstein et al.,¹⁷ of which 662 were the primary caregivers. It was found that 27.3% of spouses of hospice users (a place that conducts PC) had better improved scores on the Depression Scale of the Center for Epidemiological Studies compared to 20.7% of spouses who did not use hospice; however, the difference was not statistically significant ($p = 0.10$). Among the predictors of

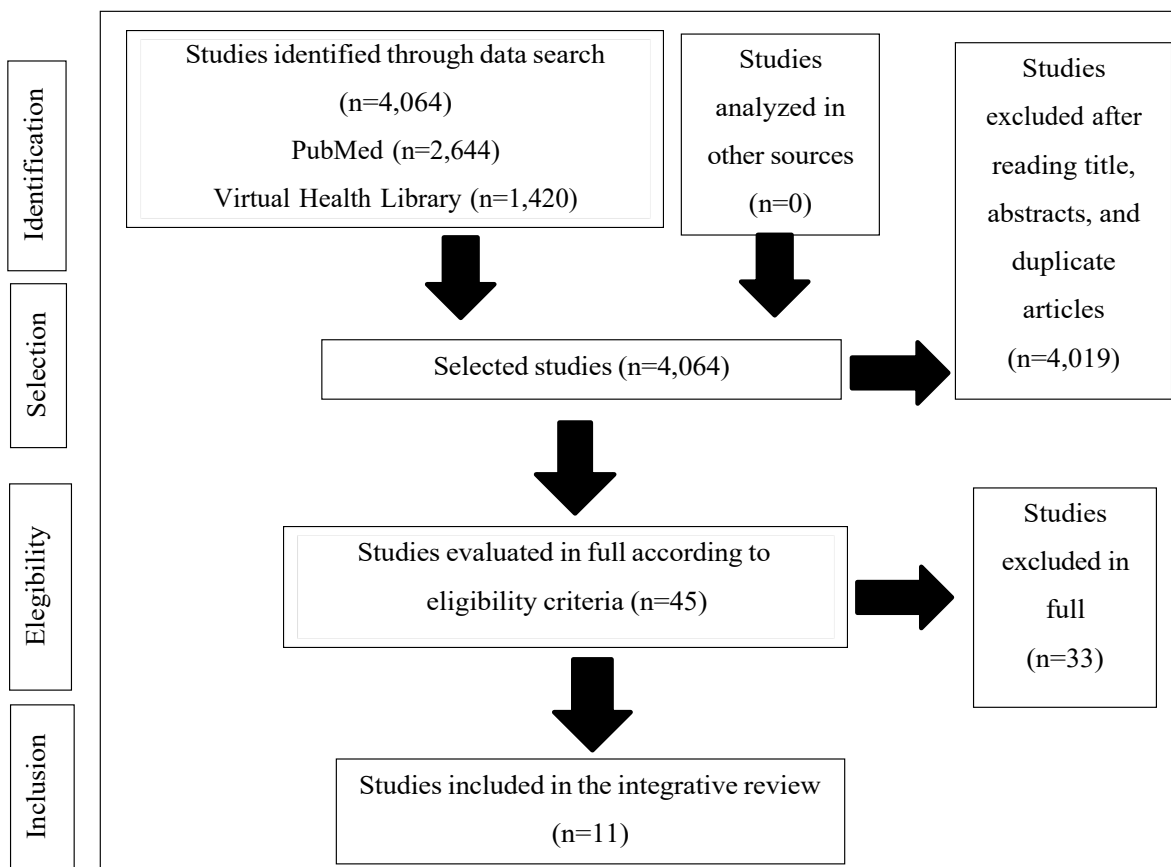


Figure 1. Flowchart of bibliographic references obtained from PubMed and Virtual Health Library databases during the period from 2000 to August 2020.

Chart 1. Characteristics of the 11 selected articles

Reference	Title	Journal	Type of study	Research objective or question	Results
Haley et al. ¹²	Predictors of depression and life satisfaction among spousal caregivers in hospice: application of a stress process model	Journal of Palliative Medicine	Qualitative study	To evaluate the components of the stress process model in 80 caregivers of inpatients with dementia or lung cancer.	Objective measures of patient commitment or amount of care provided are not strong predictors of caregiver depression or life satisfaction. Caregivers who subjectively rated caring tasks as less stressful had less depression and greater life satisfaction.
Christakis and Iwashyna ¹³	The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses	Social Science & Medicine	Cohort study	Observe at the duration of bereavement for widowers and whether the nature of end-of-life care a deceased person receives may be associated with their spouse's mortality risk.	The findings suggest a possible beneficial impact of hospice on the spouses of dying patients as a favorable end-of-life type of treatment. Palliative care can mitigate the increase in normal mortality associated with the widow.
Hunstad and Svindseth ¹⁴	Challenges in home-based palliative care in Norway: a qualitative study of spouses' experiences	International Journal of Palliative Nursing	Qualitative study	Gain a broader understanding of the changes that occur throughout the progression of the terminal phase by interviewing seven caregivers (spouses) of individuals who died having received palliative care at home in three municipalities in Norway.	Home care was well accepted, although none of the participants planned to give or receive palliative care at home. - Full-time assistance, holistic care and affirmation of the importance of the role of care were important factors for the exercise of palliative care at home.
Irwin et al. ¹⁵	Association between hospice care and psychological outcomes in Alzheimer's spousal caregivers	Journal of Palliative Medicine	Cohort study	To examine psychological and physical outcomes among 32 caregivers of spouses of patients with Alzheimer Disease.	Most spouses had depressive symptoms over time, with no significant difference related to hospice use. A minority of spouses of hospice users had improved scores on the depression scale, compared to spouses of deceased people who did not use hospice.
Borland et al. ¹⁶	How does involvement of a hospice nurse specialist impact on the experience on informal caring in palliative care? Perspectives of middle-aged partners bereaved through cancer	European Journal of Cancer Care	Qualitative study	Retrospectively explore partners' understandings and experiences of caring for a loved one with a terminal illness.	The recruitment of nurses allowed caregivers to feel relief from the caregiver's burden, through the sharing of experience and a specialized approach. Active and empathic listening and the search for the patient's well-being were highlighted as support tools provided by nurses.

Continue...

Chart 1. Continuation.

Reference	Title	Journal	Type of study	Research objective or question	Results
Ornstein et al. ¹⁷	Association between hospice use and depressive symptoms in surviving spouses	JAMA Internal Medicine	Cohort study	To determine the association between the use of palliative care and depressive symptoms in spouses.	Most surviving spouses had increased depressive symptoms after death, regardless of the offspring's use of hospice. The findings suggest that additional supports are needed if depressive symptoms are to be substantially reduced. The relationship between palliative care use and reduced symptoms of depression was strongest one to two years after death.
Tabler et al. ¹⁸	Missed opportunity; hospice care and the family	Journal of Social Work in End-of-Life & Palliative Care	Qualitative study	Explore the ways in which caregivers need to grieve before or after the death of their spouse/partner who was in hospice care for cancer.	- Caregivers' high satisfaction with hospice may be more associated with the quality of care provided to their spouse/partner than with the grieving support they received.
Wagner et al. ¹⁹	Acceptability and feasibility of a meaning-based intervention for patients with advanced cancer and their spouses: a pilot study	American Journal of Hospice and Palliative Medicine	Qualitative study	To test the feasibility and effectiveness of brief psychotherapy for patients with advanced cancer and their partners.	The intervention increased partners' awareness of the severity of cancer and its consequences, but also increased their perception of coping ability. There was an increase in peace and a decrease in anxiety and depression in the spouses.
Martínez et al. ²⁰	Dignity therapy; a promising intervention in palliative care: a comprehensive systematic literature review	Palliative Medicine	Systematic review	To analyze the results of — dignified therapy in patients with advanced life-threatening diseases.	- Patients, family members, and professionals perceived that the end-of-life experience improved. - For family members, it can be an opportunity to communicate more with the patient, as well as to get to know everyone's perceptions in the context of terminality, even helping with grief.

Continue...

Chart 1. Continuation.

Reference	Title	Journal	Type of study	Research objective or question	Results
Kotwal et al. ²¹	Til death do us part: end-of-life experiences in married couples in a nationally-representative survey	Journal of the American Geriatrics Society	Qualitative study	To examine end-of-life experiences among aged couples. To determine whether these end-of-life experiences of the first spouse were associated with the end-of-life experiences of the second spouse.	Second spouses were more likely to use hospice if the first spouse used hospice. Second spouses were less likely to perform palliative care when the first spouse had not.
Hinrichs and Christie ²²	Focus on the family: a case example of end-of-life care for an older LGBT veteran	Clinical Gerontologist	Case report	Explore the health of the aged LGBT+ population through the report of a couple of women, one of whom was accompanied by the Veterans Assistance Hospice until her death.	- The patient's wife was reluctant to accept help due to previous negative experiences with social service agencies related to her sexual orientation. The interdisciplinary team collaborated in meeting the medical needs of the veteran and the emotional and psychosocial needs of the wife, until the death of the former. The case highlights unique needs and challenges that may arise in end-of-life care for LGBT+ veterans and their families.

LGBT+: lesbians, gays, bisexuals, transvestites, transsexuals.

depression in caregivers, the female gender, health and behavioral problems with the caregiver, negative social interactions, and a reduced number of visitors stand out in the work of Haley et. al.¹²

Caregiving scenario

The work of Hunstad et al.¹⁴ carried out with seven caregivers (spouses) in three different communities in Norway showed that none of the participants regretted that their spouse's PC had been performed at home. The most important determinants of satisfaction with PC were professional help available 24 hours a day and a holistic care because it involved the family. The author emphasizes the importance of not only physical care, but also psychological, spiritual, and psychosocial care being provide by all parts of the family. An experienced and well-informed care team in the role of care facilitator can be critical in this parting process, as shown by Borland et al.¹⁶

In turn, in the work of Tabler et al.,¹⁸ telephone interviews were carried out with 19 caregivers, documenting their experiences transitions from hospice to bereavement. All of these caregivers' partners were in hospices due to cancer. The sample consisted of 12 women and seven men with a mean age of

65.5 years. Although care must be comprehensive, and should include family, caregivers reported that the focus of hospice was solely on the patient. Caregivers were grateful for all the attention that came with not suffering and caring for their loved one. However, they suggested that additional efforts could be made to identify and address caregivers' specific needs to support the dying process and the grief over loss.

Psychotherapeutic interventions

The review by Martínez et al.²⁰ describes dignity therapy (DT), which is considered a brief and individualized psychotherapy aimed at alleviating psychoemotional and existential suffering and improving the experience of patients whose lives are threatened by the disease. This therapy gives patients the opportunity to reflect on things that are important to them or that they would like to remember or pass on to others. The work shows that DT is viewed positively, but there are challenges with its use in patients with cognitive impairment, frail patients or patients with amyotrophic lateral sclerosis.

In the study by Wagner et al.,¹⁹ carried out with 12 couples in which the patients were diagnosed with stage IIB to IV lung cancer (ten patients) or breast cancer (two patients), interventions were made contemplating not only patients, but also their partner/spouse. Four activity sessions were held, focusing on three main topics or modules, namely:

1. Meaning in life;
2. Hopes for the future; and
3. Social connection.

Interestingly, more significant changes were found between partners than between patients. The results showed that at the end of the intervention, there was a decrease partners' depression and anxiety. In light of this, the author emphasizes that it would be valuable in the future to continue to follow-up with partners/spouses after the patients' death to determine whether the effects of the intervention also helped with grief.

Comparing the literature

Most studies that examined depression and anxiety in partners of aged patients under PC found a reduction in these symptoms after the intervention, even compared to groups in which partners did not receive any support during the terminal period.^{15,19}

The way the partner or spouse views the grieving process has also been shown to be more strongly related to the quality of PC provided to the partner during the last moments of life than to the strategies used to support grief in the post-death stage.¹⁸ Grief is defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM- 5)²³ as the state of having lost through death someone with whom the person had an intimate relationship. This state includes various grief and pain responses. Franco and Polido²⁴ highlight the importance of PC in preventing prolonged complex grief, as it allows anticipatory grief to be processed and family to be involved in the illness process.

Another important aspect is the situations in which the spouse also assumes the role of caregiver. Here we see a difference in the depression variable compared to partners who did not perform the job of caregiver, which is important to identify the role of partners in providing PC. A study by Götze et al.²⁵ showed that there was a higher rate of depression among caregiving spouses when analyzing psychological

parameters collected at the beginning of home care and two months after the patient's death. One can observe the importance of considering the difference in the level of involvement and in the role of the spouse in the context of PC implementation. One of the studies analyzed in this review showed that those who held the role of caregivers evolved with lower depression levels.¹⁷ In contrast to this data, the need for the caregiver to stop working completely could be related to isolation and loss of self-esteem.¹⁶

The literature has also shown that there are protective and less stressful factors during the PC process, that positively affect the caregiver's response to terminally ill patients and have a lower depression score.¹² This should be considered especially when the caregiver is the patient's spouse and corroborates the application of PC and the quality of life of this population. Thus, risk factors (caregiver stressors, caregiver health, and negative social interactions) and protective factors (caregiving and social resource ratings) need to be included as predictors of family caregiver well-being (diagnosis of depression and level of life satisfaction) in the practical application of PC.

Goldzweig et al.,²⁶ evaluated the variables of depression, distress, and support in 242 caregivers and spouses of patients diagnosed with cancer and undergoing PC, within six months of treatment. The result was consistent with the studies in the present review regarding spousal support. When it occurs in the context of PC, it has a positive effect on the levels of depression of these caregivers.

In the systematic review by Fernández-Isla et al.²⁷ on caregivers' satisfaction with PC teams, it was shown that symptom control, psychological support after death, preparation for the death of the family member, and maintenance of contact after death help during grief.

The difficulties or facilitations of couples in communicating about cancer-related concerns are evident in the literature and affect the emotional aspect, leading to suffering and changes in the stability of the relationship.²⁸ The systematic review by McLean and Jones²⁸ on cancer patients' mortality and the relationships with their partners, identified factors as predictors or correlated to both the patient and the spouse suffering, *i.e.*, the patient's condition, demographic and psychological factors, social support and resources, level of marital satisfaction, and quality of family functioning.

It is also suggested that a strong marriage and more affection from the partner can help keep the spirits of the spouse with cancer up during this difficult time. Families with high levels of conflict, low levels of expressiveness, and low levels of cohesion suffered more intense grief and higher psychological morbidity in the six and 13 months after the death of a family member.²⁸ Although this analysis does not refer to studies carried out only with the aged population, as cancer does not exclusively affect this age group, it corroborates the importance of bonds, as well as their quality, as a protective factor during terminality.

The case report by Hinrichs and Christie²² brings the specificity of PC to a couple belonging to the LGBT+ population. Support from the US Veterans Care Hospice staff helped alleviate the spouse's concern about his emotional and financial dependence on his wife. This allowed the patient to be accompanied by her partner in a more peaceful and less stressful way until the end of her life. The study therefore highlights that homosexual couples have similar needs to heterosexual ones, which must be equally recognized and addressed for positive clinical outcomes.

Another important association that has been demonstrated is how the spousal process in PC may influence the decision of the partner when also confronted with this moment of life.²¹ In this context, the closer the death, the stronger the associations for hospice use and advance planning. Findings are relevant to the way physicians frame PC discussions and potential interventions and the timing at which they occur.

Strengths and limitations

In the research carried out, it was found that there are no national publications on this subject and even at the international level, the studies are sparse. In this sense, it is noteworthy that the main limiting factor was to find articles that fully answered the research question, since the excerpt was about the patient's spouse on PC.

The articles found on the effects of PC on the patient's spouse, for the most part, do not compare the control group, as suggested in our question. This demonstrates the lack of a quantitative approach in the articles, with a predominance of literature reviews or qualitative studies with little scientific rigor or a very small sample, making generalizations and more robust evidence in this area impossible.

The literature review carried out recognizes the importance of the family approach proposed in PC and the need to include it in scientific work. It is also suggested that specific family roles are considered, such as the spouse, as they allow more objective analyses, with a greater chance of reproducibility and replicability, resulting in studies with a higher level of evidence.

Implications for research and/or professional practice

In this context, it is important to emphasize the relevance of the spouse's participation and involvement in the conduct of PC, both for the depression and anxiety variables and for the grieving process.¹⁷ Thus, the role of physicians in promoting follow-up and spouse involvement in the dying process is essential. This aspect is consistent with another observation made in this research, which is the need to prioritize the technical and scientific training of professionals over communication skills and bonding between physicians, patients, and the team, so that it is truly possible to build a support network.

Another aspect that proved to be essential in this study was the need to improve the quality of medical and psychological technical-scientific training, as well as communication skills within the team.²⁷

Orienting patients and spouses on protective and stressful factors can both prevent further complications in their mental health and contribute to a more appropriate adequate and healthier palliative process. In professional medical practice, it is also interesting to determine whether the partner is also a caregiver. This is because, in practice, there is a significant difference in the impact on the partner's grief.

Regarding the nature of the couple's relationship, homosexual relationships need to be further explored in the PC process. Furthermore, there is still a great deficiency in the ability of health professionals in general to welcome and care for relationships other than heterosexual ones, and this is another issue related to the technical aspect that is fundamental to be highlighted for the terminality process.

CONCLUSION

As illustrated, it is often incumbent upon the partner/spouse to assume the role of caregiver. To this end, many withdraw from work, friends, and leisure activities, isolate themselves, and devote all their time to caring for the patient. In this process, depressive feelings, helplessness, and an excess of responsibility are observed, especially when the caregiver does not receive psychological and emotional support to deal with the difficulties of this process, such as the pain of the spouse, grief, and life planning after death.

In this scenario, important external factors related to each patient's medical care are perceived. The way terminally ill patients are cared for can have a lasting impact on the health of their loved ones,

especially spouses. In this study, it was found that the use of PC can provide a better understanding of the disease development process, from illness to grief. However, further research is needed to show which parts of the intervention are most useful in relation to spousal grief.

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CONFLICT OF INTERESTS

Nothing to declare.

AUTHORS' CONTRIBUTIONS

VCAV: Project administration, Formal analysis, Conceptualization, Data curation, Writing – original draft, Writing – review & editing, Investigation, Methodology, Software. ASI: Formal analysis, Conceptualization, Data curation, Writing – original draft, Writing – review & editing, Investigation, Methodology, Software. KRR: Formal analysis, Conceptualization, Data curation, Writing – original draft, Writing – review & editing, Investigation, Methodology, Software. NMTF: Formal analysis, Data curation, Writing – review & editing, Supervision.

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