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Psychology of Health

Family Coping After Death of Patients in Palliative Care: A Systematic Review

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Abstract: Emotional care has proven important in the face of experiences of loss through death, influencing the perception of grief and individual well-being. This study aimed to verify the coping resources adopted by family members after the death of patients under palliative care. The JBI SUMARI method for qualitative systematic reviews was used. Eleven of the 158 articles were retained, synthesized, and grouped by credibility, then classified into thematic categories after metasynthesis. It was concluded that family members face emotions such as regret, fear, and sadness, exacerbated by communication difficulties and uncontrolled physical symptoms. Preparation for death stands out as an effective coping method, highlighting the importance of clear communication and collaborative care planning with the team. Although Palliative Care is valued, early access remains limited.

Keywords: family, death and dying, palliative care, coping behavior, caregivers

Enfrentamento Familiar Pós-Morte de Pacientes em Cuidados Paliativos: Revisão Sistemática

Resumo: O cuidado emocional demonstrou-se importante diante de vivências de perda por morte, interferindo na percepção do luto e no bem-estar do indivíduo. O objetivo deste estudo foi verificar os recursos de enfrentamento adotados por familiares após a morte de pacientes acompanhados por equipes de cuidados paliativos. Para esta pesquisa foi utilizado o método proposto pela JBI SUMARI para revisões sistemáticas qualitativas. Dos 158 artigos, onze foram retidos, sintetizados e agrupados de acordo com seu nível de credibilidade, classificados posteriormente em categorias temáticas, após submissão de metassíntese. Concluiu-se que os familiares enfrentam emoções como arrependimento, medo e tristeza, agravadas pela dificuldade de comunicação e observação de sintomas físicos não controlados. A preparação para a morte se destaca como um método eficaz de enfrentamento, sublinhando a importância de comunicação clara e planejamento dos cuidados em conjunto da equipe. Embora os Cuidados Paliativos sejam valorizados, seu acesso precoce ainda é limitado.

Palavras-chave: família, morte, cuidados paliativos, enfrentamento, cuidadores

Afrontamiento Familiar Después de la Muerte de Pacientes en Cuidados Paliativos: Revisión Sistemática

Resumen: El cuidado emocional ha demostrado ser importante ante experiencias de pérdida por muerte, influyendo en la percepción del duelo y el bienestar del individuo. El objetivo de este estudio fue verificar los recursos de afrontamiento adoptados por los familiares tras la muerte de pacientes atendidos por equipos de cuidados paliativos. Se utilizó el método propuesto por JBI SUMARI para revisiones sistemáticas cualitativas. De 158 artículos, se retuvieron once, que fueron sintetizados y agrupados según su nivel de credibilidad, luego clasificados en categorías temáticas tras la metasinapsis. Se concluyó que los familiares enfrentan emociones como arrepentimiento, miedo y tristeza, agravadas por dificultades de comunicación y la observación de síntomas físicos no controlados. La preparación para la muerte destaca como un método eficaz de afrontamiento, subrayando la importancia de una comunicación clara y la planificación conjunta de los cuidados con el equipo. Aunque los cuidados paliativos son valorados, su acceso temprano sigue siendo limitado.

Palabras clave: familia, muerte, cuidados paliativos, afrontamiento, cuidadores

According to the definition of the World Health Organization (WHO), published in 1990 and revised in 2002 and 2017, Palliative Care is an:

> an approach that improves the quality of life of patients (adults and children) and their families facing problems associated with life-threatening illnesses. It prevents and relieves suffering through the early identification, correct

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assessment, and treatment of pain and other physical, psychosocial, or spiritual problems. (World Health Organization, 2020).

Thus, the main objective of Palliative Care (PC) is to promote the well-being of patients and their loved ones, considering their values and life history. Thus, each case is treated individually, with appropriate conduct for therapeutic proportionality, also helping with the demands and needs of family members (Connor & Bermedo, 2021).

It is known that family members of patients undergoing PC can experience feelings of gratitude and privilege when caring, but due to the various experiences during diagnosis and treatment, they can experience physical and emotional effects caused by the intense care of the patient and the change in their routines, such as wear and tear, fatigue, stress, and psychological illness (Breen et al., 2018). Therefore, caring for family members has become an important topic of study, since these experiences can interfere with the post-death bereavement experience and the individual's well-being, requiring support and coping resources as a way of avoiding further complications (Holm et al., 2019). Caregivers with lower rates of depression and complicated grief also used personal coping strategies, as well as family support, to help them manage the feelings and behaviors that come with living with death (Fox et al., 2020).

Given the above, it can be said that PC also advocates family care, due to its therapeutic modality focused on comprehensive care, to promote an environment of support and resilience, helping in the acquisition of functional coping behaviors in the face of finitude, recognizing communication as a key factor in the team-patient-family relationship. The appropriation of the topic of PC by family members has helped in the understanding and more assertive management of care, that is, objective and compassionate communication by the team with family members about the end of life provides emotional benefits in the face of the proximity of death, not only for the patient, but also for the family member after their death and in the experience of their mourning (Braga et al., 2021; Breen et al., 2018). This study aimed to verify the coping resources adopted by family members after the death of patients accompanied by palliative care teams.

Method

This is a systematic review according to the methodology of the Joanna Briggs Institute (Piper, 2019) for systematic reviews of qualitative evidence, directed by the previous protocol of the International Prospective Register of Systematic Reviews (PROSPERO) under ID: CDR42023461310.

Methodological Procedure

The research question was developed according to the acronym PICo (Population [P], Phenomenon of Interest [I] and Context [Co]), since the aim is to understand the lived experience, it is understood that the primary studies selected are qualitative in nature. Therefore, the question of this review was: what family members use coping resources after the death of patients who have been assisted in palliative care? This review considered primary studies that provided qualitative data. Descriptive qualitative studies and mixed studies were included, considering their qualitative part and, consequently, their results.

The search strategy aimed to locate studies published since the 1990s due to the visibility and understanding of the concept of care for the families of patients undergoing PC concerning the World Health Organization and its publication that stimulated research in the area, encouraging research into best practices, effective interventions and ways to improve the well-being of patients and their families, as well as influencing the development of health policies at a global level, promoting the inclusion of PC in health systems. (Connor & Bermedo, 2021).

Searches were carried out in the following databases: PubMed and Medline, Web of Science, Scopus, PsycINFO, Embase, SCIELO, and LILACS, including studies published in all languages; however, all the articles had abstracts in English, and no translation tool was needed for other languages. The strategies used resulted from the intersection between controlled descriptors and synonyms using Boolean operators (AND and OR) and the use of truncation (“”).

The literature search was carried out from January to May 2024, resulting in 158 articles. All identified citations were grouped and loaded into EndNote X9 bibliographic software (Clarivate Analytics, Philadelphia) and 26 duplicates were removed. After removing the duplicates, a total of 132 articles with potential relevance remained, and the titles and abstracts were assessed for relevance concerning the objectives of this systematic review, 114 articles were excluded, leaving 18 articles for retrieval of the full text, and detailed assessment concerning the eligibility criteria.

After reading the full text, 7 studies were eliminated because they did not meet the inclusion criteria, leaving 11 studies to assess methodological quality according to the JBI Critical Appraisal Tool Checklist for Qualitative Research. There were no disagreements between the reviewers at each stage of the study selection process. The results of the research were reported in full in the final systematic review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram.

Quality assessment and metasynthesis

The qualitative studies eligible for inclusion in the review were critically appraised by two independent reviewers for methodological quality, using the standardized critical appraisal tool of the Joanna Briggs Institute System for Unified Management, Assessment, and Review of Information-JBI SUMARI (Piper, 2019) for qualitative research. The results of the critical appraisal were reported in tabular form. After the critical appraisal, studies that did not meet 70% of the quality threshold were excluded. These decisions were based on the evaluation criteria integrated into JBI SUMARI (Piper, 2019).

Data was extracted from the articles included in the review by two independent reviewers, using the standardized JBI SUMARI data extraction tool for qualitative evidence. The extracted data included specific details on authors/year/country, phenomena of interest, populations, study methods, experiences important to the review question, and specific objectives. Qualitative research findings relevant to the question were grouped using the JBI SUMARI protocol (Joanna Briggs Institute, Adelaide, Australia). This involved synthesizing findings to generate a set of statements representing this aggregation, bringing together findings classified according to their similarity of meaning. These categories were then subjected to meta-synthesis to produce a single comprehensive set of synthesized findings to be used as the basis for evidence-based practice.

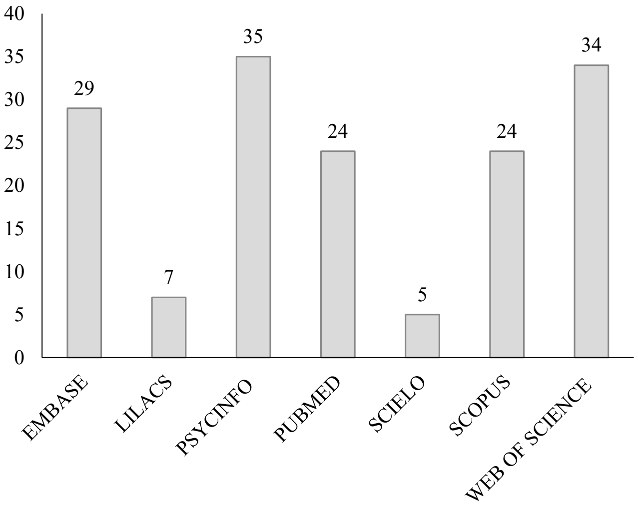
The synthesized results of this review were rated according to the ConQual approach, a process for assessing the confidence of synthesized results. The abstract included the main elements of the review and detailed how the ConQual score was developed. Included in the abstract were the title, population, phenomena of interest, and context for the specific review. Each synthesized finding from the review was presented alongside the type of research informing it, the score for reliability and credibility, and the overall ConQual score.

Results

The initial search found 158 records using pre-defined search strategies specific to each database, and the largest number of articles was found in the PsycINFO database as shown in Figure 1.

Figure 1

Numerical distribution of studies according to database



After methodological evaluation by the two reviewers, only eleven studies met the inclusion criteria, according to the objective of this systematic review on the experience of family caregivers and their coping resources adopted after the death of patients accompanied by palliative care teams, represented in this systematic review as shown in Figure 2.

The critical evaluation of the methodological quality of the articles included in this systematic review is shown in Table 1, using the ConQual critical evaluation tool, developed by JBI SUMARI (Piper, 2019), assigning a value (S) to each question if it complies with the criteria and a value (*N*) if it is negative and lacks quality rigor.

Figure 2

Fluxograma PRISMA

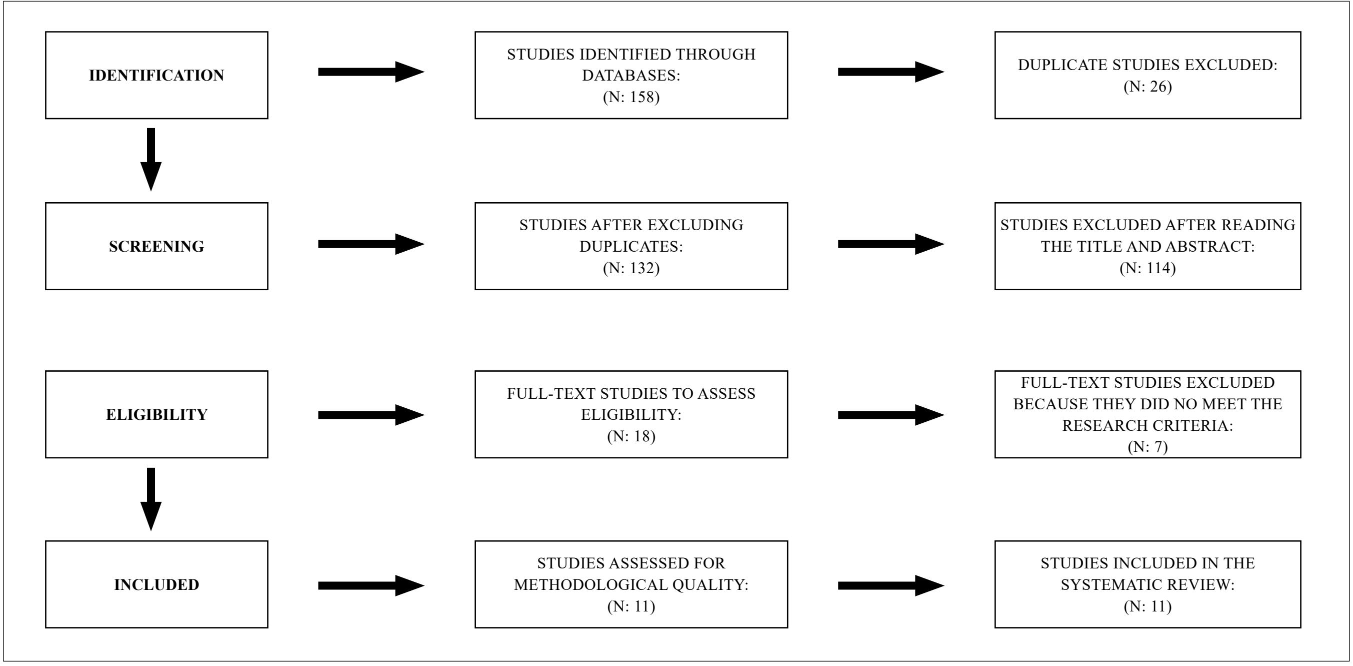


Table 1
Assessment of the methodological quality of the included studies

Main Author	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Aoun et al. (2021)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Aoun et al. (2011)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Digiacomo et al.	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Hudson	Y	Y	Y	Y	Y	N	N	Y	Y	N
Lennaerts-Kats et al.	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Lee et al.	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Mason e Hodgkin	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
McGinley e Waldrop	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Thomas et al.	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Tong et al.	Y	Y	Y	Y	N	Y	N	Y	Y	Y
Ho et al.	Y	Y	Y	Y	Y	Y	N	Y	Y	Y

Note. Yes: Y); (N: No); (O: Obscure).

Critical evaluation criteria for qualitative studies (ConQual), following the JBI SUMARI methodological protocol: (1) Is there congruence between the stated philosophical perspective and the research methodology? (2) Is there congruence between the research methodology and the research question or objectives? (3) Is there congruence between the research methodology and the methods used to collect data? (4) Is there congruence between the research methodology and the representation and analysis of the data? (5) Is there congruence between the research methodology and the interpretation of the results? (6) Is there a statement that locates the researcher culturally or theoretically? (7) Is the influence of the researcher on the research and vice versa addressed? (8) Are the participants and their voices adequately represented? (9) Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? (10) Do the conclusions drawn in the research report seem to flow from the analysis or interpretation of the data?

It is worth noting that none of the eleven studies met evaluation criterion 7, The influence of the researcher on the research and vice versa, as determined by JBI SUMARI. It is also worth noting that eight studies met nine of the ten evaluation criteria determined by JBI SUMARI.

The eleven studies shown in Table 2 were articles published between 2006 and 2023. These studies used interviews (structured and semi-structured) as an approach to data collection, as well as sociodemographic questionnaires and scales in the mixed studies selected to analyze their qualitative part. The data from the studies was analyzed using a qualitative approach, with content analysis, thematic analysis, narratives, and interview transcripts. The samples included family caregivers of patients accompanied by palliative care teams. The studies originated from Australia (a total of six studies), the Netherlands (one study), the United States of America (one study), the United Kingdom (one study), Canada (one study), and Singapore (one study). Sample sizes ranged from 8 to 393 participants.

The systematic literature review generated synthesized findings that derived 11 study findings that were aggregated into 3 categories, each with its own subcategories. Of the 11 study findings, all were classified as unequivocal, as described in Table 3.

Table 2

Characteristics of the included studies

Author	N	Phenomenon of Interest	Context	Study method	Findings
Aoun et al. (2021) Australia	393	The experience of the bereaved caregiver and their coping after the death of a patient with neurodegenerative disease.	After death	A national qualitative questionnaire survey using a P13 tool to identify reactions to prolonged bereavement.	Bereavement support was considered fundamental. Caregivers who had a high-risk index for complicated grief did not have many internal or external resources to help them cope.
Aoun (2011) Australia	16	The caregiver's experience before and after the death of family members with neurodegenerative diseases.	Before and after death	Exploratory qualitative research, using a sociodemographic questionnaire, semi-structured interviews and the prolonged bereavement assessment tool (P13).	Family caregivers who presented characteristics of complicated bereavement had access to PC with the patient at a late stage, impacting on their preparation for the loss.
DiGiacomo 2013 Australia	21	As experiências de mulheres idosas em relação ao cuidado conjugal no final da vida.	After death	Qualitative, longitudinal research using semi-structured interviews.	The study highlighted the feminization of aging, emphasizing the need for professional/assistance work to meet the needs of these women.
Hudson (2006) Australia	45	Family caregivers' perceptions of death and the professional strategies that helped them prepare for death.	After death	Qualitative, exploratory research using a structured questionnaire and an Inventory of Traumatic Grief (ITG).	Most caregivers perceived positive characteristics in their experience, due to effective communications and support provided by specialized PC teams.
Lennaerts-Kats et al. (2022) Netherlands	8	The needs of Parkinson's patients in the palliative phase and their family caregivers.	During and after death	Mixed, exploratory research using a semi-structured questionnaire and the Hoehn and Yahr, Schwab and England and unified Parkinson's disease assessment scales.	Bereaved family members felt that life today was a balancing act between "mourning" and "moving on", which was often a lonely journey. For two caregivers interviewed, death was a relief for the patient.
Lee et al. (2022) Australia	14	The experiences of caregivers of patients with mesothelioma (lung cancer).	During and after death	Qualitative study, using semi-structured interviews.	Bereavement may have been negatively affected by the lack of information and precarious assistance in PC. Caregivers who had access to PC had their emotional burden reduced.
Mason and Hodgkin (2019) Australia	10	The experience of the palliative caregiver in rural Australia.	During and after death	Qualitative study, using semi-structured interviews.	Being listened to, having choices, obtaining family and professional support were considered important by the participants. Being referred to the PC specialty was a significant factor.
McGinley and Waldrop (2020) USA	108	Communication and care and their influence on the well-being of family caregivers during bereavement.	After death	Qualitative study, using semi-structured interviews.	The results indicate that families are more likely to feel emotionally prepared for loss and bereavement when health professionals are available to communicate clearly, consistently and compassionately.
Thomas et al. (2018) United Kingdom	59	The experiences of family caregivers who have recently cared for an elderly person at the end of life.	After death	Qualitative study, using semi-structured interviews.	It was found that the quality of clinical practice could be improved if teams specializing in PC in community settings identified and addressed significant support needs related to the primary concerns of family caregivers.
Tong et al. (2023) Canada	23	The experience of family caregivers with MAiD (Medical Assistance in Dying), and with bereavement.	After death	Qualitative study, using semi-structured interviews.	Restrictions on hospital visitors had a negative impact on communication and interaction. These experiences resulted in immense emotional distress.
Ho et al. (2019) Singapore	26	The nature of marital interaction patterns among Asian parents of chronically ill children in palliative care.	After death	Qualitative study, using semi-structured interviews.	The results revealed that the participants respected and acknowledged their spouse's personal coping strategies and also reflected on their new ability to communicate openly about their emotions related to their child's absence.

Table 3

Presentation of the metasynthesis with the findings, categories, and synthesized finding

Findings	Thematic Categories	Synthesized Discovery
- Feelings of family members involved in the bereavement process (U) N: seven times - Preparation for death as a coping resource (U) N: four times - The importance of formal and informal support (U) N: four times - Rituals: farewell and funeral N: three times - Avoidance strategies: keeping busy, not thinking about it, postponing conversations (U) N: three times - Difficulty in "accepting terminality" (U) N: three times	*Feelings and coping strategies after death* - Emotional reactions to death - Feelings of anger, sadness, isolation and relief - Preparation for death vs. avoidance	Family members often faced negative feelings related to loss, symptom management in the face of finitude and inadequate communication with the team. Preparation for death and farewell rituals help with coping, despite the reduction in informal support over time. Clear information and adequate planning provided emotional security, and support from the healthcare system, family members and support groups are crucial.
- Positive experience of palliative care and clear/objective communication (U) N: four times - Negative aspects associated with late referral/access to palliative care (U) N: twice - Need for information in advance of death and care planning (U) N: five times	*Characteristics and observations about the PC experienced by family members* - CP as a positive feature - Late referral as a negative feature - The importance of communication and care planning shared with the team	Family members described the experience of palliative care positively, but highlighted the failure of early referral, which negatively affected grieving, while early access allowed for better preparation and acceptance of death, highlighting the need for constant support and information for care planning, experiencing death and bereavement.
- Lack of compassion when passing on information (U) N: four times - Insufficient information (U) N: five times	*Ineffective communication and lack of professional bereavement support* - Emotional distress at the non-empathic behavior of the professional - Difficulty acquiring information during treatment - Lack of specialized support and seeking help during bereavement	The lack of compassion in communication by non-palliative care physicians negatively impacted family members, who stressed the need for palliative care education and professional bereavement support, emphasizing that effective communication is crucial to coping with loss and reducing isolation and anguish after death.

Note. (U): unequivocal; (C): reliable; N* = Number of times it appeared in the articles.

Discussion

The analysis of the qualitative interviews of the selected studies provided three thematic categories, which will be analyzed in terms of their similarity, heterogeneity, and individual findings of the studies in question.

Feelings and coping strategies after death

Some caregivers indicated feelings of regret when reflecting on their changed role in the face of loss, as well as feelings of hopelessness and fear in dealing with finitude (Aoun et al., 2021; DiGiacomo et al., 2013). Feelings of anger and sadness were described in the studies by Aoun et al. (2021), DiGiacomo et al. (2013), and Hudson (2006), one of the causes being the poor management of their loved one's physical symptoms in the face of the progression of the disease and finitude according to DiGiacomo et al. (2013), and the difficulty of communicating with staff (Hudson, 2006; Tong et al., 2023). Isolation was cited by the authors Aoun et al. (2021), Hudson (2006), and Tong et al. (2023), as a feeling caused by the loss, associated with the feeling of loneliness or physical distance from the care team (Mason & Hodgkin, 2019).

The feeling of relief was described as a perception of the end of suffering caused by the illness (Hudson, 2006; McGinley & Waldrop, 2020). The farewell at the end of the illness, cited by Hudson (2006), proved to be a ritual that helped with coping, as did the funeral and the experience shared with other family members and friends; however, the gradual disappearance of informal support over time is emphasized (Lennaerts-Kats et al., 2022).

Some family members found themselves questioning their own self-efficacy in defending their loved one's wishes, while others reflected on whether or not they "made the right decision", especially when the wishes were not acknowledged or documented (McGinley & Waldrop, 2020). Avoidance strategies such as "keeping busy", "not thinking about it" and "postponing conversations" emerged in the interviewees' statements (Aoun et al. 2011, 2021; Ho et al., 2019).

Preparation for death was shown to be a fundamental aspect of coping, with constant learning and the importance of clear information for future care planning being highlighted, providing security and understanding of their needs, which are met, impacting on emotional quality during treatment and mourning (Hudson, 2006; McGinley & Waldrop, 2020; Thomas et al., 2018; Tong et al., 2023). Positive strategies have been identified as support from the health system, Family, and bereavement support groups (Lee et al., 2022).

The findings in the literature corroborate the results summarized, especially concerning the feelings experienced and the benefit of "preparing for death." A healthy family dynamic, with space for communication and the expression of feelings and ideas, can facilitate a process of adaptation to the situation of loss. The farewell ritual seems to benefit both the patient and the family, helping them to cope with death and bereavement, relieving negative feelings, and improving the quality of death for the patient and the quality of life for family members (Delalibera et al., 2015).

Characteristics and observations about palliative care experienced by family members

Family members described the experience as positive, according to Aoun et al. (2011), Hudson (2006), and Mason and Hodgkin (2019). However, access to PC was still restricted to a few years or only months before death, indicating a flaw in the system by failing to refer patients when they are diagnosed with a chronic disease with an irreversible prognosis (Aoun et al., 2011). There have been changes in the bereavement of family members who are negatively affected by the lack of early involvement in palliative care (Lee et al., 2022).

Early referral to PC allowed for greater bonding with the team and physical, intellectual and emotional preparation for the loss, according to Mason and Hodgkin (2019); as well as effective communication, which allowed for greater acceptance and preparation to deal with death (Hudson, 2006). The need for support and information to prepare for future care was described as essential in the palliative care process, helping to prepare for death and later, mourning (DiGiacomo et al., 2013; Hudson, 2006; Lennaerts-Kats et al., 2022).

Based on what has been presented, we can see the relevance of educational actions in PC aimed at professionals, patients, and their families since death is a reality inherent to life. However, the way in which this reality is faced can have better meanings if there are conversations that enable them to make their own choices and provide more autonomy in participating in decisions and options related to care and the end of life (Leitão et al., 2024).

There is a consensus that holding family conferences improves communication between the family, the patient, and the interprofessional team, providing a bond between them, identifying the needs of the context, and developing a care plan focused on these demands. Adopting this method makes it possible to provide high-quality PC, as it allows us to identify and meet the multidimensional needs of the patient and family, alleviate their suffering, and promote well-being during treatment and bereavement (Girão, 2022).

Communication and professional bereavement support

Participants consistently reported a lack of compassion in the transmission of information by non-palliative physicians, causing a negative impact on family caregivers (Aoun et al., 2011). Efficient communication provides family members with coping skills, helping to reduce isolation and anguish, as well as emotional pain, satisfying the needs of patients and family members, and impacting end-of-life and bereavement experiences. (Ho et al., 2019; McGinley & Waldrop, 2020; Tong et al., 2023).

Bereavement support was not always offered after the patient's death; part of the sample reported having received support, while another part did not even remember the existence of any support offered (Aoun et al., 2011). In a study that analyzed risks for complicated grief, it was evident that the high-risk group waited for support from specialists, remaining disappointed with the denial and contrast in expectations (Thomas et al., 2018). In contrast, family members reported that they felt bereavement support in the face of expressions of compassion and empathy from healthcare professionals or through bereavement support programs offered by interprofessional teams (Hudson, 2006; Lennaerts-Kats et al., 2022).

Effective communication requires healthcare professionals to pay attention to how they communicate with patients and their families in PC, which involves dedicating time, attention, and willingness to discuss any subject and reflecting on their own personal barriers. It is important to include end-of-life issues such as symptoms, fears, wishes, expectations, unfinished business, and preferences in the conversation (Rodrigues & Bernardino, 2024).

Although some PC services offer bereavement support, this still technically falls short of what it should be, especially when the bereavement care phase is separated from the care and support provided before the death. PC services should be able to offer more intentional and targeted bereavement care for the population they support, not just for family members of patients who have obtained PC but build bereavement programs and services to serve the entire bereaved population, being more comprehensive and integrative rather than substitutive (Aoun et al., 2017).

Bereavement support was effective in reducing grief, depression, and anxiety. However, the precariousness of the provision of programs and post-mortem follow-up are still restricted in most places where PC is offered, demonstrating that its development is necessary and still lacks solid bases and evidence and that more robust studies and research are needed as a strategy to highlight its potential and emerging demands, providing a scenario of significant bereavement support, as well as improvements in family care, as recommended by PC. (Hudson et al., 2017; Kustanti et al., 2021).

Family members are confronted by a range of emotions including regret, hopelessness, fear, anger, and sadness, often exacerbated by the difficulty in managing the patient's symptoms and the lack of effective communication with the care team, subsequently impacting their experience of grief. Some adopt avoidance strategies, such as occupying themselves, avoiding deep thought, and putting off difficult conversations, as ways of dealing with grief without direct confrontation. However, as a positive and striking feature of the functional coping resource, "preparation for death" emerges as an essential element for coping with bereavement more adaptively, highlighting the need for continuous learning and clear communication to plan future care safely and with an understanding of the needs involved.

Although PC is often viewed positively by families, early access remains limited, which negatively impacts the grieving process. This early involvement in care is fundamental for more comprehensive emotional preparation for death, again emphasizing the importance of effective communication and ongoing support. On the other hand, a lack of compassion in the communication of information by non-palliative care professionals can have a negative impact on families, leading to an unpleasant experience in the aftermath of their loved one's death. Despite the existence of some bereavement support services, many families are unaware of their availability or are unable to receive the support they need, and there is an urgent need to improve the availability of assistance to the bereaved and the accessibility of these services.

Recommendations for practice and research

PC services need to develop and integrate bereavement support into the care provided to family members, even after the patient's death, ensuring that it is as much a priority and as technical as PC during the treatment and end-of-life phase. It is essential to develop more comprehensive and integrative bereavement programs, which do not replace but complement informal care (family, friends, and community) and formal care (for those who exist in places/institutions that offer PC). In addition, more research is needed to strengthen the evidence base on the benefits of bereavement support and help develop better practices to meet the emotional needs of family members.

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