SELF-CARE ACTIONS PERFORMED BY ADULTS IN PALLIATIVE CARE:
AN INTEGRATIVE REVIEW

AÇÕES DE AUTOCUIDADO REALIZADAS POR ADULTOS EM CUIDADOS PALLIATIVOS:
REVISÃO INTEGRATIVA

ACCIONES DE AUTOCUIDADO REALIZADAS POR ADULTOS EM CUIDADOS PALLIATIVOS: REVISIÓN INTEGRATIVA

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ABSTRACT

Objective: To identify self-care actions performed by adults in palliative care. Method: An integrative review was carried out in MEDLINE, CINAHL, SCOPUS, Web of Science, and LILACS, by crossing the descriptors “cuidados paliativos”, “cuidados paliativos na terminalidade da vida”, “atitude frente à saúde”, “cuidado terminal”, “morte”, “autocontrole”, and “autocuidado” and their English translations. The time frame used in the searches was between 2017 and 2021, with a final sample of 15 articles. Results: There was a predominance of level VI evidence and studies with level A methodological rigor. Twenty-one self-care actions were found in all multidimensional aspects (physical, psychological, social, and spiritual). Conclusion: The advance directives of will and the expression of hope were the most predominant. These, when performed, were able to guarantee the patient's autonomy and, consequently, dignity.

Descriptors: Palliative Care; Hospice Care; Attitude to heath; Terminal care; Death; Self-control; Self-care.

RESUMO

Objetivo: Identificar ações de autocuidado realizadas por adultos em cuidados paliativos. Método: Revisão integrativa, realizada nas bases de dados: MEDLINE, CINAHL, SCOPUS, Web of Science e LILACS, por meio do cruzamento dos descritores “cuidados paliativos”, “cuidados paliativos na terminalidade da vida”, “atitude frente à saúde”, “cuidado terminal”, “morte”, “autocontrole” e “autocuidado” e as respectivas traduções em inglês. O recorte temporal usado nas buscas foi entre 2017 e 2021, sendo a amostra final composta por 15 artigos. Resultados: Observou a prevalência de estudos com nível VI de evidência e rigor metodológico nível A. Encontraram-se 21 ações de autocuidado em todos os aspectos multidimensionais (físico, psicológico, social e espiritual). Conclusão: As diretrizes antecipadas de vontade e a expressão do sentimento de esperança foram as mais predominantes. Essas, quando realizadas, foram capazes de garantir a autonomia do paciente e, consequentemente, a dignidade.

Descritores: Cuidados Paliativos; Cuidados Paliativos na Terminalidade da Vida; Atitude Frente à Saúde; Cuidado Terminal; Morte; Autocontrole; Autocuidado.

RESUMEN

Objetivo: Identificar acciones de autocuidado realizadas por adultos en cuidados paliativos. Método: Se realizó una revisión integradora en MEDLINE, CINAHL, SCOPUS, Web of Science y LILACS, cruzando los descritores “cuidados paliativos”, “cuidados paliativos na terminalidade da vida”, “atitude frente à saúde”, “cuidado terminal”, “morte”, “autocontrole” y “autocuidado” y sus traducciones al inglés. El marco temporal utilizado en las búsquedas fue entre 2017 y 2021, con una muestra final de 15 artículos. Resultados: Predominó el nivel de evidencia VI y los estudios con nivel A de rigor metodológico. Se encontraron 21 acciones de autocuidado en todos los aspectos multidimensionales (físico, psicológico, social y espiritual). Conclusión: Las directivas anticipadas de voluntad y la expresión de esperanza fueron las
más predominantes. Éstos, cuando se realizaban, podían garantizar la autonomía del paciente y, en consecuencia, la dignidad.

**Descriptors:** Cuidados Paliativos; Cuidados Paliativos al Final de la vida; Actitud Frente a la Salud; Cuidado Terminal; Muerte; Autocontrol; Autocuidado.

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**INTRODUCTION**

Healthcare for people with life-threatening illnesses has changed over the decades, becoming a practice that aims to ensure the quality of life for the patient and family, from the diagnosis of the disease (dying process) to death.¹

The philosophy of Palliative Care (PC) has always been present in history, characterized by illness and suffering in multiple dimensions. Thus, PC is configured as care for the person, not the disease, valuing subjectivity, well-being, relief from suffering, comfort, respect, and dignity for human beings in the face of the process of finitude.²³

Initially, this care was defined as “total and active care directed at patients beyond the possibility of cure”.⁴ However, this description was reformulated, starting to be defined as a differentiated approach capable of improving the quality of life of patients (adults and children) and family members in the face of problems inherent to a potentially fatal disease. This improvement is achieved through comfort, relief of suffering, and early identification, assessment, and treatment of pain and other symptoms, whether physical, psychosocial or spiritual.⁵⁶

The assistance offered by health professionals to patients under PC should be centered on humanized care, with the main objective of promoting pain and other symptom relief and care in the psychosocial and spiritual dimension at the end of life.⁶⁷

The end of life is defined as the period from the establishment of the diagnosis of the disease and the patient's prognosis in the face of a disease with no possibility of cure until the occurrence of death, which may vary from three to six months.⁸

There is also a difference between the end of life and the active phase of death, the latter being understood as the last hours of life. Despite this, both are part of terminality, also called the dying process.⁹

Due to the scope of the needs of patients undergoing PC, assistance to these patients should involve a multidisciplinary team composed of different health professionals, including nurses, who provide interventions that relieve suffering, pain, and other symptoms management, promote comfort and dignity to the patient and the family, leading to a more peaceful coping with illness and dying processes.¹⁰⁻¹¹
Over time, the perception and coping with illness and dying processes have changed, along with the evolution of humanity, influencing people's attitudes towards the process of finitude. Therefore, the nurse must recognize the patient's actions to promote health and well-being, focusing on the physical, emotional, social, and spiritual needs.

This study aimed to identify self-care actions performed by adults in palliative care, contributing to the process of building new ways of doing health in the face of death, guaranteeing the patients' autonomy and, consequently, dignity.

**METHOD**

This is an integrative review, a method that allows the analysis of relevant and significant studies for decision-making and improvement of clinical practice, knowledge synthesis, and knowledge deepening on a given subject. In addition, it points out the gaps that need to be filled in future studies.

The steps recommended by Whittemore and Knaf (2005) were followed during the development of the study: 1) identification of the problem; 2) literature search; 3) data evaluation; 4) data analysis; and 5) presentation/synthesis of knowledge based on the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) checklist.

The PICo framework was used to construct the research question, where P – population: adults; I – interest: self-care actions; and Co – context: patients under palliative care. The framework resulted in the following guiding question: What self-care actions are performed by adults in palliative care when approaching the end of life?

The data collection was carried out between August and September 2021 via the Portal of Journals of the Coordination for the Improvement of Higher Education Personnel (CAPES), through remote and free access, individually, via the Federated Academic Community (CAFe), in the following electronic databases: Medical Literature Analysis and Retrieval System Online (MEDLINE), Cumulative Index to Nursing and Allied Health Literature (CINAHL), SCOPUS (Elsevier), Web of Science, and Latin America and the Caribbean Literature on Health Sciences (LILACS). Health Sciences Descriptors (DeCS) and Medical Subject Headings (MeSH) were used during the searches in the Virtual Health Library (VHL).

The articles were selected from the combination of the following DeCs and MeSH terms: palliative care, hospice care, attitude to health, terminal care, death, self-control, and self-care, combined by the Boolean operators “OR” and “AND”, using the Title/Abstract keyword search. Four crossings were carried out in each database as a search strategy, as described in Chart 1. The review was limited to studies published between 2017 and 2021, aiming at retrieving up-to-date scientific evidence.
The following inclusion criteria were defined: articles available in full format and free of charge in all selected databases, written in English, Spanish, or Portuguese, that could answer the guiding question and published within the time frame. The following exclusion criteria were adopted: abstracts, theses, dissertations, reviews, editorials, and letters to the reader.

A total of 32,229 scientific studies were found. In the first phase of the search, publications that did not meet the inclusion criteria were excluded. Then, the previous screening was conducted to identify the association with the theme through the information contained in the titles and abstracts. Sixty studies were selected for full-text screening, of which 45 were excluded for not answering the guiding question. Finally, 15 articles that met the required criteria made up the final sample. Figure 1 demonstrates the study selection process and composition of the final sample.
The data extraction was conducted through an instrument with important variables such as title, authors, year of publication, study location, journal, objectives, methods, and self-care actions performed by adults in palliative care. 

The evaluation of the methodological rigor of the selected studies occurred through an instrument adapted from the Critical Appraisal Skills Program (CASP)\textsuperscript{20}. This checklist consists of 10 questions. A 'yes' was attributed when the criterion was properly described (score 1), and a 'no' when the criterion was not described (score 0). The total scores were counted, ranging from zero to 10, in which, according to the score obtained, two categories were presented: level A (6 to 10 points) - good methodological quality and reduced bias, and level B (less than or equal to 5 points) – satisfactory methodological quality with potential increased bias. The present review used the CASP tool to classify the studies.

Melnyk and Fineout – Overholt's (2011)\textsuperscript{21} classification was used to assess the level of evidence of the studies, as follows: level I – evidence from systematic reviews or meta-analysis of relevant clinical trials; level II – evidence derived from at least one well-designed randomized controlled clinical trial; level III – well-designed non-randomized clinical trials; level IV – well-designed cohort or case-control studies; level V – systematic reviews of qualitative or descriptive studies (weak evidence); level VI – evidence derived from a single qualitative or descriptive study; and level VII – opinion of authorities or reports of expert committees. Self-care actions performed by adults in palliative care were identified from the selected studies.
The sample consisted of 15 articles. As for the language, two (A10, A13) were written in Portuguese and 13 in English (A1, A2, A3, A4, A5, A6, A7, A8, A9, A11, A12, A14, A15).

Regarding the origin/location of the analyzed publications, it was possible to observe that most of the studies were developed in Brazil (46.66%) (A9, A10, A11, A12, A13, A14, A15), while the other eight remaining countries composed 53.33% of the total sample.

Only three studies (A9, A10, and A14) were published in nursing journals, and 12 in other health disciplines. Concerning the study designs, most studies were qualitative (53.33%) or quantitative (26.66%), classified as level VI (100%) scientific evidence. Concerning the CASP tool, 80% of studies were level A, as shown in Chart 2.

We identified 21 self-care actions performed by adults in palliative care, as illustrated in Chart 2.

**Chart 2** - Characterization of the articles that made up the sample, according to authors, title, country, year of publication, database, objective, and indicators of nursing outcomes. Recife, Pernambuco, Brazil, 2022.
<table>
<thead>
<tr>
<th>ID</th>
<th>AUTHORS</th>
<th>TITLE</th>
<th>COUNTRY</th>
<th>DATABASE</th>
<th>METHOD</th>
<th>LEVEL OF EVIDENCE / CASP</th>
<th>SELF-CARE ACTIONS CARRIED OUT BY ADULTS</th>
</tr>
</thead>
</table>
| A1 | WANG et al., 2021. | Advance directives and end-of-life care: knowledge and preferences of patients with brain Tumours from Anhui, China | China   | SCOPUS   | Cross-sectional study             | VI / Level A             | - Participates in decisions about hospitalization;  
|    |                  |                                                                       |         |          |                                   |                          | - Participates in decisions about resuscitation;  
|    |                  |                                                                       |         |          |                                   |                          | - Writes advance will directives.        |
| A2 | SCHERER et al., 2021. | Association Between Self-reported Importance of Religious or Spiritual Beliefs and End-of-Life Care Preferences Among People Receiving Dialysis | USA     | SCOPUS   | Cross-sectional study             | VI / Level A             | - Discusses spiritual experiences;  
|    |                  |                                                                       |         |          |                                   |                          | - Discusses spiritual concepts.          |
| A3 | SANDERSON et al., 2019. | “I want to die in my sleep”-how people think about death, choice, and control: Findings from a Massive Open Online Course | Australia | WEB OF SCIENCE | Qualitative study             | VI / Level B             | - Participates in decisions related to care;  
|    |                  |                                                                       |         |          |                                   |                          | - Participates in funeral planning;  
|    |                  |                                                                       |         |          |                                   |                          | - Maintains current desire;  
|    |                  |                                                                       |         |          |                                   |                          | - Writes advance directives of will;  
|    |                  |                                                                       |         |          |                                   |                          | - Shares feelings about dying.           |
| A4 | BUŽGOVÁ; ZAPLETALOVA, 2021. | Assessment of Older Adults’ Attitudes to Death, Palliative Treatment, and Hospice Care in the Czech Republic | Czech republic | WEB OF SCIENCE | Cross-sectional study | Level VI / Level A | - Participates in decisions related to care;  
- Participates in decisions about hospitalization;  
- Maintains current desires;  
- Shares feelings about dying. |
| A5 | KOBAYASHI et al., 2021. | Impact of self-decision to stop cancer treatment on advanced genitourinary cancer patients | Japan | WEB OF SCIENCE | Retrospective study | Level VI / Level A | - Participates in decisions related to care;  
- Participates in funeral planning;  
- Controls treatment choices. |
| A6 | KIM et al., 2020. | Attitudes toward advance directives and prognosis in patients with heart failure: a pilot study | South Korea | WEB OF SCIENCE | Viability study | Level VI / Level A | - Participates in decisions about resuscitation;  
- Writes advance directives of will;  
- Controls food and drink intake. |
| A7 | VALIKHANI; SARAFRAZ; MOGHIM, 2018. | Examining the role of attachment styles and self-control in suicide ideation and death anxiety for patients receiving chemotherapy in Iran | Iran | CINAHL | Qualitative study | Level VI / Level B | - Shares feelings about dying. |
| A8  | BACZEWSKA et al., 2020. | Hope of Recovery in Patients in the Terminal Phase of Cancer under Palliative and Hospice Care in Poland | Poland | MEDLINE | Descriptive study | Level VI / Level A | - Expresses hope. |
| A9  | DO PRADO et al., 2019. | Cancer patients with advanced disease: concerns and expectations experienced in the terminality of life | Brazil | LILACS | Qualitative study | Level VI / Level A | - Brings the business up to date;  
- Expresses hope;  
- Solves important problems;  
- Shares feelings about dying;  
- Maintains a sense of control over remaining time;  
- Gradually moves away from loved ones. |
| A10 | SILVA et al., 2020. | Transition to palliative care: facilitating actions for cancer client-centered communication | Brazil | LILACS | Qualitative study | Level VI / Level A | - Participates in decisions related to care;  
- Controls treatment choices. |
| A11 | ZILLI et al., 2021. | Knowledge of the self facing the experience of illness by cancer and palliative care | Brazil | LILACS | Qualitative study | Level VI / Level A | - Expresses hope;  
- Participates in funeral planning; |
| A12 | TOMASZEWSKI et al., 2017. | Demonstrations and necessities on the death and dying process: perspective of the person with cancer | Brazil | LILACS | Qualitative study | Level VI / Level A | - Shares feelings about dying;  
- Maintains a sense of control over remaining time;  
- Expresses readiness for dying |
| A13 | SCOTTINI; FROM SIQUEIRA; MORITZ, 2018. | Patient’s rights to advance directives | Brazil | LILACS | Cross-sectional study | Level VI / Level B | - Expresses hope;  
- Exchanges affection with others;  
- Reviews life achievements;  
- Discusses spiritual experiences;  
- Discusses spiritual concepts;  
- Maintains physical independence. |
| A14 | PRADO et al., 2019. | Experiencing the death-dying process: a phenomenological analysis of patients with terminal cancer | Brazil | LILACS | Qualitative study | Level VI / Level A | - Expresses hope;  
- Reviews life achievements. |
| A15 | LIME; MACHADO, 2018. | Main caregivers facing death experience and its meanings | Brazil | LILACS | Qualitative study | Level VI / Level A | - Recalls memories of life;  
- Discusses spiritual experiences;  
- Discusses spiritual concepts. |
The studies that addressed self-care actions carried out by adults in palliative care when approaching the end of life originated from different countries, showing that finitude is an object of study with a global dimension and direct repercussions for dying and having a dignified death.

A literature review on end-of-life planning found six different countries with publications on the subject, in addition to identifying that the number of publications on the subject has been increasing, portraying the concern with the knowledge of issues related to end-of-life and palliative care.22

Concerning the research designs, most studies were qualitative and quantitative. Qualitative studies make it possible to verify the subjective aspects of social phenomena and human behavior. Quantitative studies, on the other hand, aim to quantify a problem, opinions, and information on a given subject and understand its dimension using different statistical techniques.23

Among the self-care actions carried out by adults in palliative care when approaching the end of life, catching up on business stood out, in which the patient, based on knowledge of the prognosis, carries out planning for pending issues unresolved in life, expressing his real wishes, feelings, and concerns.24-25

Regarding existential demands, there was a discussion about spiritual concepts and patients' verbal reports of life experiences with the spiritual dimension. When debating the spiritual dimension, the authors investigated how each individual expresses life's meanings and purposes, in addition to experiencing their connections with the moment, themselves, other people, nature, and the sacred.26-29

It is emphasized that spirituality contributes positively to existential well-being, positively impacting the psychological dimension and the process of coping with serious illnesses, thus favoring a more dignified end of life.30-31

Awareness of patients' religious and spiritual beliefs can be beneficial for care planning in the face of serious illnesses, helping the patient to deal with challenges and treatment decisions at the end of life.32-33

Given the above, spirituality must be considered throughout nursing care, especially during death. Thus, nurses will be able to approach the spiritual dimension, initially identifying the spiritual needs of patients in order to build a multidimensional care plan.

In the literature, it was seen that expressing hope was an action to deal with the process of finitude, characterized by acceptance of the dying process, belief in recovery, trust in the healthcare team, and the will to live.25,27,34,35

The hope of living is linked to the patient's will and desires to get rid of medical treatments, making clear the need to reach and understand the real meaning of life. In addition, this hope is also the result of how the patient will face the disease, a fact related to the support of family, friends, and health professionals, and the way of dealing with one's faith, present or not, during this health-disease-death process.27,36

The support of family members in this process of finitude is directly linked to feelings of love and affection, being able to encourage the patient to reconcile relationships and exchange
affection with other individuals. The health professional, the caregiver, and the family must create communication strategies to identify the patient's needs and concerns at the end of life.27

Another action found was the gradual removal of the patient from loved ones as a way of saying goodbye to family members. Given this, the health professional needs to listen to the patient to identify his needs and promote reunions, family conversations, and flexible visiting hours, in addition to promoting a favorable environment for this removal to occur in a light and peaceful way.25,37

Based on the assumption of identifying the patient's needs and concerns at the end of life, the Advance Directives of Will (ADW) are a strategy used by individuals to document, in a preventive way, their wishes and preferences regarding care and treatments, guaranteeing comfort and dignity at the end of life.38-42

The ADW supports treatment guidelines and patient decision-making regarding care, the hospitalization process, and discussions about resuscitation, artificial ventilation, all-in-one nutrition, life sustainability measures, hemodialysis, and the choice of the place of death.40-46

In addition, the ADW is a document that allows the patient, family, and health professionals to build a care plan to meet the patient's wishes, especially concerning the future and possible occurrences that may make it impossible for the patient to communicate healthcare preferences.39,47

Still, regarding treatment choices, studies show that in the ethical context of palliative care, there is a commitment to allow the patient to participate in the construction of the care plan together with the multidisciplinary team, respecting the principle of autonomy. The patient must be aware of all the possible complications of the disease, and the patient's wishes and preferences regarding the therapeutic alternatives offered by the professional team must be met.1,43,44

In palliative care, one of the biggest challenges is reconciling the patient's autonomy in the end-of-life process with the therapeutic expectations of the health team, considering that the prognosis is delicate but essential to define the care planning. Thus, some instruments, such as the Palliative Performance Scale (PPS), allow the nurse to evaluate the patient and classify his ability to perform basic activities of daily living and document functionality and prognosis, contributing to better decision-making during the creation of care plans or in advance directives with the patient and family.39,48

According to some studies, discussing dying issues, expressing feelings of preparation for death, and participating in funeral planning were key actions for building "death awareness", and this awareness is capable of encouraging people to plan their future, bringing death back to the public as an "everybody's issue".25,34,40,44,49

Thus, giving space to the patient to express himself in the face of the end of life makes it possible for health professionals to recognize the demands of the patients and, thus, offer quality care that allows seeing the individual as a whole and not just clinically.34

It is also noticed that talking and thinking about dying and death are issues that terrify individuals due to how they understand the finitude process. In addition, discussing death clarifies and prepares the patient for finitude, reducing suffering and maintaining autonomy throughout the end-of-life trajectory, involving decision-making, the process of acceptance, and preparation for death.49-50
The acceptance phase is considered one of the stages experienced by the patient, in which the person gradually accepts the current reality and begins to understand the limits arising from the illness process more consciously. In this way, the patient maintains a sense of control over the remaining time, completes significant objectives, solves important problems, and maintains physical independence and functionality during death, respecting wills, wishes, and autonomy.²⁵,²⁷,³⁴,⁵¹

Individuals who experience dying and death have a threatened future and, right from the start, see only concerns and uncertain expectations. With the acceptance process, wishes and goals begin to surface, causing people to recall life memories, review achievements, and, thus, have more control over personal assets, mainly maintaining recent wishes.²⁵,²⁷,²⁸,⁴⁰,⁴⁵

The self-care actions reinforce the importance of giving voice to patients, questioning and exposing uncertainties, insecurities, and real needs, allowing those who are in finitude not only to die without suffering and pain but also to express multidimensional feelings and needs in the face of death.²

The measure to achieve a dignified end of life includes factors and actions related to the patient himself. Thus, the nurse needs to consider these issues in professional practice, especially in selecting indicators to assess and monitor end-of-life patients in palliative care.

CONCLUSION

Self-care actions carried out by adults in palliative care are related to respect for the patient’s autonomy, narratives about dying and death, care planning through shared decisions, dialogues about the remaining time of life, and communication and the end of life.

Among the most prevalent actions, we can mention the construction of advance directives of will and the expression of hope, which is directly linked to the planning of care based on humanization, respect for autonomy, and the guarantee of dignity to achieve a good death.

The study limitations include the number of articles in the sample due to the use of a time restriction. As an implication for health, the results of this research can be incorporated into continuing education activities for professionals, subsidizing quality care for patients in palliative care.

CONTRIBUTIONS

All authors contributed equally to the construction of the research project, collection, analysis, and discussion of data, writing and critical review of the manuscript’s content, and approval of the final version of the study.

CONFLICT OF INTERESTS

Nothing to declare.

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