

RESEARCH

Open Access



# Understanding the role of home-based palliative care in supporting patient dignity: a scoping review

Flávia de Araújo Cordeiro Valentim<sup>1\*</sup>, Nádia Marisa Sotério de Oliveira<sup>1</sup>, Vicente Paulo Alves<sup>1</sup> and Manuel Luís Vila Capelas<sup>2</sup>

## Abstract

**Background** Home-based palliative care (HBPC) plays a crucial role in preserving the dignity of patients with terminal illness and their families. However, the factors influencing this experience from the perspective of patients, family caregivers, and healthcare professionals remain insufficiently explored.

**Aim** This study aimed to map and analyze the role of HBPC on patient dignity, considering the perspectives of patients, family caregivers, and healthcare professionals.

**Methods** A scoping review was conducted following the Joanna Briggs Institute (JBI) methodology and reporting according the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA)-ScR guidelines. Six databases (PubMed, Scopus, Web of Science, Cochrane Library, CINAHL, and PsycArticles) were searched up to December 2024, yielding a total of 5,259 records. Studies that focused on patient dignity in HBPC were eligible. Reports, protocols, editorials, and gray literature were excluded. A narrative synthesis was used to identify and categorize the key themes related to dignity in HBPC.

**Results** Five qualitative studies met the eligibility criteria. The key factors supporting patient dignity included autonomy, emotional support, effective symptom management, and supportive care environments. Challenges involved caregiver burden, inadequate training, organizational barriers, and lack of infrastructure in home care services.

**Conclusion** HBPC has the potential to preserve patient dignity when practices such as empathetic communication, respect for autonomy, and pain control are prioritized. Nevertheless, limitations such as underrepresentation of culturally diverse contexts and the exclusion of gray literature constrain the strength of the evidence base. Future research should incorporate culturally diverse perspectives, assess quality using tools such as CASP, and expand the scope to include gray literature and regional databases.

**Keywords** Dignity, Review, Caregivers, Patients, Health personnel, Home care services, Palliative care

\*Correspondence:

Flávia de Araújo Cordeiro Valentim  
flavia.cordeiro@a.ucb.br

<sup>1</sup>Stricto Sensu Postgraduate Program in Gerontology, Catholic University of Brasília, Brasília, Brazil

<sup>2</sup>Faculdade de Ciências da Saúde e Enfermagem, Centro de Investigação Interdisciplinar em Saúde (CIIS), Universidade Católica Portuguesa, Lisboa, Portugal



© The Author(s) 2025. **Open Access** This article is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License, which permits any non-commercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if you modified the licensed material. You do not have permission under this licence to share adapted material derived from this article or parts of it. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by-nc-nd/4.0/>.

## Introduction

Home-based palliative care (HBPC) offers essential support for people with advanced illnesses through a holistic approach to managing complex symptoms. It is increasingly valued as an alternative to hospital-based care, which is often costly and associated with unsatisfactory experiences for patients and their families [1]. Research indicates that HBPC not only improves the quality of life for patients with nonmalignant chronic conditions but also reduces hospital admissions and healthcare costs in the final days of life for dementia patients [2, 3].

Preserving patient dignity is a central goal of palliative care, as it mitigates existential suffering and strengthens relationships among patients, families, and healthcare providers [4, 5]. Chochinov's seminal Dignity Model, for instance, identifies three core domains that influence dignity at the end of life: illness-related concerns, the dignity-conserving repertoire (personal and spiritual perspectives), and social dignity [6]. Dignity violations have been associated with increased desire for death and diminished will to live, whereas their preservation supports psychological resilience [7].

Although dignity has been explored from multiple perspectives [8–10], the home setting introduces dynamics that differ from institutional environments, as relationships among patients, family caregivers, and healthcare professionals are closely intertwined [11]. This context directly influences the domains of Chochinov's Dignity Model, particularly social dignity, where the blurred boundaries between clinical and personal roles become blurred and deeply prominent [12]. Family caregivers often assume duties that can affect their ability to support patients' dignity, while healthcare professionals must balance clinical competence with psychosocial sensitivity [11, 13]. For patients, the quality of the caregiver–patient relationship plays a key role in maintaining dignity [14].

Despite the growing recognition of dignity's importance, little is known about the evidence addressing the intersection between patient dignity, HBPC, and the perspectives of patients, family caregivers, and healthcare providers. A scoping review is particularly well-suited for investigating this topic, as it enables the mapping of existing evidence, identification of knowledge gaps, and clarification of conceptual boundaries—especially in emerging or under-researched areas [15]. Given the complex dynamics affecting patient dignity in HBPC, this scoping review aims to map and analyze the role of HBPC on patient dignity, considering the perspectives of patients, family caregivers, and healthcare professionals, thereby identifying gaps and opportunities for future research.

## Methods

This scoping review followed the Joanna Briggs Institute (JBI) methodology [15] and was reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis extension for Scoping Reviews (PRISMA-ScR) guidelines [16]. The JBI framework was used to ensure a rigorous and transparent review process from question formulation to data synthesis and presentation. The rationale for choosing a scoping review is its suitability for mapping existing literature in a complex field, identifying key concepts, and uncovering research gaps without appraising the quality of studies, which is ideal for this topic [15].

A preliminary search conducted in November 2024 in PROSPERO and the Open Science Framework (OSF) revealed no existing reviews addressing the same research topic. The review protocol was registered in PROSPERO (CRD420251026645) and OSF [17].

### Research question and eligibility criteria

The central question was structured using the PCC (Population, Concept, Context) framework: What is the role of home-based palliative care (HBPC) on patient dignity from the perspective of patients, family caregivers, and healthcare professionals?

The inclusion criteria encompassed studies involving patients of any age, family caregivers, or healthcare professionals (Population); studies that focused on patients' dignity (Concept); and studies that focused on HBPC regardless of cultural, geographic, or social setting (Context). Studies addressing multiple care settings were included only if the home-based context was clearly delineated. The search strategy included all study designs, regardless of publication date. Systematic reviews were also considered if they met the inclusion criteria.

Exclusion criteria included studies conducted entirely outside the home context (e.g., hospitals, long-term care facilities, or nursing homes), as well as those that dealt with palliative care in general without focusing on the dignity experience. Research protocols, editorials, opinion articles, conference abstracts, and full papers that were not available or accessible were also excluded. Gray literature—such as policy reports, governmental guidelines, and unpublished theses—was not included in this review, which may have led to the omission of relevant context-specific evidence. The exclusion of gray literature is acknowledged as a limitation and is discussed in detail in the final section of this manuscript (see “Limitations”).

Table 1 presents the inclusion and exclusion criteria applied in the scoping review, along with the rationale for each criterion.

**Table 1** Inclusion and exclusion criteria

Criteria	Inclusion	Exclusion	Justification
Population	Patients (any age), family caregivers, healthcare professionals	Studies without one of these groups explicitly included	Inclusion of at least one of these three perspectives is essential to achieving a comprehensive understanding of dignity in home-based palliative care.
Concept	Focus on patient dignity in HBPC.	Articles addressing palliative care in general without reference to dignity or the patient's experience in the home context	The review's primary focus is on dignity. Articles without this focus do not directly contribute to answering the research question.
Context	Home-based palliative care setting	Exclusive focus on hospitals, nursing homes, or other institutional settings	As the research focuses on home-based care, the isolated inclusion of other contexts would deviate from the review's objectives.
Study type	Primary studies and secondary research (e.g., systematic or scoping reviews); no restriction on date/language	Editorials, opinion papers, protocols, inaccessible full texts, gray literature	Including both primary and secondary research ensures the coverage of original evidence and broader syntheses. Excluding protocols, opinion pieces, and inaccessible articles maintains methodological rigor; inaccessible studies were also excluded for feasibility reasons.

### Search strategy

The search strategy was developed by two authors and included MeSH and uncontrolled terms combined using Boolean operators (Supplementary Material I). PubMed, CINAHL, Cochrane Library, PsychArticles, Scopus, and Web of Science electronic databases were searched from inception to December 5, 2024. No regional databases (e.g., LILACS, African Index Medicus) were consulted, which may have limited the geographic diversity of the included studies. No language restriction was applied. Articles in languages not spoken by the review team were translated with external support.

### Evidence selection

All references were imported into the Rayyan software [18], and duplicates were identified and removed. Two reviewers independently screened the titles and abstracts using a double-blind process. Discrepancies were resolved through discussion. Full-text screening was conducted by one reviewer, and the reasons for exclusion were documented. The selection process was illustrated using a PRISMA-ScR flow diagram [16]. During the search, two reports could not be retrieved as full-text access could not be obtained via institutional libraries or author contact. The main reasons for excluding studies were not addressing dignity in relation to HBPC; not focusing on the predefined population (e.g., non-family caregivers); not being empirical research, such as protocols, editorials, or opinion papers; and not focusing on HBPC, being conducted only in other contexts (e.g., as hospitals or nursing homes). Two reports could not be retrieved in full (Fig. 1).

### Data extraction

Data were extracted using a customized Excel form (Supplementary Material II). The following data were collected: author/year, country, study objective, method, participants, and central outcomes related to the effects of home care on patient dignity.

As per the JBI recommendations, no formal quality assessment was conducted; however, this decision are addressed in the Limitations. In future reviews, the inclusion of critical appraisal tools, such as CASP for qualitative studies, may enhance the interpretability and reliability of the findings.

### Data analysis and presentation

The analysis followed four steps: (1) detailed reading of the included articles, (2) identification of data aligned with the research question, (3) data organization by stakeholder perspective, and (4) consistency assessment between results and authors' conclusions. Following JBI guidelines, a narrative synthesis was adopted to organize and interpret the findings [19], guided by the methodological framework of Popay et al. [20]. Frequency counts from the content analysis were incorporated to highlight the recurrence of emergent themes, thereby enhancing interpretability without overemphasizing individual studies.

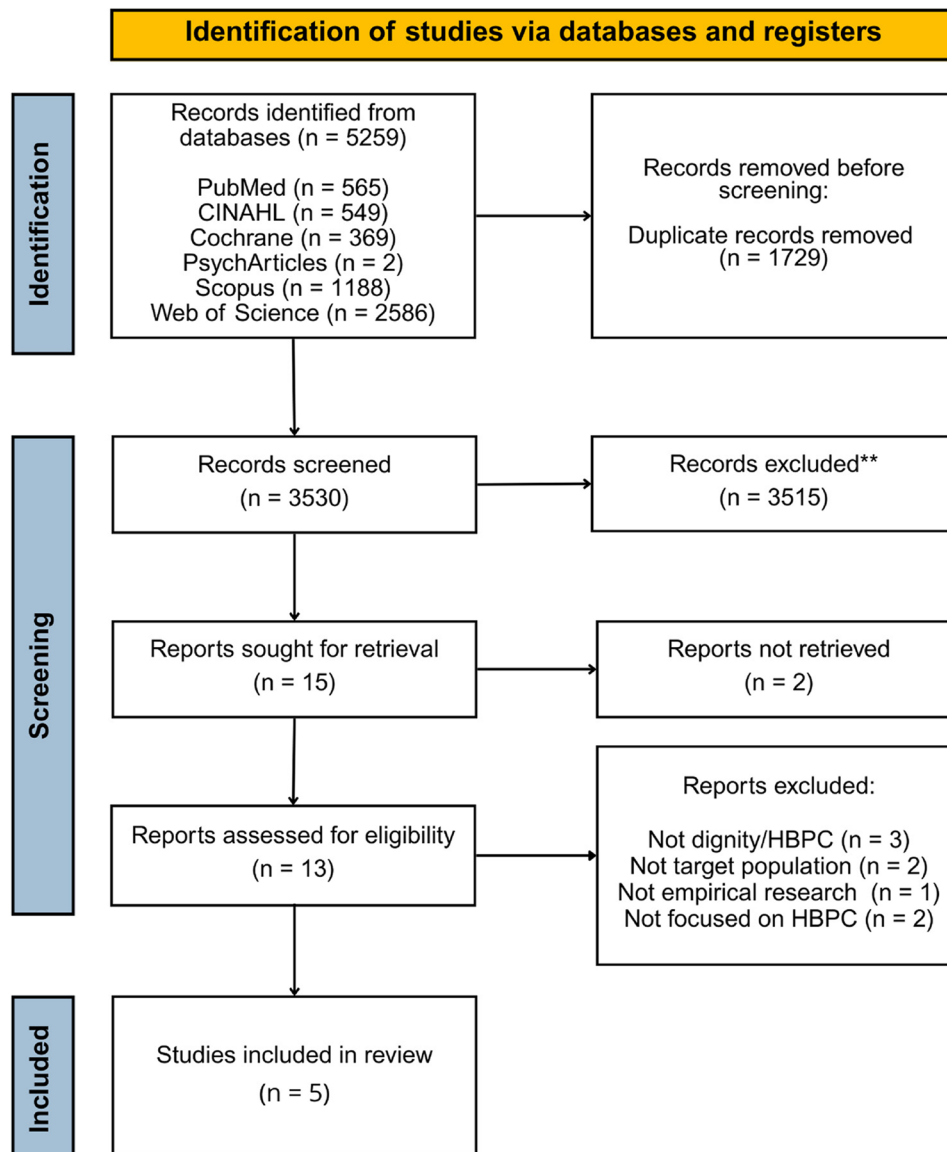
### Results

Five studies met the eligibility criteria of this review (Fig. 1). They were published between 2011 and 2022 and used predominantly qualitative methodologies. Studies were conducted in Norway ( $n=2$ ), Sweden ( $n=1$ ), Iran ( $n=1$ ), and Indonesia ( $n=1$ ). One study only involved patients [21], two exclusively involved healthcare professionals [22, 23], and two included family caregivers [24, 25] (Table 2).

To supplement the analysis, a basic qualitative content analysis was performed to generate a summary of the frequency count of the main themes, which provided an overview of which dimensions of dignity were most addressed across the stakeholders' perspectives (Table 3).

### Demographic characteristics

A total of 94 participants were included: 25 patients, 5 family caregivers, and 64 healthcare providers. Table 4



**Fig. 1** The PRISMA flowchart of data screening

summarizes the participant demographics, health conditions, and professional backgrounds. Gender information for healthcare professionals [22, 23, 25] and age information for family caregivers were reported only in a subset of studies [21]; therefore, the corresponding percentages reflect available cases.

The patients were predominantly female (84.0%) and presented conditions such as stroke, brain tumors, chronic kidney disease, diabetes mellitus, heart failure [24], and cancer [21, 25]. Ages ranged from 43 to 83 years, with almost half (47.4%) between 70 and 80 years [21, 24]. Healthcare professionals included nurses [22, 23, 25], physicians [23, 25], social workers, psychologists, nursing assistants, and chaplains [25], mostly aged between 40 and 60 years ( $n=27$ ; 73.0%) [23, 25]. All

family caregivers reported were male [24, 25]; only one study reported an age of 63 years [24].

The included studies explored how dignity is perceived and preserved in this context. Healthcare professionals in Sweden emphasized that safety, autonomy, and personal integrity are central to preserving dignity at the end of life at home [22]. In Iran, professionals identified a lack of infrastructure and insufficient organizational support as major barriers to dignified home-based palliative care [23]. In Norway, older women with incurable cancer associated dignity with autonomy, hope, and being valued, while loss of control and social alienation were linked to diminished dignity [21]. In Indonesia, patients and caregivers reported that dignity fluctuates with disease progression and is reinforced by respect and support from

**Table 2** Methodological characteristics of the included studies

Author/Year	Country	Aim	Design	Participants	Finding
Karlsson and Berggren (2011) [22]	Sweden	To describe the factors contributing to dignified end-of-life care at home	Hermeneutic phenomenological qualitative study with interviews.	10 healthcare professionals	Identified that respect for safety, autonomy, and personal integrity are fundamental elements for preserving dignity.
Heydari et al. (2019) [23]	Iran	To explore healthcare professionals' perceptions of HBPC for terminally ill cancer patients.	Qualitative study with individual interviews and one focus group.	25 healthcare professionals	Organizational lack of infrastructure and insufficient organizational support are significant barriers to dignity.
Staats et al. (2021) [21]	Norway	To explore the experiences of dignity and loss of dignity among older women with incurable cancer receiving care at home.	Descriptive qualitative study with individual interviews.	13 patients	Dignity is closely linked to autonomy in decision-making, the preservation of hope, and the experience of being valued.
Wulandari and Arianti (2021) [24]	Indonesia	To investigate the dignity of adult patients with palliative care needs at home.	Phenomenological qualitative study with interviews and observation.	6 patients, 1 family caregiver	The perception of dignity fluctuates with disease progression and the attitudes of family and professionals. Respect and support strengthen dignity.
Staats et al. (2022) [25]	Norway	To explore healthcare professionals' perceptions of dignity-preserving care for older women with incurable cancer at home.	Exploratory qualitative study with focus group.	6 patients, 4 family caregivers, 29 healthcare professionals	The perception of dignity fluctuates with disease progression and the attitudes of family and professionals. Respect and support strengthen dignity.

**Table 3** Frequency of thematic categories across studies

Thematic Category	Stakeholder Perspective(s)	No. of Studies Mentioning Theme
Autonomy and decision-making	Patient, Professional	5
Emotional and spiritual support	Patient, Family	4
Communication challenges	Family, Professional	4
Pain and symptom control	Professional	3
Infrastructure and access	Professional, Family	3
Legacy and meaning	Patient	2
Interprofessional collaboration	Professional	2

family and professionals [24]. Finally, a subsequent Norwegian study highlighted the importance of autonomy, personalized and gender-sensitive care, and interprofessional collaboration in sustaining dignity at home [25].

Although dignity was not the explicit focus of Heydari et al. [23], this study was retained in the review, as it investigated healthcare providers' perceptions of home-based palliative care for terminally ill patients in Iran. These

views included essential dimensions inherently related to dignity, such as autonomy, end-of-life communication, spiritual support, and organizational barriers. Moreover, the study's conclusion explicitly refers to the importance of enabling patients to "experience death with dignity," thus confirming its thematic relevance. The inclusion of this study was considered important for two reasons: (i) it contributes to cultural diversity by incorporating evidence from a Middle Eastern context, and (ii) it aligns with the exploratory nature of scoping reviews, which aim to map the available literature, encompassing studies that may tangentially or implicitly relate to the central theme.

The main factors that support and undermine dignity in HBPC, organized by stakeholder group, are summarized in Table 5. This comparative structure provides a clearer synthesis of how each stakeholder contributes to or inhibits the preservation of dignity at home.

A conceptual diagram of thematic interactions was elaborated (Fig. 2), facilitating a more intuitive understanding of how dignity is co-constructed in HBPC."

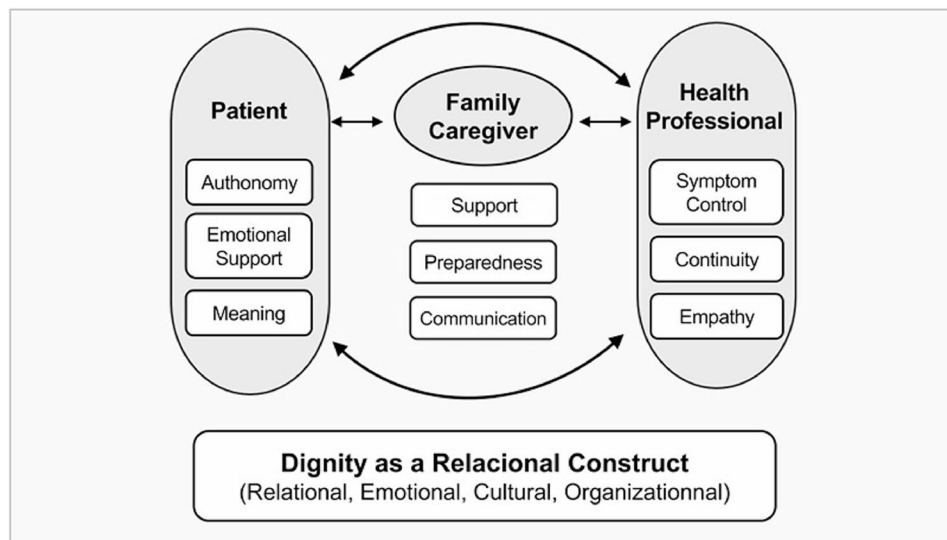
**Table 4** Participant characteristics of the included studies

Category	Total (n)	Female (n, %) <sup>a</sup>	Male (n, %) <sup>a</sup>	Age group (years) <sup>a</sup>	Health conditions	Professions
Patients	25	21 (84.0%)	4 (16.0%)	43–83	Stroke, brain tumor, chronic kidney disease, diabetes mellitus, heart failure, cancer	-
Family caregivers	5	0 (0.0%)	5 (100.0%)	63 (one study)	-	-
Healthcare professionals	64	39 (67.2%)	19 (32.8%)	33–60	-	Nurses, doctors, social workers, psychologists, nursing assistants, and chaplains

<sup>a</sup>Gender data for healthcare professionals [22, 23, 25] and age information for family caregivers [21] were reported only in a subset of studies; percentages reflect available cases

**Table 5** Summary of factors influencing dignity in HBPC

Stakeholder	Factors Supporting Dignity	Factors Undermining Dignity
Patient	<ul style="list-style-type: none"> <li>- Autonomy in decision-making</li> <li>- Emotional support</li> <li>- Preservation of identity</li> <li>- Hope and meaning</li> <li>- Welcoming environment</li> </ul>	<ul style="list-style-type: none"> <li>- Loss of autonomy</li> <li>- Excessive dependence</li> <li>- Lack of control</li> <li>- Hopelessness</li> <li>- Privacy violations</li> </ul>
Family Caregiver	<ul style="list-style-type: none"> <li>- Emotional and physical support</li> <li>- Respect for patient preferences</li> <li>- Promotion of independence and self-esteem</li> <li>- Clear communication</li> </ul>	<ul style="list-style-type: none"> <li>- Emotional burden</li> <li>- Lack of preparedness</li> <li>- Communication difficulties</li> <li>- Uncontrolled symptoms</li> </ul>
Healthcare Professional	<ul style="list-style-type: none"> <li>- Pain control</li> <li>- Continuity of care</li> <li>- Respect for autonomy and integrity</li> <li>- Personalized, gender-sensitive care</li> <li>- Interprofessional collaboration</li> </ul>	<ul style="list-style-type: none"> <li>- Lack of infrastructure</li> <li>- Inadequate training</li> <li>- Negligence</li> <li>- Poor communication</li> <li>- Excessive interference in autonomy</li> </ul>



**Fig. 2** Conceptual model of dignity dynamics in HBPC

**Discussion**

This is, to our knowledge, the first scoping review to provide a multidimensional overview of how HBPC affects patient dignity, drawing on the perspectives of patients, family caregivers, and healthcare professionals. The findings reveal both protective and risk factors and indicate that dignity in HBPC is a complex, multifactorial construct shaped by relational, structural, and cultural factors.

**Theoretical models of dignity**

The results align with and expand upon three key theoretical models of dignity. Chochinov’s Dignity Model offers a foundational framework, organizing dignity-related experiences into three domains: illness-related concerns, a dignity-conserving repertoire, and social dignity inventory [6]. Our findings reflect these domains, particularly in the emphasis on autonomy, meaning-making, and relational respect.

Complementing this, the reciprocity model conceptualizes dignity as co-constructed through interpersonal interactions [26]. This perspective is especially relevant in HBPC, where the boundaries between personal and clinical spaces are blurred, and dignity is negotiated daily through communication, empathy, and shared decision-making.

In contrast, the unidimensional model—which views dignity as an intrinsic, individual attribute [27]—was challenged by our findings. Instead, dignity emerged as dynamic and context-dependent, influenced by the quality of care, the nature of family relationships, and the presence or absence of systemic support.

**Multidimensional nature of dignity in HBPC**

The findings reinforce the view of dignity in HBPC as a multidimensional construct shaped by clinical practices, relational dynamics, and systemic conditions. It is preserved through empathetic communication, symptom

control, respect for autonomy, and recognition of family relationships, while caregiver burden, loss of autonomy, and systemic failures contribute to its erosion. These results align with prior evidence showing that dignity is sustained when patients retain decision-making power, find personal and spiritual meaning, and are supported in leaving a legacy [28]. Interventions such as dignity therapy have demonstrated efficacy in enhancing personal worth, hope, and spirituality at the end of life, further validating the relevance of these dimensions in HBPC contexts.

Communication emerged as a central element across all dimensions of dignity. Clear, respectful dialogue and shared decision-making help prevent misunderstandings and foster agency. Adjusting language around terminality and creating space for active listening are key strategies for maintaining dignity [29]. Practices grounded in the dignity model—such as empathy, active listening, and respect for autonomy—are feasible and effective in home settings, especially when delivered by well-trained inter-professional teams with adequate time for each visit [30].

Importantly, the review exposes a major cultural gap in the literature: the five included studies reflect Western or Asian contexts, excluding Latin American, African, or Indigenous perspectives where dignity may be grounded in collective identity, ancestral ties, or spiritual narratives. These omissions limit the cultural applicability of the findings and highlight the pressing need for inclusive, localized research.

#### **Role of healthcare professionals**

Healthcare professionals play a pivotal role in either preserving or undermining dignity. Practices such as pain control, continuity of care, and respect for patient autonomy were consistently associated with dignity preservation. Conversely, lack of infrastructure, inadequate training, and poor communication were identified as dignity-eroding factors. Notably, the absence of explicit discourse on dignity in clinical routines suggests a need for deeper conceptual integration into professional training and practice [25].

#### **Family support and spirituality**

Family support emerged as one of the central themes in preserving dignity. Emotional and physical support from family members was consistently associated with dignity preservation, while caregiver burden and lack of preparedness were linked to dignity erosion. These findings are consistent with prior syntheses that underscore the centrality of familial and social support to the well-being of both patients and caregivers, particularly in resource-constrained settings [31]. Furthermore, evidence suggests that faith and family support were key sources of dignity for patients receiving palliative care, as demonstrated by

Sailian et al. (2024). Collectively, these insights reinforce the need for structured caregiver training and psychosocial support interventions aimed at sustaining dignity throughout the palliative trajectory [32].

For family caregivers, dignity-preserving care involves both their essential supportive role and the considerable burden they frequently experience. Evidence indicates that caregiver dignity itself may be affected, particularly when resources or emotional preparation are lacking [33]. At the same time, dimensions such as emotional preparedness and legacy-building—though underexplored in the reviewed studies—highlight the potential for caregiving to foster relational and existential growth when adequate institutional support is provided [33]. These findings reinforce the growing advocacy for caregiver dignity interventions and integrated support mechanisms, especially in settings with limited home-care infrastructure.

#### **Gender patterns in caregiving**

The predominance of female patients and male caregivers observed in the included studies likely reflects the characteristics of these specific samples rather than a universal trend. Evidences indicate that most family caregivers are women, with estimates suggesting that around 70% of caregiving roles are undertaken by females in different settings [34–36]. At the same time, caregiving experiences vary by gender and are shaped by sociocultural context, race/ethnicity, and structural conditions [35, 37]. Taken together, these findings suggest that gender norms influence how dignity is preserved or undermined in HBPC, underscoring the need for more inclusive and gender-sensitive approaches in research and practice.

#### **Comparison with institutional settings**

Compared to institutional settings, HBPC offers both unique opportunities and challenges. While hospitals may provide more structured care environments, the home setting fosters familiarity, identity preservation, and personalized care. However, it also exposes patients and caregivers to infrastructural limitations, emotional burden, and inconsistent professional support. These findings echo previous studies that advocate for integrated care models and community-based resources to ensure continuity and quality of care [38, 39].

#### **Unique contribution of this review**

This review contributes uniquely to the literature by mapping dignity-related experiences across three stakeholder groups—patients, family caregivers, and healthcare professionals—and identifying both protective and risk factors in HBPC. It integrates theoretical models with empirical findings, offering a conceptual foundation for future research and practice. By highlighting the

relational, cultural, and systemic dimensions of dignity, this review advances a more holistic understanding of what it means to preserve dignity in the context of home-based palliative care.

The findings of this review resonate with and expand upon Chochinov's Dignity Model [6]. Factors such as "maintaining control over decisions" and "preserving identity," identified in our analysis, align directly with the model's core themes, such as the continuity of self and role performance. This review also contributes to the model by contextualizing these themes specifically within the home-care setting, illustrating how daily interactions among the patient, family, and healthcare professionals become the primary vehicle through which dignity is either preserved or violated.

On a policy level, this review underscores the urgency of investing in structured HBPC programs, especially in resource-limited settings. Concrete strategies—such as national training programs, caregiver subsidies, and digital coordination tools—can help integrate dignity-based care into everyday practice.

Examples such as the WHO palliative care competencies and the PALLIUM Latin America initiative offer models of how this integration can be adapted to different cultural and economic contexts.

Taken together, the theoretical and practical implications of this review support a shift in palliative care from an exclusively clinical model toward one that explicitly recognizes the relational, emotional, and cultural dimensions of dignity.

### Implications for research

While this review identified essential factors that influence patient dignity in home-based palliative care (HBPC), it also highlighted critical gaps in the current evidence base that must be addressed by future research efforts.

The narrow geographic scope of the included studies (limited to four countries) underscores the need for research in underrepresented contexts, particularly in Latin America, sub-Saharan Africa, and Indigenous communities. These cultural settings may define and enact dignity differently, prioritizing communal belonging, spiritual connection, or ancestral values.

Future reviews should expand their search strategy to include regional databases such as LILACS, SciELO, and African Index Medicus, as well as gray literature repositories such as OpenGrey and institutional archives. This would help capture unpublished studies, policy documents, and government programs that are highly relevant but often excluded from academic indexing systems.

There is also a need for mixed-method and quantitative research to complement the predominantly qualitative findings in this area. Instruments such as the Patient

Dignity Inventory (PDI) or the Dignity Impact Scale could help operationalize and compare outcomes across populations and interventions.

Although formal critical appraisal is not required in scoping reviews, future evidence syntheses would benefit from applying tools such as the CASP checklist for qualitative studies. Doing so may enhance the interpretability of the results and guide best practices in the field.

Greater attention should be given to the concept of "dignity-in-care" as it applies to caregivers and professionals, not just patients. Research exploring how these roles affect and are affected by dignity may help refine support structures and reduce systemic burnout.

Finally, implementation science approaches may be valuable for understanding how dignity-related interventions can be adapted and sustained in different healthcare systems, particularly in resource-limited settings.

In sum, the research agenda on HBPC and dignity should be broadened methodologically, geographically, and epistemologically to reflect a truly global and inclusive understanding of what it means to die with dignity at home.

### Implications for practice

The findings of this scoping review have several practical implications for improving the delivery of dignity-preserving home-based palliative care (HBPC), especially in settings facing limited resources and professional training gaps. There is a clear need to incorporate dignity-related competencies into professional training programs for home-care providers. These include not only technical skills in symptom management but also communication, empathy, active listening, and culturally sensitive care. Institutions could integrate these topics into their continuing education and professional accreditation requirements.

Training should address gender-specific and cultural preferences, especially in relation to older women or patients from collectivist traditions, as indicated in the included studies. It is essential to provide care that respects identity, privacy, and spiritual values.

Structured support systems must be implemented for family caregivers, who often shoulder the emotional and physical burden of care without adequate preparation or recognition. Practical strategies include:

- Short-term training modules on end-of-life care at home.
- Psychological support and respite services.
- Access to professional consultation (telehealth, helplines).
- Legal and financial guidance in care planning.

The organization of HBPC services should be restructured to foster continuity of care, interdisciplinary

coordination, and community engagement. This includes developing integrated care teams (nurses, physicians, social workers, chaplains), digital tools for information sharing, and mobile palliative care units.

Lastly, healthcare systems should establish mechanisms to assess and monitor dignity-related outcomes in routine care through satisfaction surveys, narrative feedback, and dignity-conserving practices checklists.

Together, these measures can enhance the quality, humanity, and cultural appropriateness of end-of-life care at home.

### Limitations

This review has limitations that may affect the generalizability and comprehensiveness of its findings. The small number of included studies ( $n=5$ ) and their geographic concentration (Norway, Sweden, Iran, and Indonesia) limit the generalizability and cultural representativeness. The exclusion of gray literature may have led to the omission of relevant evidence, especially from low- and middle-income countries; the predominance of Western or Asian qualitative studies may have narrowed the conceptual diversity of dignity, potentially overlooking relational or community-oriented meanings emphasized in other cultures. The search strategy was not peer-reviewed by a professional librarian, which may have reduced its comprehensiveness; future reviews will include librarian validation to enhance rigor. In addition, no formal quality appraisal of the included studies was conducted, as per the nature of scoping reviews. Nevertheless, this limits the interpretability of the findings and should be addressed in future systematic reviews through tools such as the CASP checklist. In addition, the search strategy was not peer-reviewed by a professional librarian; future reviews will include librarian validation to enhance methodological robustness. Finally, although thematic frequency analysis was used to enhance synthesis, the findings may still reflect publication and selection biases inherent to indexed literature.

### Conclusion

The role of home-based palliative care (HBPC) on patient dignity is complex and multifactorial, shaped by the interplay of patients, family caregivers, and healthcare professionals. For patients, dignity is closely linked to autonomy, emotional support, and a welcoming environment, while its erosion is associated with loss of control, unmanaged symptoms, and poor communication. Family caregivers contribute to dignity preservation through emotional and physical support; however, caregiver burden and lack of training can negatively affect patients' well-being. Healthcare professionals support dignity by ensuring symptom management, continuity of care, and respect for individual preferences. Nevertheless,

they face barriers related to insufficient infrastructure, limited training, and challenges in interprofessional collaboration.

This review highlights the relational dimension of dignity in HBPC and underscores the importance of interdisciplinary practice, caregiver training and support, and adequate service infrastructure. Mapping both protective and risk factors, it provides a comprehensive view of how dignity is shaped in daily interactions. The comparative analysis of stakeholder perspectives provided valuable insights into the ways dignity is preserved or undermined at the end of life.

While these factors appear to enhance dignity, the evidence remains limited by the small number of available studies, their qualitative focus, and their concentration in specific cultural contexts. Future research should prioritize underrepresented regions, adopt more diverse methodologies, and expand the evidence base by including grey literature and regional databases such as LILACS and SciELO. Strengthening this knowledge is essential to inform practice and policy and to advance a more global understanding of what it means to preserve dignity at the end of life in the home setting.

### Abbreviations

CASP	Critical Appraisal Skills Programme
HBPC	Home-based palliative care
JI	Joanna Briggs Institute
LILACS	Latin American and Caribbean Health Sciences Literature
OSF	Open Science Framework
PCC	Population, Concept, Context
PDI	Patient Dignity Inventory
PRISMA-SCR	Preferred Reporting Items for Systematic Reviews and Meta-Analysis extension for Scoping Reviews
PROSPERO	International Prospective Register of Systematic Reviews
SCIELO	Scientific Electronic Library Online
WHO	World Health Organization

### Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12904-025-01884-2>.

Supplementary Material 1

Supplementary Material 2

### Acknowledgements

The authors would like to thank the Coordination for the Improvement of Higher Education Personnel – Brazil (CAPES), Financing Code 001, for the support provided during the doctoral research period of the first author at the Universidade Católica Portuguesa. We also acknowledge the contribution of interdisciplinary reviewers and translators who assisted in processing the literature published in non-English languages.

### Authors' contributions

FV: conceptualization, data curation, formal analysis, investigation, methodology, visualization, writing – original draft. NO: data curation, visualization, writing – review and editing. VA: project administration, supervision, validation, writing – review and editing. ML: conceptualization, methodology, project administration, resources, software, supervision, validation, writing – review and editing.

## Funding

The present work was carried out with the support of the Coordination for the Improvement of Higher Education Personnel - Brazil (CAPES), Financing Code 001, during the doctorate research period of the first author at Universidade Católica Portuguesa (UCP).

## Data availability

No datasets were generated or analysed during the current study.

## Declarations

### Ethics approval and consent to participate

It is not applicable as this is a review article based on secondary data from published papers.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

Received: 22 June 2025 / Accepted: 28 August 2025

Published online: 06 January 2026

## References

- Mushtaq NS. Exploring the patients' and family members' perspectives on home-based palliative care. *Int J Palliat Nurs*. 2024;30:548–55.
- Miranda R, Smets T, De Schreye R, Faes K, Van Den Noortgate N, Cohen J, et al. Improved quality of care and reduced healthcare costs at the end-of-life among older people with dementia who received palliative home care: a nationwide propensity score-matched decedent cohort study. *Palliat Med*. 2021;35:1701–12.
- Hamano J, Takeuchi A, Mori M, et al. Comparison of survival times of advanced cancer patients with palliative care at home and in hospital. *PLoS One*. 2023;18:e0284147.
- Dakessian Sallian S, Salifu Y, Saad R, Preston N. Dignity of patients with palliative needs in the Middle East: an integrative review. *BMC Palliat Care*. 2021;20:112.
- Hadler RA, Goldshore M, Rosa WE, Nelson J. What do I need to know about you? The patient dignity question, age, and proximity to death among patients with cancer. *Support Care Cancer*. 2022. <https://doi.org/10.1007/s00520-022-06938-2>.
- Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. *Soc Sci Med*. 2002;54(3):433–43.
- Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity in the terminally ill: a cross-sectional, cohort study. *Lancet*. 2002;360:2026–30.
- Chua KZY, Quah ELY, Lim YX, et al. A systematic scoping review on patients' perceptions of dignity. *BMC Palliat Care*. 2022;21(1):118.
- Spaho RS, Uhrenfeldt L, Fotis T, Bjerkan J, Gåre Kymre I. Healthcare professionals' experiences of eHealth in palliative care for older people: challenges, compromises and the price of dignity. *Int J Qual Stud Health Well-being*. 2024. <https://doi.org/10.1080/17482631.2024.2374733>.
- Viftrup DT, Hvidt NC, Prinds C. Dignity in end-of-life care at hospice: an action research study. *Scand J Caring Sci*. 2021;35:420–9.
- Griffin JM, Mandrekar JN, Vanderboom CE, et al. Transitional palliative care for family caregivers: outcomes from a randomized controlled trial. *J Pain Symptom Manage*. 2024;68:456–66.
- Salifu Y, Almack K, Caswell G. My wife is my Doctor at home': a qualitative study exploring the challenges of home-based palliative care in a resource-poor setting. *Palliat Med*. 2021;35:97–108.
- Melender H-L, Hökkä M, Kaakinen P, Lehto JT, Hirvonen O. Palliative-care nurses' and physicians' descriptions of the competencies needed in their working units. *Int J Palliat Nurs*. 2022;28:38–50.
- Liang M, Xie X, Pan Y, Cheng ASK, Ye Z. A qualitative meta-synthesis of patient dignity from the perspective of caregivers. *BMC Geriatr*. 2023;23(1):351.
- Peters P MD, Godfrey C, McInerney P, Munn Z, Tricco AC, Khalil H. Scoping reviews. *JBIMan Evid Synthesis*. 2024. <https://doi.org/10.46658/JBIMES-24-09>.
- Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med*. 2018;169:467–73.
- Valentim F, de AC, Capelas MLV. (2025) Dignity in Home Palliative Care: a Scoping Review Protocol. <https://doi.org/10.17605/OSF.IO/T8N7Z>.
- Uzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan—a web and mobile app for systematic reviews. *Syst Rev*. 2016;5:210.
- Aromataris E, Lockwood C, Porritt K, Pilla B, Jordan Z, editors. (2024) *JBIManual for Evidence Synthesis*. <https://doi.org/10.46658/JBIMES-24-01>.
- Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, Britten N, Roen K, Duffy S. (2006) Guidance on the conduct of narrative synthesis in systematic reviews: A product from the ESRC Methods Programme. <https://doi.org/10.13140/2.1.1018.4643>.
- Staats K, Grov E, Husebo B, Tranvåg O. Dignity of older home-dwelling women nearing end-of-life: informal caregivers' perception. *Nurs Ethics*. 2021;28:444–56.
- Karlsson C, Berggren I. Dignified end-of-life care in the patients' own homes. *Nurs Ethics*. 2011;18:374–85.
- Heydari H, Hojjat-Assari S, Almasian M, Pirjani P. Exploring health care providers' perceptions about home-based palliative care in terminally ill cancer patients. *BMC Palliat Care*. 2019;18:66.
- Wulandari BT, Arianti A. The dignity of middle adult palliative patients at home in Bantul. *Open Access Maced J Med Sci*. 2021;9(T4):347–53.
- Staats K, Christensen K, Grov EK, Husebo BS, Tranvåg O. Healthcare professionals' perceptions of dignity-preserving care for older home-dwelling women with incurable cancer in Norway. *J Women Aging*. 2022;34:567–81.
- Choo PY, Tan-Ho G, Dutta O, Patinadan PV, Ho AHY. Reciprocal dynamics of dignity in end-of-life care: a multiperspective systematic review of qualitative and mixed methods research. *American Journal of Hospice and Palliative Medicine*. 2020;37:385–98.
- Kant I. *Fundamentação Da metafísica Da moral*. Campinas, SP: Fundação de Desenvolvimento da Unicamp - Funcamp; 2025.
- Cuevas PE, Davidson P, Mejilla J, Rodney T. Dignity therapy for end-of-life care patients: a literature review. *J Patient Exp*. 2021;8:2374373521996951.
- Sutar R, Chaudhary P. Prognostic disclosure in cancer care: a systematic literature review. *Palliative Care and Social Practice*. 2022;16:26323524221101077.
- Hadler RA, Weeks S, Rosa WE, et al. Top ten tips palliative care clinicians should know about dignity-conserving practice. *J Palliat Med*. 2024;27:537–44.
- Salifu Y, Ekpor E, Bayuo J, Akyirem S, Nkhoma K. Patients' and caregivers' experiences of familial and social support in resource-poor settings: a systematically constructed review and meta-synthesis. *Palliat Care*. 2025. <https://doi.org/10.1177/26323524251349840>.
- Sailian SD, Salifu Y, Preston N. Dignity enhanced through faith & family support in palliative care: a qualitative study. *BMC Palliat Care*. 2024. <https://doi.org/10.1186/s12904-024-01478-4>.
- Yang C, Shen B, Liu J, Zhu H, Xu W. Effectiveness of family dignity intervention for patients in palliative care and their family caregivers—a systematic review and meta-analysis of randomized controlled trials. *Support Care Cancer*. 2025;33:61.
- Kim MJ. Caregiving, gender, and health: the moderating role of age. *Sociol Perspect*. 2023;66:1015–38.
- Cohen SA, Nash CC, Greaney ML. Place-based, intersectional variation in caregiving patterns and health outcomes among informal caregivers in the United States. *Front Public Health*. 2024;12:1423457.
- Pacheco Barzallo D, Schnyder A, Zanini C, Gemperli A. Gender differences in family caregiving. Do female caregivers do more or undertake different tasks? *BMC Health Serv Res*. 2024;24:730.
- Ramirez-Perdomo C, Cantillo-Medina C, Perdomo-Romero A. Time for care: male and female voices based on their caregiving experiences. *Healthcare*. 2024;12(22):2245.
- Brian Cassel J, Kerr KM, McClish DK, Skoro N, Johnson S, Wanke C, Hoefer D. Effect of a Home-Based palliative care program on healthcare use and costs. *J Am Geriatr Soc*. 2016;64:2288–95.
- Roberts B, Robertson M, Ojukwu EI, Wu DS. Home based palliative care: known benefits and future directions. *Curr Geriatr Rep*. 2021;10:141–7.

## Publisher's Note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.