The Effect of Home Palliative Care on Patient Dignity: A Scoping Review

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Abstract

Introduction: Home-based palliative care plays a vital role in preserving the dignity of terminally ill patients and their families. However, the factors influencing this experience from the perspective of patients, family caregivers, and healthcare professionals are not fully understood.

Aim: To map existing evidence on the effects of home-based palliative care on patient dignity, considering the perspectives of patients, family caregivers, and health professionals.

Methods: A literature search was conducted in PubMed, Scopus, Web of Science, Cochrane, CINAHL, and PsycINFO, including studies published until December 2024. Eligible studies addressed dignity in the context of home-based palliative care. Opinion reports, case reports, and gray literature were excluded.

Results: Five studies that used qualitative methods were included. Key factors supporting the preservation of dignity include patient autonomy and self-determination, family support, effective symptom management, and supportive care environments. Challenges include caregiver burden, organizational barriers, and lack of infrastructure in home care services.

Conclusion: Home-based palliative care can contribute to preserving patient dignity when structured support is provided and patient autonomy is respected. However, structural and organizational challenges remain significant barriers. Future research should explore strategies to enhance health service integration and caregiver support to promote humane and equitable home-based palliative care.

INTRODUCTION

Home-based palliative care (HBPC) offers essential support for people with advanced illnesses through a holistic approach to managing complex symptoms. This service is valued because it provides an alternative to hospital stays, which tend to be expensive and result in 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 the dignity of patients is one of the main goals of palliative care, as it helps to alleviate existential suffering and improve the relationships among patients, their families and health providers [4, 5]. Patients whose dignity was violated reported a desire to die and a lower desire to live, in contrast to those whose sense of dignity was preserved [6]. For terminally ill patients, the sense of dignity is influenced by concerns related to their health status, social factors, and the psychological and spiritual dimensions inherent to the individual [7].

Multiple studies have investigated the perception of dignity through various lenses[8–10], yet the home environment reveals specific dynamics because of the intertwined relationships among family caregivers, health professionals and patients. Family caregivers often take on responsibilities that may affect their ability to support patients' dignity[11]. Similarly, healthcare professionals providing HBPC must balance the imperatives of clinical excellence with psychosocial sensitivity[12]. For patients, the quality of the caregiver–patient relationship plays a key role in maintaining dignity, highlighting the need to explore how these dynamics affect dignity preservation[13].

To date, little is known about evidence addressing the intersection between patient dignity, HBPC, and the perspectives of patients, family caregivers, and healthcare providers. A scoping review is particularly suited for investigating such aspects, as it aims to map a wide range of evidence, identify knowledge gaps, and clarify concepts, making it ideal for exploring emerging or underresearched topics[14].

Given the complex dynamics affecting patient dignity in HBPCs highlighted above, this scoping review aims to systematically map and analyze the effects of HBPCs on patient dignity from the perspective of patients, family caregivers, and healthcare professionals in the literature to identify gaps and opportunities for future research.

METHODS

This scoping review was conducted in accordance with the Joanna Briggs Institute (JBI) methodology[14] and reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analysis extension for Scoping Reviews (PRISMA-ScR) guidelines[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[16]. As this review did not involve human participants and used only secondary data, ethics committee approval was not needed.

Research question and eligibility criteria

The central question followed the PCC framework (population, concept, context): What are the effects of home-based palliative care (HBPC) on patient dignity from the perspective of patients, family caregivers, and health professionals?

The eligibility criteria included studies involving patients of any age, family caregivers, or health professionals (populations); studies that explored the effects of HBPC regardless of cultural, geographic, or social setting (context); and studies that focused on patients' dignity (concept). Studies addressing multiple care settings were included only if the home-based context was clearly distinct. Quantitative, qualitative, and mixed-methods studies were considered, as were systematic reviews that met the inclusion criteria, regardless of publication date.

Studies conducted entirely outside the home context, such as hospitals, long-term care institutions or nursing homes, were excluded, as were those that dealt with palliative care in general without focusing on the experience of dignity. Research protocols, editorials, opinion articles, conference abstracts, and full papers that were not available or accessible were also excluded.

Search strategy

The search strategy was developed on the basis of the question of review by two authors and was composed of MeSH terms and uncontrolled terms combined through the Boolean operators AND and OR (Supplementary material I).

The PubMed, CINAHL, Cochrane, PsychArticles, Scopus, and Web of Science electronic databases were searched from inception to 5 December 2024. No language restrictions were applied. If a record was published in a language not spoken by the review team, external translation support was used. The gray literature was not considered for the purposes of this study.

Evidence selection

References retrieved from the searches were imported into Rayyan software[17]. Duplicates were identified and removed by the first author. Two authors reviewed the records on the basis of the examination of the title and abstract blindly and independently (double-blind) based on the eligibility criteria. Differences during the selection process were resolved through discussion until consensus was reached. Full-text screening of potentially eligible studies was conducted by one reviewer and the primary reasons for exclusion were recorded. The search results and inclusion process were documented via the PRISMA-ScR flow diagram[15] (Fig. 1).

Data extraction

Data of interest were manually extracted by one of the reviewers via a customized tool developed in Excel software (Supplementary material II). The extracted information included author/year, country, study objective, method, participants, and central outcomes related to the effects of home care on patient dignity. As the objective was to map all the literature related to the topic, no evaluation of the quality of the evidence was carried out.

Analysis and presentation of data

The analysis process included four stages: (1) detailed reading of the selected articles, (2) identification of relevant information on the basis of the review question, (3) data organization, and (4) assessment of consistency between the data and reported conclusions. The findings were presented through a narrative synthesis.

RESULTS

Five studies met the eligibility criteria of this review (Fig. 1). They were published between 2011 and 2022; used predominantly qualitative methodologies; and were conducted in Norway (n = 2), Sweden (n

= 1), Iran (n = 1), and Indonesia (n = 1). One study included only patients[18], while two exclusively involved health professionals[19, 20] and two included family caregivers [21, 22] (Table 1).

Table 1
Methodological characteristics of the included studies.

Author/Year	Country	Objective	Design	Participants	
				n	Sample
Karlsson and Berggren (2011)[20]	Sweden	To describe factors contributing to dignified end-of-life care at home	Hermeneutic phenomenological qualitative study with interviews.	10	Healthcare professionals
Heydari *et al.* (2019)[21]	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
Staats *et al.* (2021)[19]	Norway	To explore 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
Wulandari and Arianti (2021)[22]	Indonesia	To investigate the dignity in adult patients with palliative care needs at home.	Phenomenological qualitative study with interviews and observation.	6 1	Patients Family caregiver
Staats *et al.* (2022)[23]	Norway	To explore health professionals' perceptions of dignity-preserving care for older women with incurable cancer at home.	Exploratory qualitative study with focus group.	6 5 29	Patients CF Healthcare professionals

In total, 94 individuals participated in the studies, which were distributed among patients (n = 25), family caregivers (n = 5) and health professionals (n = 64). Table 2 presents details on the participants’ age ranges, health conditions, and professional backgrounds. Gender data were drawn from Staats *et al.*[18, 22] and Wulandari and Arianti[21].

Table 2
Participant characteristics of the included studies.

Category	Total (n)	Female (n)	Male (n)	Age group (years)	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%)	-	-	-
Healthcare professionals	64	39 (67,2%)	19 (32,8%)	33–60	-	Nurses, doctors, social workers, psychologists, nursing assistants, chaplain

Patients were predominantly female (84.0%) and had health conditions such as stroke, brain tumors, chronic kidney disease, diabetes mellitus, heart failure[21] and cancer[18, 22]. In studies reporting participant age or age range[18, 21], the participants were adults aged between 43 and 83 years, with nearly half (47.4%) between 70 and 80 years. Health professionals include nurses[19, 20, 22], physicians[20, 22], social workers, psychologists, nursing assistants and chaplains[22]. In studies that reported the age or age group[20, 22], most professionals were between 40 and 60 years of age (n = 27; 73.0%). In studies involving family caregivers, all participants were male [21, 22]; only one study reported an age of 63 years [21].

The studies addressed different aspects of dignity in home-based palliative care, drawing on the perspectives of patients, caregivers, and healthcare professionals. Karlsson and Berggren[19] reported that patient dignity in HBPCs is preserved when safety, autonomy and integrity are respected. Pain management, continuity of care, and respect for individual preferences were highlighted as essential to ensure dignified care, while the lack of these components can compromise dignity, generating physical and emotional suffering for patients.

Heydari *et al.*[20] highlights that infrastructure and organizational support impact the dignity of terminally ill cancer patients. While HBPC offers comfort and family closeness, the lack of cooperation and service infrastructure for end-of-life care was seen as a barrier. Government support is considered essential for effective and well-structured HBPCs, making it a cost-effective and advantageous option for patients.

Staats *et al.*[18] examined the experiences of older women with incurable cancer receiving care at home. Maintaining decision-making control, finding hope and meaning despite illness, feeling valued, and living in a welcoming environment were seen as dignity-preserving factors. Conversely, loss of self-determination, hopelessness, privacy violation, and feelings of alienation compromise quality of life and well-being. Interactions with family members and health professionals were seen as necessary to maintain dignity, suggesting that the quality of care outweighs the importance of physical location in the final days.

Wulandari and Arianti[21] explored how family relationships influence patient dignity on the basis of patient and caregiver perspectives. Emotional and physical support, autonomy in decision-making, and perceived quality of life shaped patients' sense of dignity. A fluctuating sense of dignity was observed depending on disease progression and how patients were perceived by family and health care providers. Patients who felt supported and valued expressed a greater sense of dignity, whereas those who suffered from neglect or lack of communication expressed feelings of vulnerability and loss of mastery over their lives. Although dependence due to chronic diseases compromises dignity, home care contributes to increasing independence and self-esteem. Active listening and respect for patient preferences helped them feel valued and understood, whereas psychological and emotional support helped reduce their feelings of uselessness and loss of control and reinforced their dignity throughout the care process.

Staats and colleagues [22] reported that while the term dignity was not commonly used in healthcare professionals' daily vocabulary, it was recognized as a guiding principle when caring for older women at home. Dignity-preserving home care emphasizes personal identity, a sense of home, autonomy and gender-sensitive preferences. Professionals also reported challenges in delivering such care, emphasizing the importance of interprofessional collaboration to ensure the quality of end-of-life care. The authors advocate integrating gender perspectives into professional training and public health policies.

The main factors that modulate patient dignity during HBPC are summarized in Tables 3 and 4.

Table 3
Factors that support dignity in home-based palliative care.

Perspective	Key aspects	Authors
Patient	Maintaining decision-making control, emotional support, preserving identity, living in a welcoming environment	Staats *et al.*[19] Wulandari and Arianti[22]
	Autonomy in decision-making, hope, psychological support.	Staats *et al.*[19] Karlsson and Berggren[20]
Family Caregiver	Offer emotional and physical support, respect patient wishes, promote independence and self-esteem.	Staats *et al.*[19] Wulandari and Arianti[22]
	Clear communication, active listening to value the patient.	Wulandari and Arianti[22]
Healthcare Professional	Ensure pain control, continuity of care, respect for the patient's autonomy and integrity.	Karlsson and Berggren[20] Staats *et al.*[23]
	Team collaboration, personalized care respecting gender and individual preferences.	Staats *et al.*[23] Heydari *et al.*[21]
	Psychological support, family closeness, respect for basic needs	Heydari *et al.*[21] Staats *et al.*[19]

Table 4
Factors that undermine dignity in home-based palliative care.

Perspective	Key aspects	Authors
Patient	Loss of autonomy, excessive dependence, lack of control over personal decisions.	Staats *et al.*[19] Wulandari and Arianti[22]
Family Caregiver	Uncontrolled physical and emotional pain, hopelessness, privacy violation.	Karlsson and Berggren[20] Staats *et al.*[19]
	Emotional burden, lack of preparedness for disease progression, difficulty in maintaining communication.	Wulandari and Arianti[22] Heydari *et al.*[21]
Healthcare Professional	Negligence, absence of dialog and support, excessive interference in the patient's autonomy.	Wulandari and Arianti[22]
	Lack of infrastructure and organizational support, barriers to interprofessional collaboration.	Heydari *et al.*[21] Staats *et al.*[23]
	Inadequate training in palliative care, respect for dignity.	Staats *et al.*[23]
	Lack of clear communication with patients and families, making it difficult to make decisions.	Staats *et al.*[19] Wulandari and Arianti[22]

DISCUSSION

To our knowledge, this is the first scoping review to provide a comprehensive overview of the effects of HBPC on patient dignity, incorporating the perspectives of patients, family caregivers, and healthcare professionals. Although HBPC has been widely investigated in palliative care research, the articles included in this review revealed that dignity in this context is multifactorial and suffers from the effects of the ecosystem constituted by the interactions between these actors.

Our findings indicate that patient dignity in HBPC is a multidimensional phenomenon, supported by practices that recognize the uniqueness of the patient, value the role of family caregivers, and require well-trained interprofessional teams. Dignity is preserved through empathetic communication, adequate pain control, respect for autonomy, and appreciation of family relationships. In contrast, dignity is undermined by a loss of autonomy, caregiver burden, and structural or communicative failure within the care system.

From the patients' perspective, systematic reviews have shown that dignity is sustained through maintaining decision-making control, finding personal and spiritual meaning, and leaving a legacy for loved ones. Interventions such as dignity therapy have been demonstrated to be effective in enhancing the sense of personal worth, hope, and spirituality at the end of life[23]. Furthermore, the dynamic reciprocity model of dignity highlights the role of interpersonal connection, compassion, and culturally sensitive care in addressing existential suffering[24].

With respect to family caregivers, recent studies support our findings by showing that dignity at home is influenced by interventions that enhance patients' spiritual well-being, sense of purpose, and hope[25]. The preservation of dignity is strongly linked to emotional preparedness for death and the desire to leave a legacy, aspects not mentioned in the reviewed studies[23]. These findings challenge the unidimensional view of the caregiving experience as solely burdensome and point to its potential as a space for personal and relational growth, provided that institutional support is available.

In relation to healthcare professionals, the challenges identified in the included studies—such as lack of infrastructure, inadequate training, and the absence of dignity as an explicit concept in daily practice—remains current. Interprofessional collaboration is equally essential. Integrated and interdisciplinary HBPC models have been identified as effective in ensuring quality care, reducing unnecessary hospitalizations, and addressing the physical, emotional, and spiritual needs of patients and families[26]. These models rely on effective communication, shared therapeutic goals, and ongoing team training.

Moreover, dignity is often implicitly understood in clinical practice, but deeper conceptual understanding is needed to guide ethical and sensitive care. Collaboration across interdisciplinary teams and the development of relational competencies are vital to providing dignified care at home[24]. Communication is essential in all dimensions of dignity, as clarity in information and respect for patient preferences help prevent misunderstandings and promote shared decision-making. Adjusting language around terminality and creating spaces for active listening are key to preserving dignity at the end of life[27].

Finally, the literature emphasizes that clinical practices based on the dignity model — such as active listening, empathy, and respect for autonomy — are possible and effective even in the home setting. This is particularly the case when they are delivered by well-trained teams with sufficient time for each visit[28].

Implications for Research

While our review identified key factors affecting patient dignity, it also revealed a significant gap in the literature concerning cultural and socioeconomic influences on these experiences, underscoring the need for more diverse and inclusive research in this domain. The reviewed studies were conducted primarily in Western and Asian contexts. In addition, quantitative studies may help measure the impact of different home-based care interventions on patient dignity, complementing the qualitative evidence currently available. Another relevant research area involves the development and evaluation of support programs for family caregivers to reduce the emotional and physical burdens associated with caregiving at home. Further studies are needed to explore the influence of public policy in preserving dignity in home care, strategies to increase patient participation in decision-making, cross-cultural perspectives on dignity in palliative care, and the impact of socioeconomic conditions on access to dignified care. Future systematic reviews should investigate effective interventions to minimize organizational barriers and ensure continuity of care in home-based settings.

Implications for Practice

One of the key practical implications is the need for training healthcare professionals to address the emotional and existential needs of patients and family caregivers, ensuring patient-centered and compassionate care. In addition, strategies to support family caregivers should include targeted training, psychological support programs, and the implementation of home care services designed to reduce caregiver burden. Finally, our findings suggest that improved coordination among healthcare teams and community services is essential to ensure that patients receive adequate and continuous care that respects their needs and preferences at the end of life.

CONCLUSION

The effects of home-based palliative care (HBPC) on patient dignity are influenced by factors intrinsic to patients, family caregivers and healthcare professionals. Patients value self-determination, emotional support, and a welcoming environment, whereas loss of autonomy, physical pain, and lack of communication may negatively affect their sense of dignity. Family caregivers play an active role in providing emotional and physical support; however, overload and lack of training can negatively affect patients’ well-being. Healthcare professionals help maintain dignity by ensuring pain control, 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 also emphasized the relational dimension of dignity in home-based palliative care. By identifying both protective and risk factors for dignity, this review offers a more comprehensive understanding of this phenomenon.

The comparative analysis of perspectives provided valuable insight into how dignity is shaped at the end of life. The findings underscore the importance of an interdisciplinary approach, training and supporting family caregivers, and improving the facilities of HBPC services. These insights may inform clinical practice and guide future research aimed at enhancing the dignity of patients receiving HBPC.

However, this review has limitations. With respect to the databases used, it was not possible to exhaust all available sources, which may have resulted in the omission of relevant studies. The number of studies included limits, the breadth of available evidence and the generalizability of the results. Methodological variability among the studies may have hindered data synthesis and reduced comparability. Additionally, most of the studies were conducted in specific geographic settings, which may limit the applicability of the findings to other regions or healthcare systems. Finally, cultural influences on the perception of dignity may be present, given the regional focus of the included studies.

Abbreviations

HBPC : Home-based palliative care

JBI: Joanna Briggs Institute

OSF: Open Science Framework

PCC: Population, concept, context

PRISMA-SCR: Preferred Reporting Items for Systematic Reviews and Meta-Analysis extension for Scoping Reviews

Declarations

Ethics approval and consent to participate

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

Consent for publication

Not applicable.

Availability of data and materials

All data generated or analyzed during this study are included in this published article.

Competing interests

The authors declare no competing interests.

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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.

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Figures

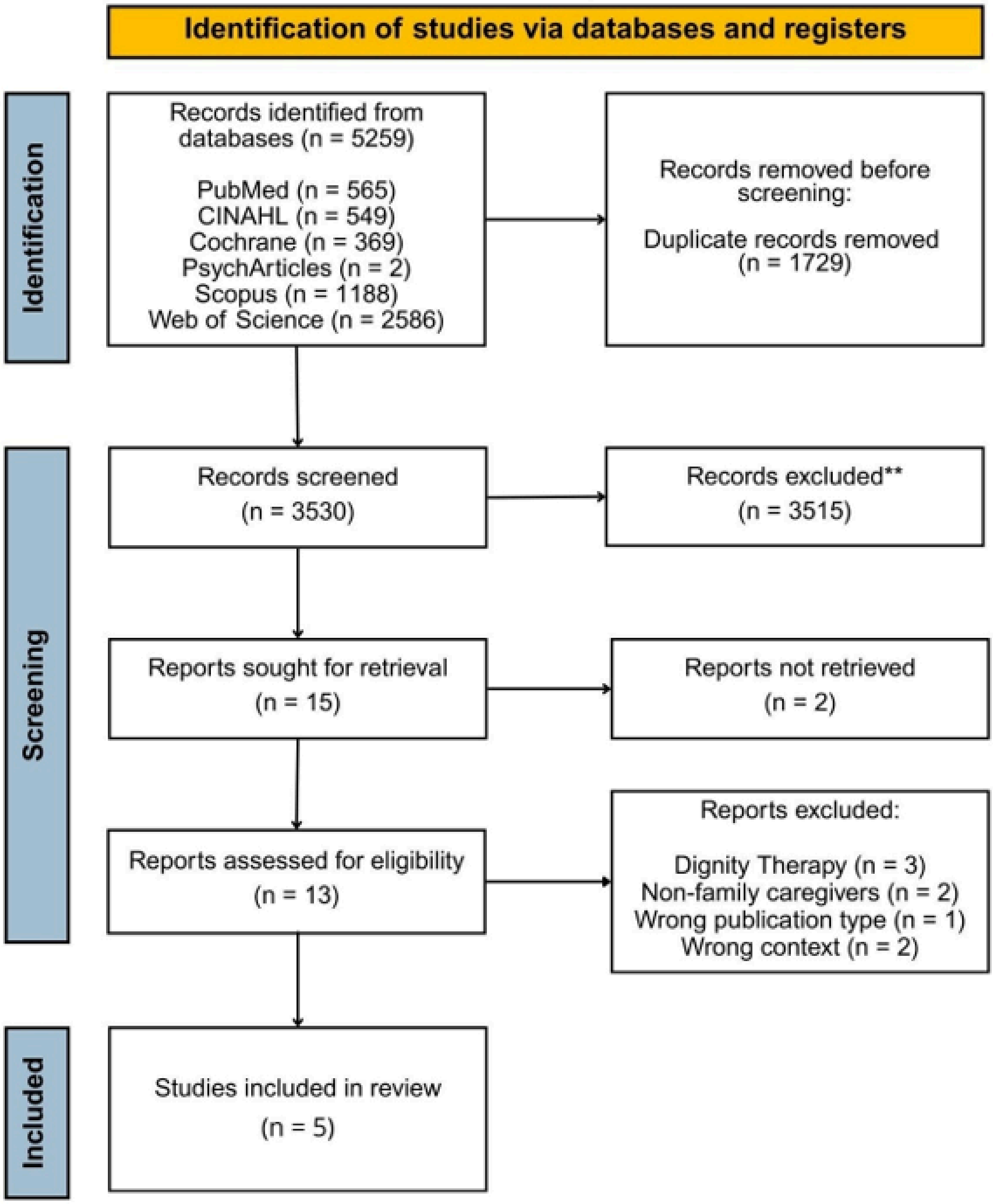

Figure 1

The PRISMA flowchart of data screening.

Supplementary Files

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