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SYSTEMATIC REVIEW ARTICLE

The care process between informal caregivers and patients with palliative care needs at home: Meta-synthesis

Processo de cuidados entre cuidador informal e doente com necessidades paliativas no domicílio: Metassíntese

Proceso de atención entre el cuidador informal y el paciente con necesidades paliativas en el domicilio: metasíntesis

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Abstract

Introduction: Informal caregivers and patients with palliative care needs are essential for a successful home-based care experience. However, little is known about the care process between informal caregivers and these patients.
Objective: To identify the factors that influence the care process between informal caregivers and patients with palliative care needs at home.
Methodology: Meta-synthesis following the Joanna Briggs Institute methodology. We included qualitative studies with informal caregivers and/or patients with palliative care needs at home. We searched MEDLINE, CINHAL, Embase, and Scopus databases (2009-2021).
Results: Thirty studies were included, with 605 participants. Eight main themes emerged: facilitating factors of informal care; complicating factors of informal care; strategies used; the influence of time in care; the influence of disease progression in care; motivations to provide home-based care; continuous learning; and caregiver's roles.
Conclusion: Informal care is a dynamic process where facilitating/complicating factors, strategies, and disease progression are interconnected. The results contribute to understanding the care process and designing person-centered, flexible, and context-sensitive care plans.

Keywords: palliative care; patient; caregivers; home; systematic review

Resumo

Introdução: O cuidador informal e o doente com necessidades paliativas são fundamentais no sucesso dos cuidados no domicílio, porém pouco se sabe sobre o cuidado que decorre entre os dois.
Objetivos: Identificar os fatores que influenciam o cuidado entre o cuidador informal e o doente com necessidades paliativas no domicílio.
Metodologia: Metassíntese seguindo a metodologia *Joanna Briggs Institute*. Incluíram-se estudos qualitativos com a perspetiva de cuidadores informais e/ou doentes com necessidades paliativas no domicílio. Pesquisa nas bases MEDLINE, CINHAL, Embase e Scopus (2009-2021).
Resultados: Incluíram-se 30 estudos com 605 participantes. Surgiram oito temas centrais: fatores facilitadores/ dificultadores dos cuidados informais; estratégias utilizadas; a influência do tempo e da progressão da doença nos cuidados; as motivações para cuidar em casa; as aprendizagens contínuas e as funções do cuidador.
Conclusão: O cuidado informal é um processo dinâmico onde se interligam fatores facilitadores/dificultadores, estratégias e a progressão da doença. Os resultados permitem compreender a experiência de cuidar e estruturar cuidados centrados na pessoa, flexíveis e adaptados ao contexto.

Palavras-chave: cuidados paliativos; doente; cuidadores; domicílio; revisão sistemática

Resumen

Introducción: El cuidador informal y el paciente con necesidades paliativas son fundamentales para el éxito de los cuidados a domicilio, pero se sabe poco sobre la atención que se presta entre ambos.
Objetivos: Identificar los factores que influyen en la atención entre el cuidador informal y el paciente con necesidades paliativas en el domicilio.
Metodología: Metasíntesis siguiendo la metodología *Joanna Briggs Institute*. Se incluyeron estudios cualitativos con la perspectiva de cuidadores informales y/o pacientes con necesidades paliativas en el domicilio. Búsqueda en las bases MEDLINE, CINHAL, Embase y Scopus (2009-2021).
Resultados: Se incluyeron 30 estudios con 605 participantes. Surgieron ocho temas centrales: factores que facilitan / dificultan los cuidados informales; estrategias utilizadas; influencia del tiempo y de la progresión de la enfermedad en los cuidados; motivaciones para cuidar en casa; aprendizaje continuo y funciones del cuidador.
Conclusión: Los cuidados informales son un proceso dinámico en el que se incluyen factores que facilitan / dificultan, estrategias y progresión de la enfermedad. Los resultados permiten comprender la experiencia de cuidar y estructurar unos cuidados centrados en la persona, flexibles y adaptados al contexto.

Palabras clave: cuidados paliativos; enfermo; cuidadores; comunidade; revisión sistemática

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Introduction

According to the World Health Organization, about 56.8 million people worldwide required palliative care (PC) in 2017 (Connor, 2020). Many people prefer to be cared for and die at home, a desire shared by caregivers and patients with palliative care needs (Gomes et al., 2013). Patients and their informal caregivers play a key role in the success and continuity of care at home (Martín et al., 2016; Robinson et al., 2017). Informal caregivers are family members or significant persons who provide regular, non-specialized (Lei n.º 52/2012, 2012), and unpaid care (Figueiredo, 2007). A patient with palliative care needs is a person with a serious, complex, progressive, or life-threatening chronic illness (Connor, 2020; Gómez-Batiste & Connor, 2017).

Patients and families have highly complex care needs (Wu et al., 2020). Previous systematic reviews have provided insights into caregivers' physical and emotional burden, roles, and experiences (Martín et al., 2016; Wu et al., 2020); the support from healthcare teams (Martín et al., 2016; Sarmento et al., 2017); and the financial costs of home-based care (Gardiner et al., 2015). However, most studies focus on caregivers' perspectives rather than on a patient-caregiver complementary perspective.

This review aims to answer the following question: "What influences the care process between informal caregivers and patients with PC needs at home?". The following specific objectives were established to identify the factors influencing the care process between caregivers and patients at home: i) To identify the factors that facilitate or hinder informal care; ii) To identify the strategies used; iii) To understand if and how the disease trajectory influences the process.

Systematic review method

The Joanna Briggs Institute (JBI) approach to meta-aggregation (Aromataris & Munn, 2020) was used to synthesize qualitative evidence. Inclusion and exclusion criteria were established according to the PICo strategy: Population (P) - patients with PC needs and informal caregivers; Phenomenon of Interest (I) - factors that facilitate or hinder the care process; strategies used; association between disease trajectory and care process; and Context (Co) – Home-based settings. Inclusion criteria were as follows: (1) Studies that described the experience of informal care by caregivers and/or patients with PC needs (studies with only one of them could be included as long as they focused on informal care); (2) Home-based settings; (3) Empirical studies with a qualitative approach; (4) Between January 2009 and August 2021; (5) In English, Portuguese, or Spanish. Exclusion criteria were: (1) Focus on formal care; (2) Quantitative or mixed-methods; (3) Participants aged < 18 years; (4) In hospital settings, PC units, or other institutions.

Search strategy for identification of studies

A three-step strategy was used (Aromataris & Munn, 2020): i) Initial search limited to MEDLINE and CINAHL databases, followed by analysis of the words in the title and abstract of the articles, as well as the index terms. Then, the descriptors were combined with Boolean operators, and the index terms were linguistically adapted to the several databases, resulting in the following Boolean phrase:

PubMed/MEDLINE*: ([terminally ill (MeSH) OR palliative patient OR careg* (MeSH) OR family (MeSH) OR relatives] AND [informal care OR family careg* OR home based palliative care] AND [factors OR obstacle OR barrier OR facilitator OR experienc* OR perspective OR perception OR aspects OR predictor] AND [home (MeSH) OR home nursing (MeSH) OR palliative home care OR community] and [qualitative research OR qualitative.mp. OR grounded theory OR phenomenology OR ethnography OR interview]) NOT ([child* AND pediatric]).*

CINAHL;EMBASE; SCOPUS: (*[terminally Ill Patients (SH) OR palliative patient OR careg* (SH) OR family (SH) OR extended Family (SH] AND [informal care OR family caregiving] AND [factors OR obstacle OR barrier OR facilitator OR experienc* OR perspective OR perception (MH) OR aspects] AND [home OR home nursing (SH) OR palliative home care] AND [qualitative studies (SH) OR qualitative$ OR grounded theory (SH) OR phenomenology (SH) OR Phenomenological Research (SH) Ethnographic Research (SH)] NOT [child* AND pediatric].)*

ii) Systematic search in MEDLINE/PubMed, CINHAL, EMBASE, and SCOPUS databases. The search was limited to studies published between January 2009 and August 2021 because it was a period of increasing awareness of the importance of informal care (Hudson et al., 2011). Additionally, grey literature (master's and doctoral theses) was searched using the Open Access Scientific Repository of Portugal. iii) The reference lists of included articles were analyzed, and more relevant studies were retrieved. Mendeley® was used for reference management.

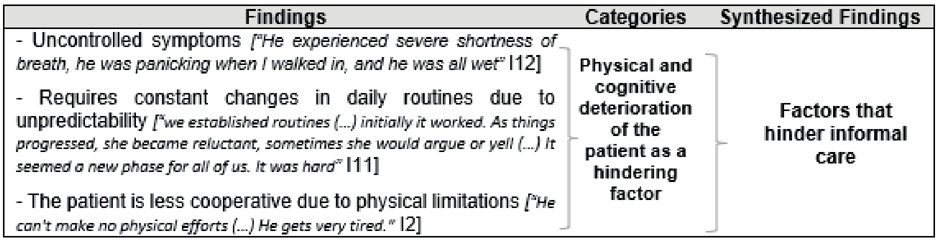
Two independent reviewers selected the studies based on the inclusion and exclusion criteria and PRISMA guidelines (Page et al., 2021). The first screening stage was based on information in the titles and abstracts. Eligible studies were retrieved in full for a second screening stage. Any disagreements between reviewers were resolved through discussion and consensus. The quality of the studies was assessed using the 10-question Critical Appraisal Skills Programme (CASP) tool (Critical Appraisal Skills Programme, 2018) with 10 questions. The first two questions are screening questions. Only studies that scored "yes" on these two questions were appraised.

Data extraction, synthesis, and analysis

Following the recommendations of COREQ (Tong et al., 2007) and JBI (Aromataris & Munn, 2020), a Microsoft Excel® table was created with the following information about each study: author(s), year, country, objectives, participants, context, and type of study. Then, each study was reread, and data were extracted, which JBI defines as findings. Each finding was accompanied by an illustration – direct quotations from the study or other supporting data. The level of credibility between the findings and their illustrations was rated as Unequivocal, Credible, or Not Supported (Aromataris & Munn, 2020). Unequivocal and credible findings and illustrations were synthesized, coded line by line based on their meaning and content, and aggregated into categories. The categories were subjected to repeated reading and comparative analysis and aggregated to form synthesized findings - major themes (Aromataris & Munn, 2020; Figure 1). All steps were conducted by the first author and validated by the second author. NVivo12® software was used for data management and analysis.

Figure 1

Example of the data synthesis process



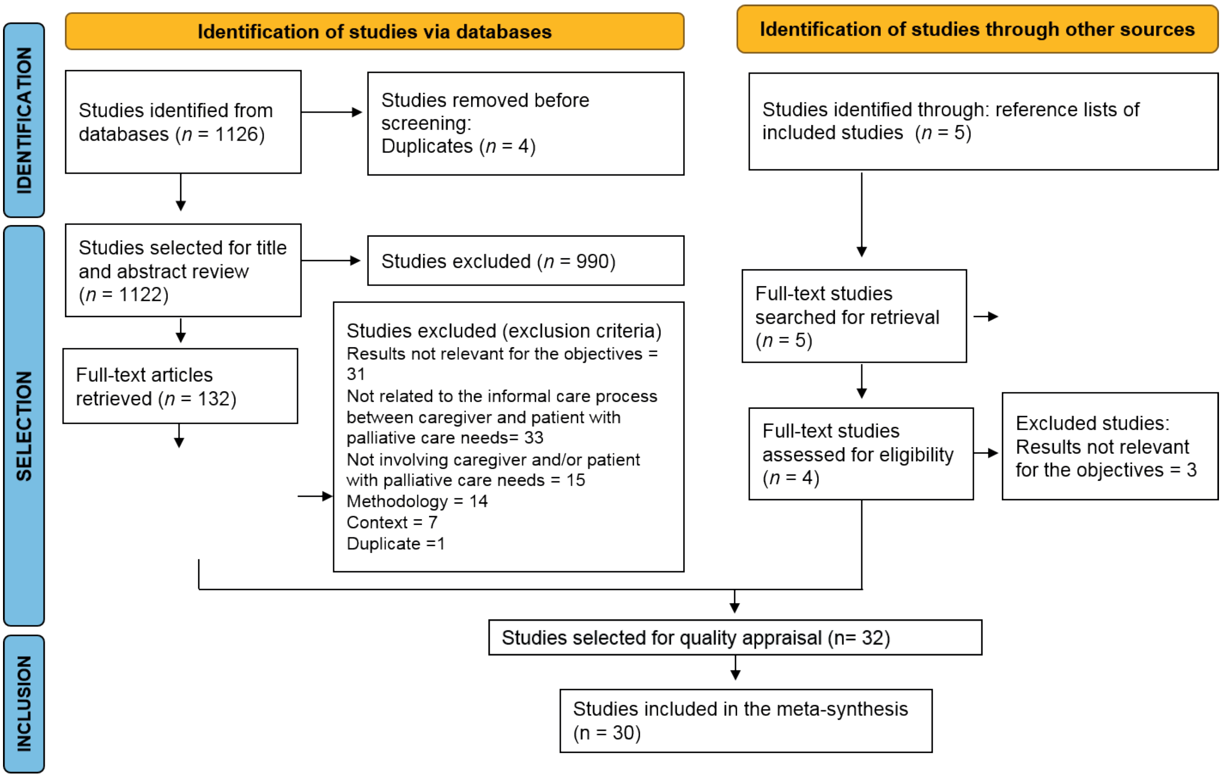
Findings	Categories	Synthesized Findings
- Uncontrolled symptoms *["He experienced severe shortness of breath, he was panicking when I walked in, and he was all wet"* I12] - Requires constant changes in daily routines due to unpredictability *["we established routines (...) initially it worked. As things progressed, she became reluctant, sometimes she would argue or yell (...) It seemed a new phase for all of us. It was hard"* I11] - The patient is less cooperative due to physical limitations *["He can't make no physical efforts (...) He gets very tired."* I2]	**Physical and cognitive deterioration of the patient as a hindering factor**	**Factors that hinder informal care**

Presentation of results

Thirty studies were included. The search, identification, and eligibility process is shown in the PRISMA 2020 flow diagram (Page et al., 2021; Figure 2). Two studies were excluded for not scoring "yes" on the first two questions of the 2018 CASP checklist. Among those included, eight scored positively on all items. None scored inconclusively or negatively in more than two items (Table 1).

Figure 2

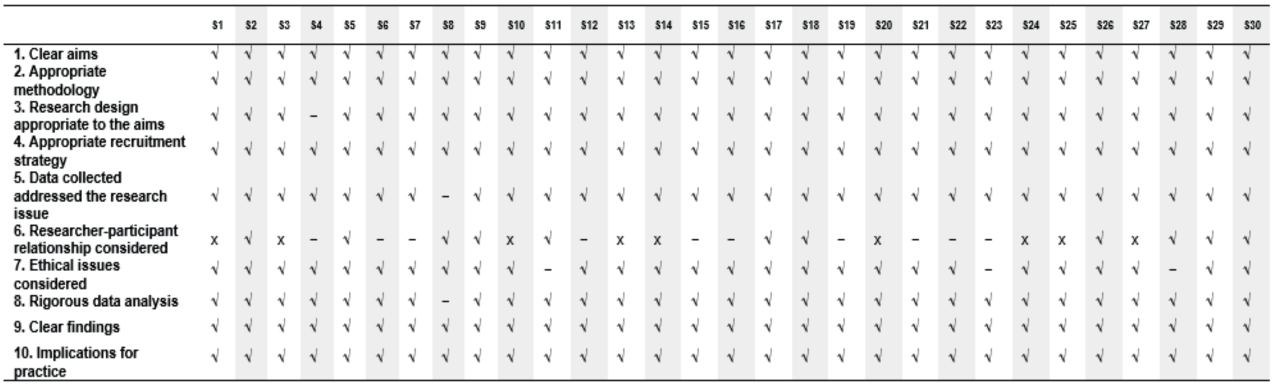
PRISMA 2020 flow diagram of the search strategy



Source: Adapted from (Page et al., 2021)

Table 1

Quality appraisal of included studies (CASP, 2018)



	S1	S2	S3	S4	S5	S6	S7	S8	S9	S10	S11	S12	S13	S14	S15	S16	S17	S18	S19	S20	S21	S22	S23	S24	S25	S26	S27	S28	S29	S30
1. Clear aims	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
2. Appropriate methodology	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
3. Research design appropriate to the aims	√	√	√	–	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
4. Appropriate recruitment strategy	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
5. Data collected addressed the research issue	√	√	√	√	√	√	√	–	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
6. Researcher-participant relationship considered	x	√	x	–	√	–	–	√	√	x	√	–	x	x	–	–	√	√	–	x	–	–	–	x	x	√	x	√	√	√
7. Ethical issues considered	√	√	√	√	√	√	√	√	√	√	–	√	√	√	√	√	√	√	√	√	√	√	–	√	√	√	√	–	√	√
8. Rigorous data analysis	√	√	√	√	√	√	√	–	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
9. Clear findings	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
10. Implications for practice	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√

Note. √ = Yes; X = No; – = Unclear.

Studies were distributed across countries as follows: Canada (*n* = 4); United States of America (*n* = 4); Australia (*n* = 3); Japan (*n* = 3); Norway (*n* = 3); New Zealand (*n* = 2); and the United Kingdom (*n* = 2). Brazil, Spain, Iran, Ireland, Jordan, Lithuania, Portugal, Sri Lanka, and Sweden had one study each. The largest number of studies were published between 2015 and 2018. The following methodologies were used: grounded theory (*n* = 8); phenomenology (*n* = 6); ethnography (*n* = 1); hermeneutics (*n* = 1); photovoice (*n* = 1); exploratory (*n* = 1); descriptive (*n* = 1); secondary analysis (*n* = 1); and other generic qualitative methodologies (*n* = 10). A total of 605 participants were included: 529 informal caregivers and 76 patients (Table 2). Only four studies addressed patients' and caregivers' perspectives simultaneously. The remaining studies focused on one of them, mostly on caregivers. Although the sample in one study included informal and formal caregivers, the information on formal caregivers was excluded. Dementia, neurodegenerative diseases, cancer, organ failure, and cerebrovascular diseases were the most predominant diseases. A total of 225 findings were coded and aggregated into 51 categories, resulting in eight synthesized findings: factors that facilitate informal care; factors that hinder informal care; strategies used in care; the influence of time in the care process; the influence of disease progression in the care process; motivations to provide home-based care; continuous learning; and informal caregiver's roles (Figure 3).

Table 2

Characteristics of the studies included in this review

Reference/ Country	Objectives/ Participants	Type of study
S1. Williams, A., Sethi, B., Duggleby, W., Ploeg, J., Markle-Reid, M., Peacock, S., & Ghosh, S. (2016). A Canadian qualitative study exploring the diversity of the experience of family caregivers of older adults with multiple chronic conditions using a social location perspective. *International Journal For Equity In Health*, *15(40)*, 1–16. https://doi.org/10.1186/s12939-016-0328-6 (Canada)	To determine the experiences of caregivers of patients with multiple chronic conditions. Informal caregivers (IC) (*n* = 40)	Grounded Theory (GT)
S2. Cameron, J., Rhodes, K. L., Ski, C. F., & Thompson, D. R. (2016). Carers' views on patient self-care in chronic heart failure. *Journal of Clinical Nursing*, 25(1–2), 144–152. https://doi.org/10.1111/jocn.13124 (Australia)	To examine CI's views on patient self-care in chronic heart failure. IC (*n* = 12)	Content analysis
S3. McConigley, R., Halkett, G., Lobb, E., & Nowak, A. (2010). Caring for someone with high-grade glioma: A time of rapid change for caregivers. *Palliative Medicine*, 24(5), 473–479. https://doi.org/10.1177/0269216309360118 (Australia)	To articulate the experiences of family caregivers of people diagnosed with high-grade glioma and describe their needs. IC (*n*=21)	GT
S4. Muthucumarana, M. W., Samarasinghe, K., & Elgán, C. (2018). Caring for stroke survivors: Experiences of family caregivers in Sri Lanka: A qualitative study. *Topics in Stroke Rehabilitation*, 25(6), 397–402. https://doi.org/10.1080/10749357.2018.1481353 (Sri Lanka)	To explore family caregivers' experiences of providing informal care for dependent stroke survivors. IC (*n* = 10)	Exploratory

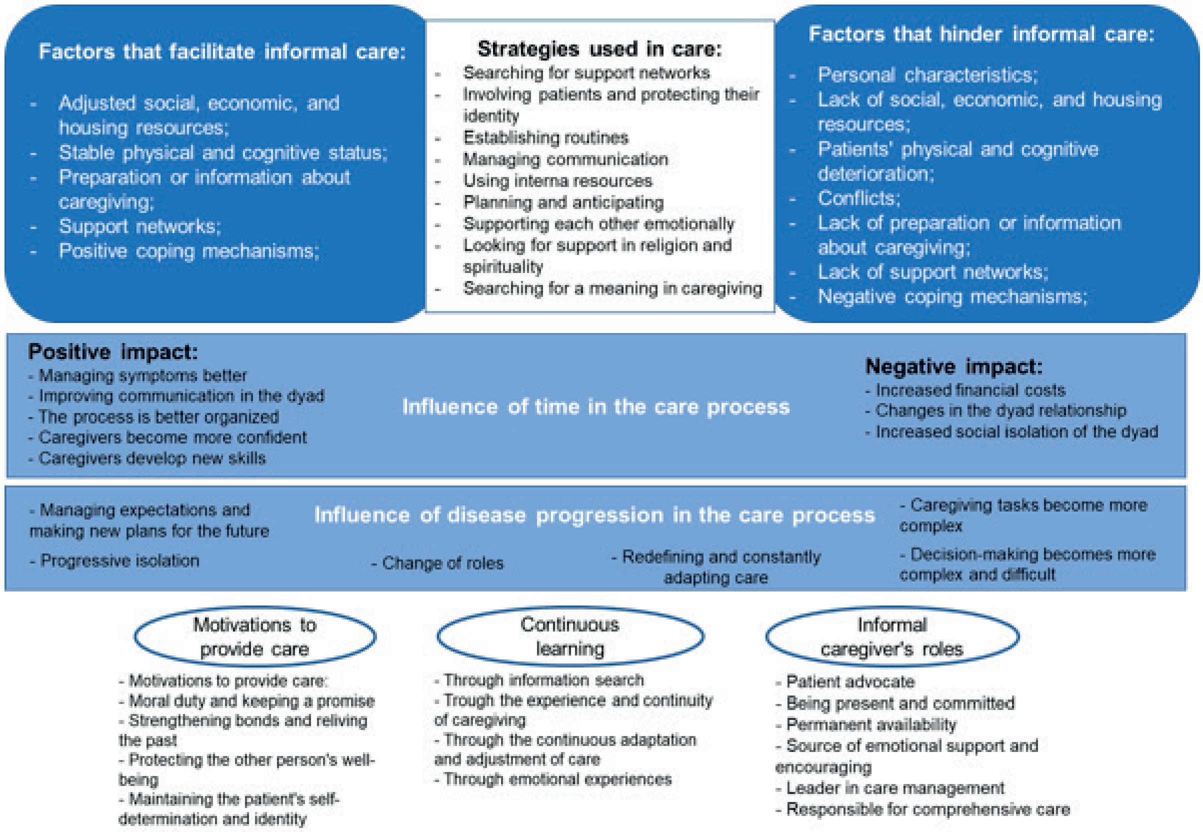
S5. Hunstad, I., & Svindseth, M. (2011). Challenges in home-based palliative care in Norway: A qualitative study of spouses' experiences. *International Journal of Palliative Nursing*, 17(8), 398–404. https://doi.org.10.12968/ijpn.2011.17.7.398 (Norway)	To explore carers' views of what determines the quality of home care at the end of life. IC (*n* = 7)	Phenomenology
S6. Sakakibara, K., Kabayama, M., & Ito, M. (2015). Experiences of "endless" caregiving of impaired elderly at home by family caregivers: A qualitative study. *BMC Research Notes*, 8(827), 1-11. https://doi.org/10.1186/s13104-015-1829-x (Japan)	To describe how the informal caregiver continues caregiving the older person at home and how daily life is restructured. IC (*n*=23)	GT
S7. Jeyathevan, G., Catharine Craven, B., Cameron, J. I., & Jaglal, S. B. (2019). Facilitators and barriers to supporting individuals with spinal cord injury in the community: Experiences of family caregivers and care recipients. *Disability and Rehabilitation*, 42(13), 1844–1854. https://doi.org/10.1080/09638288.2018.1541102 (Canada)	To explore the perceptions of patients with spinal cord injury and their family caregivers regarding the facilitators and barriers to supporting them in the community. Patients (*n* = 19); IC (*n* = 16)	Descriptive
S8. Stajduhar, K. I., Funk, L., & Outcalt, L. (2013). Family caregiver learning: How family caregivers learn to provide care at the end of life: A qualitative secondary analysis of four datasets. *Palliative Medicine*, 27(7), 657–664. https://doi.org/10.1177/0269216313487765 (Canada)	To explore how family caregivers describe learning to provide PC, with a focus on learning to provide care. IC (*n* = 12)	Secondary qualitative analysis
S9. Lerum, S. V., Solbrække, K. N., & Frich, J. C. (2016). Family caregivers' accounts of caring for a family member with motor neurone disease in Norway: A qualitative study. *BMC Palliative Care*, 15(22), 1–9. https://doi.org/10.1186/s12904-016-0097-4 (Norway)	To understand the responsibilities of IC of patients with amyotrophic lateral sclerosis, exploring their accounts. IC (*n* = 25)	Interpretative analysis
S10. Strang, S., Osmanovic, M., Hallberg, C., & Strang, P. (2018). Family caregivers' heavy and overloaded burden in advanced chronic obstructive pulmonary disease. *Journal Of Palliative Medicine*, 21(12), 1768–1772. https://doi.org/10.1089/jpm.2018.0010 (Sweden)	To explore the impact of Chronic Obstructive Pulmonary Disease on the care of patients with advanced disease and how the patient-caregiver relationship is affected. IC (*n* = 35)	Content analysis
S11. Mahoney, D. F., LaRose, S., & Mahoney, E. L. (2015). Family caregivers' perspectives on dementia-related dressing difficulties at home: The preservation of self model. *Dementia*, 14(4), 494–512. https://doi.org/10.1177/1471301213501821 (USA)	To explore the perspectives of family caregivers of patients with Alzheimer about issues that arise when the patient loses the ability to self-care. IC (*n* = 25)	GT
S12. Angelo, J., & Egan, R. (2014). Family caregivers voice their needs: A photovoice study. *Palliative and Supportive Care*, 13(3), 701–712. https://doi.org/10.1017/S1478951514000522 (New Zealand)	To explore family caregivers' experiences in caring for dying relatives. IC (*n* = 10)	Photovoice methodology
S13. Fetherstonhaugh, D., Rayner, J. A., & Tarzia, L. (2016). Hanging on to some autonomy in decisionmaking: How do spouse carers support this? *Dementia*, 18(4), 1219–1236. https://doi.org/10.1177/1471301216678104 (Australia)	To explore the role of caregivers of patients with dementia in the support to decision-making, namely the strategies used and how they facilitate the process. IC (*n* = 9); Patients (*n* = 7)	Phenomenology
S14. Oliveira, S. G., Quintana, A. M., Denardin-Budó, M. L., Moraes, N. A., Lüdtke, M. F., & Cassel, P. A. (2012). Internação domiciliar do paciente terminal: O olhar do cuidador familiar. *Revista Gaúcha de Enfermagem*, 33(3), 104–110. https://doi.org/10.1590/s1983-14472012000300014 (Brazil)	To understand family caregivers' perspectives on the relationships built among patients, family caregivers, and health team. IC (*n* = 11)	Content analysis
S15. Bravo-González, F., & Álvarez-Roldán, A. (2019). Esclerosis múltiple, pérdida de funcionalidad y género. *Gaceta Sanitaria*, 33(2), 177–184. https://doi.org/10.1016/j.gaceta.2017.09.010 (Spain)	To identify the type of support that patients with multiple sclerosis need to cope with the loss of functionality and to show how gender affects the perception of these needs. IC (*n* = 20); Patients (*n* = 30)	Phenomenology

S16. Aasbø, G., Rugkåsa, J., Solbraekke, K. N., & Werner, A. (2017). Negotiating the care-giving role: Family members' experience during critical exacerbation of COPD in Norway. *Health & Social Care In The Community*, 25(2), 612–620. https://doi.org/10.1111/hsc.12350 (Norway)	To explore how spouses and patients with Chronic Obstructive Pulmonary Disease negotiate the role of caregiver during acute exacerbations. IC (*n* = 10)	Thematic analysis
S17. Riffin, C., Van Ness, P. H., Iannone, L., & Fried, T. (2018). Patient and caregiver perspectives on managing multiple health conditions. *Journal of the American Geriatrics Society*, 66(10), 1992–1997. https://doi.org/10.1111/jgs.15501 (USA)	To explore patient and caregiver experiences, preferences, and attitudes toward care received at home. IC (*n* = 20); Patients (*n* = 20)	Constant comparison
S18. Hwang, A. S., Rosenberg, L., Kontos, P., Cameron, J. I., Mihailidis, A., & Nygård, L. (2017). Sustaining care for a parent with dementia: An indefinite and intertwined process. *International Journal of Qualitative Studies on Health and Well-Being*, 12(Sup 2), 1389578. https://doi.org/10.1080/17482631.2017.1389578 (Canada)	To understand how adult children care for parents with dementia within family and formal care contexts in Canada. IC (*n* = 9)	GT
S19. Juarez, G., Branin, J. J., & Rosales, M. (2014). The cancer caregiving experience of caregivers of Mexican ancestry. *Hispanic Health Care International*, 12(3), 120–129. https://doi.org/10.1891/1540-4153.12.3.120 (USA)	To describe the caregiving experience and the challenges of caregivers of Mexican ancestry. IC (*n* = 20)	Thematic analysis
S20. Kita, M., & Ito, K. (2012). The caregiving process of the family unit caring for a frail older family member at home: A grounded theory study. International *Journal of Older People Nursing*, 8(2), 149–158. https://doi.org/10.1111/j.1748-3743.2012.00337.x (Japan)	To explore the caregiving process of family members caring for a frail older family member with chronic illness at home. IC (*n* = 18)	GT
S21. Appleton, L., & Perkins, E. (2017). The construction of help during radiotherapy: Redefining informal care. *Psycho-Oncology*, 26, 2057–2062. https://doi.org/10.1002/pon.4420 (United Kingdom)	To explore how family and friends build and negotiate their role during radiotherapy. IC (*n* = 22)	GT
S22. Ehrlich, K., Emami, A., & Heikkilä, K. (2017). The relationship between geographical and social space and approaches to care among rural and urban caregivers caring for a family member with Dementia: A qualitative study. International *Journal of Qualitative Studies on Health and Well-Being*, 12(1), 1–11. https://doi.org/10.1080/17482631.2016.1275107 (Japan)	To explore and better understand family caregivers' experiences in rural and urban areas and the sociocultural spheres that these two areas represent. IC (*n* = 23)	Hermeneutics
S23. Goudarzi, F., Abedi, H., Zarea, K., Ahmadi, F., & Hosseinigolafshani, S. Z. (2018). The resilient care of patients with vegetative state at home: A grounded theory. *Journal Of Caring Sciences*, 7(3), 163–175. https://doi.org/10.15171/jcs.2018.026 (Iran)	To explain the process of home-based care of patients in vegetative state. IC (*n* = 17) and 5 professional caregivers (whose information was excluded from this review)	GT
S24. Totman, J., Pistrang, N., Smith, S., Hennessey, S., & Martin, J. (2015). You only have one chance to get it right: A qualitative study of relatives' experiences of caring at home for a family member with terminal cancer. *Palliative Medicine*, 29(6), 496–507. https://doi.org/10.1177/0269216314566840 (United Kingdom)	To explore the emotional challenges faced by home caregivers, and their experiences of health-care professionals. IC (*n* = 15)	Thematic analysis
S25. Hynes, G., Stokes, A., & McCarron, M. (2012). Informal care-giving in advanced chronic obstructive pulmonary disease: Lay knowledge and experience. *Journal Of Clinical Nursing*, 21(7–8), 1068–1077. https://doi.org/10.1111/j.1365-2702.2011.03944.x (Ireland)	To explore informal caregivers' experiences providing home-based care to a family member with Chronic Obstructive Pulmonary Disease. IC (*n* = 11)	Phenomenology
S26. Gill, G. J. (2009). The experience of family caregiving of the terminally: A phenomenological study. *Capella University*. (USA)	To identify the experiences and needs of family caregivers of terminally ill patients. IC (*n* = 4)	Phenomenology

S27. McKinlay, E., Vaipuna, K., O'Toole, T., Golds, H., & Adams, A. (2021). Doing what it takes: A qualitative study of New Zealand carers' experiences of giving home-based palliative care to loved ones. *The New Zealand Medical Journal*, 134(1533), 21–32. (New Zealand)	To explore caregivers' experiences of providing home-based care. IC (*n* = 13)	Thematic analysis
S28. Teixeira, M. J., Abreu, W., Costa, N., & Maddocks, M. (2020). Understanding family caregivers' needs to support relatives with advanced progressive disease at home: An ethnographic study in rural Portugal. *BMC Palliative Care*, 19(73), 1–11. https://doi.org/10.1186/s12904-020-00583-4 (Portugal)	To explore family caregivers' experiences of caring for a relative with advanced disease and their perceptions of met and unmet care needs. IC (*n* = 11)	Ethnographic
S29. Al-Rawashdeh, S., Ashour, A., Alshraifeen, A., & Rababa, M. (2020). Experiences on providing home care for a relative with heart failure: A qualitative study. *Journal of Community Health Nursing*, 37(3), 129–140. https://doi.org/10.1080/07370016.2020.1780043 (Jordan)	To explore the lived experiences of persons providing care to relatives with heart failure. CI (*n* = 29)	Phenomenology
S30. Kontrimiene, A., Sauseriene, J., Blazeviciene, A., Raila, G., & Jaruseviciene, L. (2021). Qualitative research of informal caregivers' personal experiences caring for older adults with dementia in Lithuania. *International Journal of Mental Health Systems*, 15(12), 1–10. https://doi.org/10.1186/s13033-020-00428-w (Lithuania)	To determine the experiences of caregivers of older adults with dementia. CI (*n* = 31)	Thematic analysis

Figure 3

Synthesis of the findings



Factors that facilitate informal care - The existence of adjusted social, economic, and housing resources (S1;S12;S15;S27); patients' stable physical or cognitive status and low dependence index (S29); preparation to provide care/access to adequate information (S7;S9); the ability to prevent complications and adjust care (S3;S4;S20;S28); the presence of health professionals through 24/7 face-to-face or telephone support, which promotes confidence in the dyad

(S2;S5;S12;S12;S14;S24), access to reliable information, validation of the care provided, and problem solving; the non-differentiated help at home, which reduces patient isolation, prevents disease progression (S6), facilitates the continuity of care (S14), and reduces caregiver burden (S6;S7); the informal support network, emotionally linked to the dyad (S6;S7), which allows sharing experiences, reducing isolation (S24), sharing tasks and responsibilities (S4; S6-7; S27; S30), supporting in unexpected moments (S3), and allowing the caregiver to rest (S4;S25;S30).

Factors that hinder informal care - Personal characteristics - gender differences between the dyad, constraints in intimate care (S1;S11), or the patient's young age, which hinders the acceptance of dependence (S29); the lack of social, economic, and housing resources that limit the access to technical aids and support materials (S7;S23;S29), the patient's physical and cognitive deterioration associated with uncontrolled symptoms that cause incapability and precipitate the use of hospital services (S10;S12;S19); progressive frailty, which makes care complex and unpredictable (S1-2;S11-12;S25;S29); the nearness of death (S14); the difficulties in therapeutic management (S26-27); the existence of internal or familiar conflicts that break trust (S1;S7;S17), decrease support (S27), and lead to unequal division of responsibilities (S1;S18); the lack of knowledge about care (S7;S19;S23;S29) and available health and social recourses (S4;S28;S30); the lack of support from health professionals due to gaps in home support (S5;S8;S19;S24;S27;S29-30); exclusive focus on the patient or technical aids, without a holistic perspective (S5); communication failures with the dyad (S5;S7;S30) and/or with other teams (S1;S7;S24); patients' negative coping mechanisms - frustration, anger (S7; S29), and reluctance to care or aggressiveness (S7); and caregivers' negative coping mechanisms - difficulty in delegating tasks or patient overprotection (S7; S15; S17; S30).

Strategies used in care – they search for formal and informal support networks (S3; S9; S12-15; S17-18; S20; S23; S29); initially, they are reluctant to accept help but, with time, they understand that it is essential (S1; S3; S12; S20); informal support (family/friends) is the first choice due to familiarity (S13; S17; S20; S23); home-based support is relevant in situations of conflicts, lack of family support, or when caregivers need rest (S17-18;S29). Other strategies emerged: Involving patients in decisions and tasks adjusted to their physical and cognitive skills (S2;S11;S13;S17;S22;S24); establishing routines to provide stability (S9-11;S20-22), planning and anticipating activities (S10;S20;S25); using internal resources, such as hope, resilience, or satisfaction in small achievements (S4;S11;S23;S26); managing communication among themselves and with others (S9-11;S18;S21); supporting themselves emotionally (S10;S15;S21); seeking support in religion and spirituality (S5;S23-24) and searching for a personal meaning in care as learning for life (S1;S11).

Influence of time in the care process – Positive impact: They learn to manage their symptoms better (S16;S20); communication between the dyad improves (S19); the care process becomes more organized: initially, it is disorganized and creates conflicts, but, with time, they start creating their routines (S1;S20;S30); they gain confidence in care management (S2;S30); the patient adapts to the limitations and the caregiver improves his/her response skills (S2;S16;S25;S30). Negative impact: It increases financial costs (S4) and can wear down the dyad's relationship, especially when the patient's behavioral changes generate feelings of loss and isolation in the caregiver (S10;S24).

Influence of disease progression in the care process - There is role reversal, with caregivers performing tasks that used to be performed by the patients and reconciling several roles (S3;S19;S30); they manage their expectations and make new plans for the future (S3); progressive social and family isolation (S10;S12;S14;S25;S27;S29); care are redefined and constantly adapted to the patient's needs and skills, focusing on their wishes (S2;S5-6;S10;S11;S18;S-20-21;S26); tasks become complex and unpredictable, require more time, and are focused on the caregiver, who must acquire new skills (S2;S11;S16;S19-20;S25;S27-28); caregivers make most decisions, and these decisions become more difficult due to the high level of uncertainty or lack of information (S1;S3;S5;S8;S13-14;S16-17;S24-27).

Motivations to provide home-based care - Moral duty to provide the care they received from the patient in the past (S1;S19;S27;S29-30); the social expectation that the family provides care (S1;S9;S21; S29); honor a promise made to the patient (S18;S27); emotional bond; the idea of home as a safe place (S9; S27); to ensure the patient's well-being (S4;S19;S21;S26; S28), self-determination, and identity (S5;S9;S18;S22; S27).

Continuous learning - Active search for information (Internet, other caregivers, professionals); accumulated experience and "trial and error" (S8;S11; S30); emotional experiences, namely coping with feelings such as concern or ambivalence between loving the patient but being afraid to continue providing care (S19;S29;S30).

Informal caregiver's roles - Being a patient advocate, especially if the patient cannot make decisions (S3;S17); Being present, confidant, and trustworthy (S15;S19;S24); Is always available (S9;S24;S30); Is a source of emotional support (S2;S16;S27;S29); Assumes the role of care leader and ensures care continuity at home (S9–10;S17;S21;S27); Ensures comprehensive care, such as helping the patient in daily activities, preventing complications, providing differentiated technical care, and promoting comfort (S2-3;S6;S10-12;S15-16;S19;S21;S23-24;S26-28).

Interpretation of results

This review aimed to systemize the process of informal care from the perspective of caregivers and patients. It revealed that this process is more complex than demonstrated because it is dynamic and influenced by facilitating and complicating factors that do not depend exclusively on those involved but extend to the social context and support networks. Based on these factors, with a more or less conscious proactive attitude, the dyad implements strategies that facilitate the experience and increase the quality of care. The following three factors are crucial: the motivations to provide care (allow us to understand why care is initiated and maintained in this context), continuous learning (ensure the adjustment of care), and caregiver's roles (crucial in home-based care). The influencing factors were aligned with previous studies (Bruinsma et al., 2022; Robinson et al., 2017; Short, 2017; Martín et al., 2016). Support networks play an important role, particularly the support from healthcare teams. Based on these results, these teams should be trained to provide person-centered care and be multidisciplinary to ensure holistic responses adapted to each family. Only one study (S26) mentioned the distinct role of PC teams, underlining their ability to articulate care with families and anticipate and respond to moments of crisis (Martín et al., 2016; Robinson et al., 2017; Sarmento et al., 2017; Short, 2017). Therefore, there is a need for policies to expand home-based PC (Connor, 2020; Gómez-Batiste & Connor, 2017). Home-based support was also highlighted (S6;S7;S11;S14). However, as these teams are not always prepared to care for patients with PC needs (Robinson et al., 2017), they should receive training in PC and collaboration with healthcare teams. Some patients spend years in relatively stable situations, and, despite the consequences identified (S4;S10;S24;S29), this can be a period of growth and consolidation of the care process, full of learning moments. Previous studies have described caregivers' motivations to provide care: the nature of the relationship with the patient; love for the patient; personal characteristics; and social expectations or familial obligations (Zarzycki et al., 2022). Our study identified another reason: protecting the patient's identity and self-determination.

Although we searched for studies on the perspectives of both patients and caregivers, a limitation of this review was that most of them focused on caregivers. As strengths, we highlight the use of meta-aggregation to maintain the meaning of the studies and avoid reinterpretations. We also point out the inclusion of patients with several conditions and from different cultural backgrounds, which contributed to a better understanding of the phenomenon and the transversality of findings.

Conclusion

Informal care at home is a dynamic process with an interconnection between the factors that influence it, the strategies used, and disease progression. As strategies, the dyads mainly seek support networks and involve patients in tasks and decisions, preserving their identity. Identifying facilitating and complicating factors, understanding the impact of time and disease progression, and learning from the strategies provide valuable information for planning and organizing care plans.

As implications for practice, adequate support from healthcare teams had a high impact, calling for the need to develop robust and flexible intervention programs adapted to the reality of patients and caregivers. The role of healthcare teams close to patients was also highlighted, requiring policies focused on strengthening community care teams, namely PC teams that support the dyad throughout the disease trajectory. Investing in home support networks is also essential to support daily activities and reduce caregiver burden. Finally, there is a need for policies that protect informal caregivers, acknowledge their role in society, and grant them a status that corresponds to their demands. The scarcity of studies on the perspectives of both caregivers and patients justifies further research, as well as the multidimensional understanding of PC and how they are provided.

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Investigation: Batista, S., Sapeta, P.
Validation: Sapeta, P.
Visualization: Sapeta, P.
Methodology: Batista, S.
Project administration: Batista, S.
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