The guilt experiences of post-caregivers bereaved by cancer: a scoping review

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Abstract

Background

According to preliminary research, little is known about the experiences of post-caregivers. In order to study this specific area of knowledge, it is necessary to identify the various phenomena inherent to the bereavement experience. One of these phenomena, repeatedly described in the narratives of this population, concerns the experience of guilt. The purpose of this study is to map the guilt experiences of post-caregivers bereaved by cancer. In addition, this study aims to map the motives, characteristics, predisposing factors and consequences of guilt. Considerations on how to overcome feelings of guilt will also be considered.

Methods

Review of the literature following the Scoping Review protocol of the Joanna Briggs Institute. The research included published and unpublished studies and it was performed in Portuguese and English at CINAHL Complete (by EBSCOHost), MEDLINE Complete (by EBSCOHost), Nursing and Allied Health Collection: Comprehensive (by EBSCOHost), Cochrane Central Register of Controlled Trials (by EBSCOHost), Cochrane Database of Systematic Reviews (by EBSCOHost), Cochrane Methodology Register (by EBSCOHost), Library, Information Science & Technology Abstracts (by EBSCOHost), Mediclatina (by EBSCOHost) Cochrane Clinical Answers(by EBSCOHost); PubMed (NLM); SciELO - Scientific Electronic Library Online and PROSPERO- International prospective register of systematic reviews and RCAAP - Repositório Científico de Acesso Aberto de Portugal. The search was conducted by title and abstract. All studies in Portuguese, Spanish and English were considered. No time limits were applied. 4 studies were selected as eligible.

Results

It was possible to identify 9 experiences of guilt, 13 motives that trigger it, 9 characteristics about the phenomenon, 7 predisposing factors, 4 possible consequences of its experience, and 4 considerations on how to overcome it.

Conclusions

It was possible to extract data and answer the predefined questions. However, the lack of a specific article on the present topic confirms that this is an area of knowledge to be explored. Conducting future phenomenological studies based on the experiences of guilt of post-caregivers bereaved by cancer is needed to develop new knowledge in this specific area of research.

Introduction

According to Larkin[1], there are two trajectories experienced by those who have cared for a loved one who required informal care. The first concerns the trajectory of caring. In this trajectory, the carers provide informal care for their dependent, a mission which complexity has been studied extensively in the scientific knowledge[2,3,4]. However, after the death of the person being cared for, the informal caregiver stops providing this care and enters into a new trajectory: the post-care trajectory[1,5,6,7]. In this last trajectory, concepts change and the informal carer takes on a new role, becoming a post-caregiver[1,7]. However, little is still known about this specific population[5].

Therefore, it is essential to understand more about the experiences of informal caregivers, who are going through such a challenging and destructive transition - by breaking down their past experiences as part of the process of rebuilding a new life[5,7]. This is particularly important regarding the experiences of post-caregivers bereaved by cancer, due to the prevalence of this disease: according to the World Health Organization, the leading cause of death worldwide is cancer - and it was responsible for almost 10 million deaths in 2022[8].

According to the scientific literature, one of the intrinsic experiences of those who care for a dependent with cancer is the feeling of guilt, particularly with respect to resolving ethical dilemmas[9,10]. This extends to the post-care trajectory[11,12].

In order to develop scientific knowledge about the guilt experiences of post-caregivers bereaved by cancer (which, as mentioned above, is still unexplored), it is essential to understand what has already been studied on that subject. In this way, conducting a study that maps existing knowledge about the experiences of guilt of post-caregivers bereaved by cancer is the first methodological step towards future studies that will respond to the presented gaps.

In terms of the object of the present study, the guilt experiences are the main focus. However, identifying the reasons why the target population feels guilt is essential. It is also fundamental to identify the characteristics of guilt itself, the factors that precipitate it and its consequences for the post-caregivers. Knowing how to resolve guilt is also a dimension that needs to be considered in order to understand the complexity of the phenomenon.

This review aims to understand what is already known about the experiences of guilt in post-caregivers bereaved by cancer, as proposed by Reis & Deodato[13].

Review questions

For this review, the following primary question was addressed:

1. What are the experiences of guilt of post-caregiver’s bereaved by cancer?

Secondary review questions were also defined according to the same target population and context:

1. What are the motives that trigger guilt?
2. What characteristics constitute the phenomenon of guilt?
3. What are the predisposing factors to the experience of guilt?
4. What are the consequences of living with guilt?
5. How can guilt be overcome?

Methods

This review was conducted according to the protocol defined by the Joanna Briggs Institute for the development of scoping reviews[14].

Search strategy

The first preliminary step was to conduct an initial limited search in CINAHL and PubMed databases in order to identify studies about the issue. The following keywords were used in the title of this first search: “post-caregiver”, “guilt*” and “bereavement”. With this step it was possible to identify titles, abstracts and tables of contents of each article to be analyzed.

A second search was then conducted using all the identified keywords and index terms. This allowed us to select the reference list of the identified studies. It was also possible by this process to add additional sources and delimit the keywords referring to the PCCt framework (Population, Context, Content). It was concluded that it would be necessary to expand the number of keywords and expressions that could be relevant, which would increase the size of the sample that could potentially be included in the study.

The research equation was constructed using boolean operators: [(caregiver OR carer OR informal caregiver OR family caregiver OR former carer OR post-caregiver) AND (guilt*) AND (bereavement OR grief OR mourning)]. A research equation in Portuguese was also defined: [(cuidador OR cuidador familiar OR cuidador informal OR pós- cuidador) AND (culpa) AND (luto OR pesar)]. The equations described were adapted according to the limitations of each database.

The search was conducted in May 2024 by title and abstract in the following databases: CINAHL Complete (by EBSCOHost), MEDLINE Complete (by EBSCOHost), Nursing and Allied Health Collection: Comprehensive (by EBSCOHost), Cochrane Central Register of Controlled Trials (by EBSCOHost), Cochrane Database of Systematic Reviews (by EBSCOHost), Cochrane Methodology Register (by EBSCOHost), Library, Information Science & Technology Abstracts (by EBSCOHost), Mediclatina (by EBSCOHost) Cochrane Clinical Answers(by EBSCOHost); PubMed (NLM); SciELO - Scientific Electronic Library Online and PROSPERO- International prospective register of systematic reviews and RCAAP - Repositório Científico de Acesso Aberto de Portugal. This search included studies from grey literature. All studies in Portuguese, Spanish and English were considered, regardless of the type and methodology used. No time limits were applied. The research records were processed using EndNote V8.2 software.

Eligibility criteria

In order to meet the research objectives, eligibility criteria were defined according to the PCCt (Participants, Concept, Context) framework defined by the method[14]:

- Participants (P) - The review considered all studies focused on informal carers aged 18 or over who provided informal care for a dependent (also categorized as aged 18 or over) that died during the course of an oncological disease.
- Concept (C)- This study considered the “experiences of guilt” of post-caregivers bereaved by cancer as the phenomenon of study. Studies that didn’t present “experiences of guilt” that could be extracted and/ or in which guilt was only mentioned in the body of the text without any attribution of meaning to “experience” were excluded.
- Context (Ct) - This review considered the “post-caregivers bereaved by cancer” as the context under study. Studies without reference to bereavement, grief or mourning or that indicate that carers are still providing care or studies based on anticipatory grief were excluded.

Selection process and data extraction

The initial search identified 164 studies: 124 in EBSCOHost (CINAHL Complete; MEDLINE Complete; Nursing & Allied Health Collection: Comprehensive; Cochrane Central Register of Controlled Trials; Cochrane Database of Systematic Reviews; Cochrane Methodology Register; Library, Information Science & Technology Abstracts; MedicLatina; Cochrane Clinical Answers), 33 in PubMed, and 7 in PROSPERO - International prospective register of systematic reviews. No results were found on SciELO - Scientific Electronic Library Online and RCAAP - Repositório Científico de Acesso Aberto de Portugal. In the sample, 79 articles were repeated and eliminated (n = 85).

The resulting sample (n = 85) was then analyzed independently by two reviewers, that applied the inclusion and exclusion criteria determined in the research protocol. Of the 85 articles, 68 were eliminated after examining the title and abstract resulting in 17 articles eligible for screening by full reading. It should be noted that, at this stage, no ongoing, completed, published or unpublished reviews were identified in PROSPERO - - International prospective register of systematic reviews.

After the analysis of the full texts of the 17 articles, 13 were eliminated - by applying inclusion & exclusion criteria. At this stage, a third reviewer had to intervene in order to clarify differences.

In the end, 4 primary articles were considered for the review: Gallardo et al.[15], Trevino et al.[16], Walsh et al.[17]; Hasdenteufel & Quintard[18].

However, none of them were structured from scratch by the authors with the purpose of answering the proposed research questions of this study. As an example, no article was found with the aim of identifying the reasons that trigger guilt in the post-caregivers. Nevertheless, it would be incorrect to say that there is no data available on this parameter in the scientific literature. Therefore, it was necessary to

use content analysis according to Bardin[19] as a complementary technique to analyze the sample. The mobilization of the content analysis technique in conducting scoping reviews has been presented in the scientific literature as a tool with added value in similar studies where important data needs to be extracted and categorized[20]. The search results and the sample delimitation process are presented in the Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping reviews (PRISMA-ScR) flow diagram[21] (FIGURE 1).

Results

The results are presented in 7 tables.

The first concerns the synopsis of the eligible studies, which were presented in chronological order (TABLE 1). It is possible to understand in this table that none of the articles respond directly to the objectives of the review. However, it is also possible to realize that “guilt” is a constituent element across the conclusions of the entire sample. This justifies the use of the content analysis technique according to Bardin[16] in order to extract and categorize relevant data.

The remaining 6 tables relate to the mapping of existing knowledge according to the objectives of the study: the experiences of guilt in post-caregivers bereaved by cancer (TABLE 2), the motives that led them to experience guilt (TABLE 3), the characteristics of the guilt they experienced (TABLE 4), the factors that predispose them to it (TABLE 5), the consequences of feeling guilty (TABLE 6), and the methodologies identified in order to resolve it (TABLE 7).

These tables will also guide the discussion of the results.

The guilt experiences

In response to the main research question, 9 guilt experiences of former caregivers bereaved by cancer were identified (TABLE 2). These were: “1) Environmental disturbance”[15](f = 1), “2) Suffering”[15,18] (f = 2), “3) Camouflaging guilt in other feelings”[15] (f = 1), “4) Distress”[17,18] (f = 2), “5) Burnout”[17,18] (f = 2), “6) Depression”[18] (f = 1), “7) Feeling of abandonment”[18] (f = 1), “8) Concern about what others might think because they have new friendships”[16] (f = 1) and “9) Perception of selfishness because they are building new relationships and activities”[16] (f = 1).

According to Gallardo et al. [15], the first two experiences (“1] Environmental Disturbance” and “2] Suffering”) are associated with two categorizations of guilt motives: the “1) Desired loss” and the “2) Wish for everything to end as soon as possible” (TABLE 3). However, the definition of “Environmental Disturbance” is unclear[15]. According to the same authors, guilt can be camouflaged (3) in other feelings, such as indifference, resentment and depression[15].

Walsh et al.[17] and Hasdenteufel & Quintard[18] presents “4) Distress” and “5) Burnout” as two experiences associated with guilt, directly linked to the demands of the trajectory of care. Hasdenteufel & Quintard[18] also includes “6) Depression” as one of the experiences associated with guilt, as well as the “7) Feeling of abandonment” - when the post-caregiver, perhaps unconsciously, blames the dependent for having abandoned him.

In their study, Trevino et al.[16] highlight “6) Concern about what others might think because they have new friendships” and “7) Perception of selfishness because they are building new relationships and activities” as experiences associated with guilt. Both are associated with the loss of the previous role (the carer role) and the construction of a new role (the post-caregiver role)[17]. Since no study was found with the research question in line with the main question of the present review, we can consider that the total of guilt experiences remains to be determined.

The motives of guilt

According to the sample, it was possible to identify 13 motives why the target population experienced guilt (TABLE 3). These include: “1) Desired loss”[15] (f = 1), “2) Wish for everything to end as soon as possible”[15] (f = 1), “3) Perception that the love felt towards the dependent was insufficient”[18] (f = 1), “4) Hostile thoughts towards the dependent”[18] (f = 1), “5) Not having succeeded in saving the dependent”[18] (f = 1), “6) Not being able to tell to the dependent what they wanted in life”[15] (f = 1), “7) Conviction of not having done enough for the dependent in life”[15,18] (f = 2), “8) Perception of lack of strength for not having been near the dependent at the time of death”[15] (f = 1), “9) Perception of little time available”[15,17] (f = 2), “10) Not having said goodbye/ not having been present in the last moments of the dependent’s life”[15,17] (f = 2), “11) Perception of betrayal for getting involved in new tasks or starting new relationships after the death”[16] (f = 1), “12) Responsibility for decision-making and its results”[16] (f = 1) and lastly “13) Moving on with their lives after the death”[16] (f = 1).

The 3 motives most often mentioned in the sample (f = 2) were “7) Conviction of not having done enough for the dependent in life”[15,18], “9) Perception of little time available”[15,17] and “10) Not having said goodbye/not having been present in the last moments of the dependent’s life” [15,17]. However, given the method used, it is not possible to determine whether the mapped motives are the most prevalent in the target population, and whether more reasons could trigger the phenomenon in the context under study.

The characteristics of guilt

The characteristics of guilt identified in the sample were 9 (TABLE 4).

The first characteristic is intrinsic to “guilt” itself: “1) Guilt is an intrapersonal process”[15] (f = 1), not an interpersonal one. Guilt is thus experienced by the individual in their own sphere.

The second characteristic demonstrates the strong relationship between guilt and the grieving process: “2) Guilt is a challenge in the grieving process”[16,18] (f = 2), what is in line with the characteristic identified by Hasdenteufel & Quintard[18]: “3) Guilt is as emotional reaction to grief” (f = 1). Gallardo et al.[15] and Hasdenteufel & Quintard[18] also state that “4) Guilt is the feeling most present in unresolved, pathological or dysfunctional grief”. However, Gallardo et al.[15] go further in their considerations by stating that the process of a healthy mourning is guided by objectives: “Acceptance”, “Connection with pain and anger”, “Cleaning and sanitation of the relationship (guilt)” and the “Grateful Farewell”[15]. According to these declarations, it is possible to conclude by inference/ categorization that “8) Guilt is an obstacle to the resolution of a healthy grieving (by being an obstacle in the 'Cleaning and sanitation of the relationship' phase)”[15] (f = 1) and that “9) Guilt is an obstacle to the resolution of a healthy grieving (by being an obstacle in the 'Grateful farewell' phase)”[15] (f = 1). Gallardo et al.[15] also emphasizes that “5) The resolution of guilt is not dependent on the presence of the deceased” (f = 1).

Another consideration regarding the characteristics of guilt concerns its temporality in the grief experience: “6) Guilt can be present days before the death of the dependent, and in a phase of anticipatory grieving” (this being the most frequent characteristic in the sample [f = 3])[16,17,18]. In addition, “7) Guilt may be present for a long period of time after the death of the dependent”[17,18] (f = 2).

The guilt predisposing factors

It was possible to consider 7 factors that predispose post-caregivers to feelings of guilt (TABLE 5). The first 3 factors reported by Trevino et al.[16] are related to the characteristics of the post-caregiver themselves: “1) Being a spouse” (f = 1), “2) Being female” (f = 1) and “3) The age of the post-caregiver” (f = 1). On the other hand, Hasdenteufel & Quintard[18] also emphasizes that the “4) Lower level of practical assistance prior to the loss” (f = 1), the “5) Separation from the parents during childhood” (f = 1) and the observation of the “6) Decreased quality of life of the dependent” (f = 1) are also predictors of guilt.

Walsh et al.[17] present another predisposing factor for guilt: “7) The loss of the carer role and the consequent transition to the post-caregiver role” (f = 1). In this way, the authors state that, when death occurs, post-caregivers experience a transition process characterized by the loss of a previous role (being a carer) and the construction of a new role (the post-caregiver role), which may induce guilt[17].

The consequences of guilt

According to the results of the sample, the feeling of guilt can have harmful consequences for the post-caregiver (TABLE 6).

According to Gallardo et al.[15], Trevino et al.[16] and Hasdenteufel & Quintard[18] “1) Guilt is an indicator/ risk factor for pathological grief” (f = 3), which shows that guilt plays a major role in the experience of grief. Trevino et al.[16] go further in their considerations and state that there is a relationship between guilt and the “2) Decreased quality of life related to physical and mental health” (f = 1), assuming a “3) Greater

likelihood of meeting criteria for compromised mental health" (f = 1). Similarly, these authors state that "4) Guilt can interfere with the response to mental health treatments" (f = 3).

Overcoming feelings of guilt

In general terms, the categories related to the ways of overcoming the feeling of guilt experienced by the post-caregivers are divided in two parts. The first concerns the actual declaration of its necessity. On the other hand, the second part proposes specific interventions according to the grieving process (TABLE 7).

Trevino et al.[16] consider that there is a clear need to assess guilt in bereavement (1). Furthermore, the authors state that there is a need to intervene to resolve it (2), which is corroborated by Walsh et al.[17] and Hasdenteufel & Quintard[18] (f = 3).

On the other hand, Gallardo et al.[15] propose a methodology for resolving guilt. According to the authors, resolving guilt involves mobilizing forgiveness to transmute guilt into understanding (3), and reconverting that same understanding into gratitude (4).

Discussion

In this review, 9 experiences of guilt were identified.

It was also possible to identify 13 motives that trigger guilt, 9 characteristics of the phenomenon, 7 predisposing factors and 4 possible consequences of experiencing it. It was also possible to collect 4 considerations about the methodology to resolve "guilt".

However, the fact that it was possible to extract data from the sample does not mean that all of the dimensions of the phenomenon have been completely identified, given the complexity of the problem and the lack of studies focused on the proposed research problem.

Nevertheless, the way in which "guilt" was described as an element of the studies in the sample made it possible for the reviewers to extract data by using the content analysis technique, based on the considerations of the authors and on the narratives of post-caregivers.

Therefore, one of the conclusions of this review is that further studies about this specific problematic need to be conducted. It is also needed to gain a deeper understanding on the motives that lead post-caregivers to experience guilt. The characteristics, consequences and predisposing factors of "guilt" must also be fully understood. Given the consequences identified, it revealed to be particularly important to explore more about the possible methodologies than can effectively resolve guilt.

As a possible strategy to mitigate the identified gaps in knowledge, the reviewers recommend conducting future qualitative/ phenomenological studies based on the research questions defined in the present review.

Conclusion

The review mapped 9 experiences of guilt, 13 motives that trigger it, 9 characteristics about the phenomenon, 7 predisposing factors, 4 possible consequences of its experience, and 4 considerations on how to overcome guilt in the delimited population and context. However, this was only possible using the Bardin content analysis technique, since no study was identified with research questions in line with those proposed by the present study. Conducting a phenomenological study that answers the research questions based on the experiential narratives of post-caregivers bereaved by cancer is one of the methodologies that can be adopted in order to produce knowledge about this population that has been still little studied by the scientific community.

Abbreviations

(P)
Participants
(C)
Concept
(Ct)
Context
(f)
frequency

Declarations

Author Contributions Statement

Conceptualization: HR. Supervision: SD. HR and MM developed the search strategy and conducted the search. All authors extracted and screened articles, reviewed the analysis process and were involved in writing the manuscript. The final version of the manuscript was approved by all the authors.

Competing Interest declaration

The authors declare that they have no competing interests.

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Data availability statements

Gallardo et al.[15], Trevino et al.[16] and Walsh et al. [17] are published articles which cannot be shared by the authors for copyright reasons but are available through subscription to the relevant journals/databases.

Hasdenteufel & Quintard[18] is available in the journal's official website (BMC Palliative Care) at https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-022-01096-y in Open access. DOI: https://doi.org/10.1186/s12904-022-01096-y.

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References

1. Larkin M. Life after Caring: The Post-Caring Experiences of Former Carers. British Journal of Social Work. 2008;39(6):1026–42. https://doi.org/10.1093/bjsw/bcn030
2. Bijnsdorp FM, Onwuteaka-Philipsen BD, Boot CRL,et al. Caregiver's burden at the end of life of their loved one: insights from a longitudinal qualitative study among working family caregivers. BMC Palliat Care. 2022;21(1):142. https://doi.org/10.1186/s12904-022-01031-1
3. Bijnsdorp FM, Pasman HRW, Boot CRL,et al. Profiles of family caregivers of patients at the end of life at home: a Q-methodological study into family caregiver' support needs. BMC Palliat Care. 2020;19(1):51. https://doi.org/10.1186/s12904-020-00560-x
4. Theißen T, Ullrich A, Oechsle K, et al. "Being an informal caregiver – strengthening resources": mixed methods evaluation of a psychoeducational intervention supporting informal caregivers in palliative care. BMC Palliat Care. 2024;23(1):95. https://doi.org/10.1186/s12904-024-01428-0
5. Afonso CI, D'espiney L. Reconstruction of Daily life: The Lived experience of the post-family caregiver. New Trends in Qualitative Research. 2022;20(11):e541. https://doi.org/10.36367/ntqr.11.2022.e541
6. Barlund AS, André B, Sand K, Brenne A-T. A qualitative study of bereaved family caregivers: feeling of security, facilitators and barriers for rural home care and death for persons with advanced cancer. BMC Palliat Care. 2021;20(1):7. https://doi.org/10.1186/s12904-020-00705-y
7. Mora-Lopez G, Berenguer-Poblet M, Berbis-Morelló C, et al. New Life Transition of Former Caregivers: Positive Mental Health Approach. Frontiers in Psychology. 2022 4;13. https://doi.org/10.3389/fpsyg.2022.854108
8. International Agency for research on Cancer - World Health Organization: Global Cancer Observatory: Cancer Today (World). https://gco.iarc.who.int/media/globocan/factsheets/populations/900-world-fact-sheet.pdf (2006). Accessed 30 May 2024.
9. Ullrich A, Theochari M, Bergelt C, et al. Ethical challenges in family caregivers of patients with advanced cancer – a qualitative study. BMC Palliat Care. 2020;19(1):70. https://doi.org/10.1186/s12904-020-00573-6
10. Serpentini S, Guandalini B, Tosin G, et al. Assessment of self-efficacy for caregiving in oncology: Italian validation of the caregiver inventory (CGI-I). BMC Palliat Care. 2021;20(1):166.

https://doi.org/10.1186/s12904-021-00849-5

11. Holtslander L, Baxter S, Mills K, et al. Honoring the voices of bereaved caregivers: a Metasummary of qualitative research. BMC Palliat Care. 2017;16(1):1–18. https://doi.org/10.1186/s12904-017-0231-y
12. Watts JH, Cavaye J. Being a Former Carer: Impacts on Health and Well-Being. Illness, Crisis & Loss. 2016 5;26(4):330–45. https://doi.org/10.1177/1054137316679992
13. Reis H, Deodato S. Análise ao conceito de culpa: Da divergência conceptual à sua implicação para a investigação em enfermagem. Rev. Enf. Ref. 2022;6(1):1-6. https://doi.org/10.12707/RV20178
14. Peters MDJ, Godfrey C, McInerney P, et al. In: Munn EAZ, editor. JBI Manual for evidence synthesis. Scoping reviews: Joanna Briggs Institute; 2020. p. 45.
15. Gallardo CP, Navarro DM, Rodríguez AG. El duelo de los cuidadores principales de pacientes oncológicos atendidos en domicilio. Metas de enfermería. 2003;6(57):61–4.
16. Trevino KM, Litz B, Papa A, et al. Bereavement Challenges and Their Relationship to Physical and Psychological Adjustment to Loss. Journal of Palliative Medicine. 2018;21(4):479–88. https://doi.org/10.1089/jpm.2017.0386
17. Walsh EP, Flanagan JM, Mathew P. The Last Day Narratives: An Exploration of the End of Life for Patients with Cancer from a Caregivers' Perspective. Journal of Palliative Medicine. 2020;23(9):1172–6. https://doi.org/10.1089/jpm.2019.0648
18. Hasdenteufel M, Quintard B. Psychosocial factors affecting the bereavement experience of relatives of palliative-stage cancer patients: a systematic review. BMC Palliat Care. 2022;21(1):212. https://doi.org/10.1186/s12904-022-01096-y
19. Bardin L, Análise de conteúdo. São Paulo: Edições; 2016
20. Vieira JV, Deodato S, Mendes F. The concept of futility in health: A scoping review. Clinical Ethics. 2021;16(4):347-353. https://doi.org/10.1177/1477750920977109
21. Tricco A, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMAScR): Checklist and explanation. Ann Intern Med. 2018;169:467–73 https://doi.org/10.7326/M18-0850

Tables

Table 1 - Synopsis of the eligible studies

Sample	**(1)**	**(2)**	**(3)**	**(4)**
Authors	Gallardo et al.[15]	Trevino et al.[16]	Walsh et al.[17]	Hasdenteufel & Quintard[18]
Year	2003	2018	2020	2022
Title	“El duelo de los cuidadores principales de pacientes oncológicos atendidos en domicilio”	“Bereavement Challenges and Their Relationship to Physical and Psychological Adjustment to Loss”	“The Last Day Narratives: An Exploration of the End of Life for Patients with Cancer from a Caregivers' Perspective”	“Psychosocial factors afecting the bereavement experience of relatives of palliative-stage cancer patients: a systematic review”
Source	Metas de Enfermería	Journal of palliative medicine	Journal of palliative medicine	BMC Palliative Care
Aims/ purpose	To evaluate the bereavement of the main caregivers of oncological patients cared for in their homes.	To conduct a preliminary examination of the factor structure of the Bereavement Challenges Scale (BCS) and its relationships with quality of life and mental illness.	To explore the experience of the last day of life from the perspective of the surviving caregiver.	To identify biopsychosocial and existential determinants specific to the palliative phase of cancer that influence the grieving experience of the caregiver.
Methods	An in- depth rough interview with subsequent analysis.	Administration of measures of bereavement challenges (BCS), quality of life (Medical Outcomes Study Short Form-36), prolonged grief (PG-13), and mental disorders (Structured Clinical Interview for the DSM-IV). Principal component factor analyses identified the underlying structure of the BCS. Examination of associations between the factors and caregiver quality of	The method consisted of a narrative inquiry approach. Then, the data was reviewed, coded, categorized (individually and then collectively) and thematically analyzed in order to provide a summative analysis.	Systematic review of the literature.

		life, prolonged grief, and rates of mental disorders.		
Population	12 main caregivers of oncology patients cared for in their homes.	162 bereaved cancer caregivers.	10 caregivers of deceased cancer patients at a single institution.	18 of the 645 articles identified.
Key findings for the review	The interviews revealed not only manifestations of resolved bereavement, but also defense mechanisms in the most caregivers and feelings of guilt and blame - indicative of non-resolved bereavement. The dysfunctional bereavement is a present diagnosis that can appear among the main caregivers.	The following factors were: “Challenges with Connecting with Others”; “Challenges with Change”; “Challenges Imagining a Hopeful Future”; “Challenges with Accepting the Loss” and “Challenges with Guilt”.	Six themes were captured. One of them was “Navigating the dying days and early grief period wrought with guilt and closure”. Caregivers experienced distress and guilt related to the loss of their caregiver role. The preparation of caregivers is needed.	“Guilt” is one of the terms that can describe the caregiver’s grief experience.

Table 2 - The guilt experiences	(1)	(2)	(3)	(4)	f
1) Environmental disturbance	●				1
2) Suffering	●			●	2
3) Camouflaging guilt in other feelings (such as indifference, resentment and depression)	●				1
4) Distress			●	●	2
5) Burnout			●	●	2
6) Depression				●	1
7) Feeling of abandonment				●	1
8) Concern about what others might think because they have new friendships		●			1
9) Perception of selfishness because he is building new relationships and activities		●			1

§ **(1)** – Gallardo et al.[15]; **(2)**– Trevino et al.[16]; **(3)** – Walsh et al.[17]; **(4)** - Hasdenteufel & Quintard[18].

§ **f**= frequency in which the category was identified in the sample.

Table 3 - The motives of guilt	(1)	(2)	(3)	(4)	f
1) Desired loss	●				1
2) Wish for everything to end as soon as possible	●				1
3) Perception that the love felt towards the dependent was insufficient				●	1
4) Hostile thoughts towards the dependent				●	1
5) Not having succeeded in saving the dependent				●	1
6) Not being able to tell to the dependent what he wanted in life	●				1
7) Conviction of not having done enough for the dependent in life	●			●	2
8) Perception of lack of strength for not having been near the dependent at the time of death	●				1
9) Perception of little time available	●		●		2
10) Not having said goodbye/ not having been present in the last moments of the dependent's life	●		●		2
11) Perception of betrayal for getting involved in new tasks or starting new relationships after the death		●			1
12) Responsibility for decision- making and its results		●			1
13) Moving on with his live after the death		●			1

§ **(1)** – Gallardo et al.[15]; **(2)**– Trevino et al.[16]; **(3)** – Walsh et al.[17]; **(4)** - Hasdenteufel & Quintard[18].

§ **f**= frequency in which the category was identified in the sample.

Table 4 - The characteristics of guilt	(1)	(2)	(3)	(4)	f
1) Guilt is an intrapersonal process	●				1
2) Guilt is a challenge in the grieving process		●		●	2
3) Guilt is as emotional reaction to grief				●	1
4) Guilt is the feeling most present in unresolved, pathological or dysfunctional grief	●			●	2
5) The resolution of guilt is not dependent on the presence of the deceased	●				1
6) Guilt can be present days before the death of the dependent, and in a phase of anticipatory grieving		●	●	●	3
7) Guilt may be present for a long period of time after the death of the dependent			●	●	2
8) Guilt is an obstacle to the resolution of a healthy grieving (by being an obstacle in the “Cleaning and sanitation of the relationship” phase)	●				1
9) Guilt is an obstacle to the resolution of a healthy grieving (by being an obstacle in the “Grateful farewell” phase)	●				1

§ **(1)** – Gallardo et al.[15]; **(2)**– Trevino et al.[16]; **(3)** – Walsh et al.[17]; **(4)** - Hasdenteufel & Quintard[18].

§ **f**= frequency in which the category was identified in the sample.

Table 5 - The guilt predisposing factors	(1)	(2)	(3)	(4)	f
1) Being a spouse		●			1
2) Being female		●			1
3) The age of the post-caregiver		●			
4) Lower level of practical assistance prior to the loss				●	1
5) Separation from the parents during childhood				●	1
6) Decreased quality of life of the dependent				●	1
7) The loss of the informal caregiver role and the consequent transition to the pot-caregiver role			●		1

§ **(1)** – Gallardo et al.[15]; **(2)**– Trevino et al.[16]; **(3)** – Walsh et al.[17]; **(4)** - Hasdenteufel & Quintard[18].

§ **f**= frequency in which the category was identified in the sample.

Table 6 - The consequences of guilt	(1)	(2)	(3)	(4)	f
1) Guilt is an indicator/ risk factor for pathological grief	●	●		●	3
2) Decreased quality of life related to physical and mental health		●			1
3) Greater likelihood of meeting criteria for compromised mental health		●			1
4) Guilt can interfere with the response to mental health treatments		●			1

§ **(1)** – Gallardo et al.[15]; **(2)**– Trevino et al.[16]; **(3)** – Walsh et al.[17]; **(4)** - Hasdenteufel & Quintard[18].

§ **f**= frequency in which the category was identified in the sample.

Table 7 - Overcoming feelings of guilt	(1)	(2)	(3)	(4)	f
1) Assessing guilt in bereavement*		●			1
2) Intervening towards the resolution of guilt in bereavement*		●	●	●	3
3) Mobilizing forgiveness to turn guilt into understanding**	●				1
4) Reconvert understanding into gratitude**	●				1

§ **(1)** – Gallardo et al.[15]; **(2)**– Trevino et al.[16]; **(3)** – Walsh et al.[17]; **(4)** - Hasdenteufel & Quintard[18].

§ **f -** frequency in which the category was identified in the sample.

§ *** -** Authors declare the need to intervene.

§ **** -** Authors clarify interventions to mitigate guilt

Figures

FIGURE 1 – Prisma flow diagram - preferred items presented in the Joanna Briggs Institute Guidance[21]

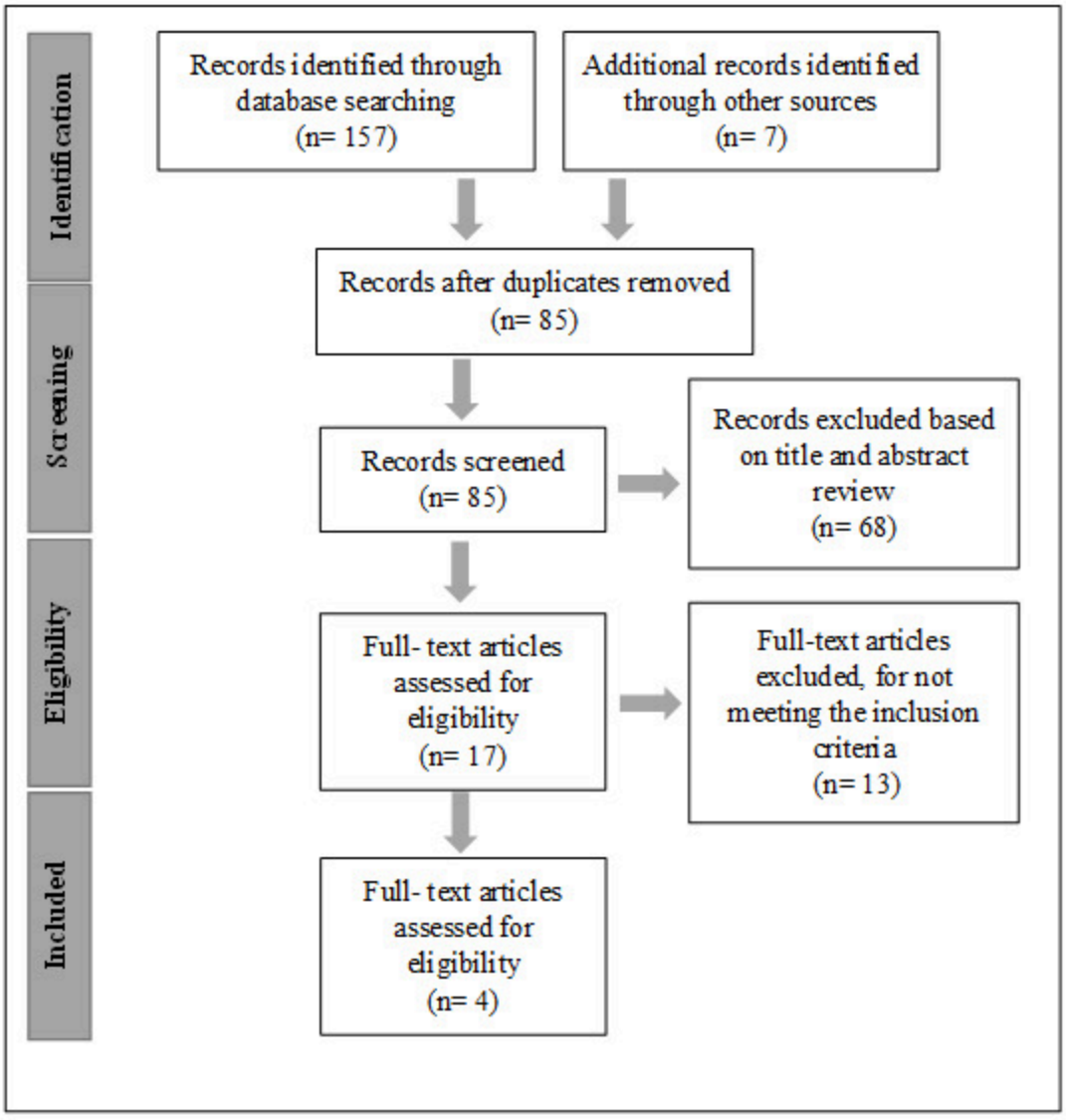

Figure 1

See image above for figure legend