

REVIEW

Impact of caregiver burden on mental health in bereaved caregivers of cancer patients: A systematic review

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Abstract

Objective: Although caregiver burden may continue to influence the mental health of cancer patients' caregivers long after bereavement, few studies have examined this issue.

Methods: A systematic review was conducted to provide a summary of (1) operationalizations of caregiver burden used in this field and (2) the effect of caregiver burden on postbereavement mental health of adult caregivers of cancer patients. A systematic search of the electronic databases PubMed, Web of Science, and PsycINFO was conducted across empirical studies published in a peer-reviewed journal up until April 2017.

Results: Caregiver burden was rarely defined, and it was operationalized in multiple and diverging ways. The 20 included papers present varying results but generally indicate that caregiver burden (especially emotional) has an adverse effect on postbereavement mental health.

Conclusions: In future studies, researchers seeking to ascertain which aspects of caregiver burden may prove an appropriate target for prevention and intervention should first use a precise operational definition of the concept.

KEYWORDS

bereavement, cancer, caregiver burden, depression, oncology, review

1 | INTRODUCTION

In 2012, a total of 8.2 million people worldwide died of cancer¹ leaving behind a vast number of bereaved relatives. Although grief is considered a normal process that helps facilitate adjustment to life without the deceased, it may be accompanied by functional and psychological impairments,² and in more severe cases result in bereavement-related mental disorders. Depending on the measurement tool used, the prevalence of complicated grief among the bereaved varies from 1.8% to 22.2%.³⁻⁶ Cancer as a cause of death has been shown to be a risk factor for complicated grief.⁶ Bereaved individuals also showed an increased prevalence of depression (54.2%).⁷ A notable comorbidity of complicated grief and depression was found,^{8,9} yet both syndromes were shown to be distinct from one another in terms of symptoms and treatment needs.¹⁰ These findings raise the question of which factors contribute to this elevated risk for mental health issues among the bereaved, especially among those who have lost a relative to cancer.

Cancer was shown to be the main cause of patients needing palliative care and to be connected with increased rates of death at

home.^{11,12} Relatives often serve as untrained informal caregivers, and in doing so, they face emotional challenges related to the patient's deterioration and impending death as well as practical challenges related to learning new skills and adopting new responsibilities including providing practical help, personal care, psychological support, transport, and coordination of treatment.^{13,14} Although this may encompass enrichment and growth in self-esteem,¹⁵ it can also strain caregiver's resources.¹⁶

Caregiver burden (CB) was defined as "the extent to which caregivers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative."¹⁷ Caregiver burden can be seen as comprising multiple dimensions of perceived stress, which are influenced by resources (eg, previous caregiving experience and social support) and stressors (eg, objective caregiving demands).¹⁶ A wide variety of conceptualizations have been proposed in previous research. *Role strain* is a widely used concept that encompasses caregiver's perceived impairment in areas of life other than caregiving such as work, finances, or health.^{16,18-21} Emotional and self-related responses to the demands of caregiving may be subsumed as *personal strain* and have been captured by a multitude of

concepts: stressfulness,^{18,21} feeling of overload, changes in self-concept,¹⁶ guilt, embarrassment, anger,²⁰ or stress and relational burden.¹⁹

Of caregivers of cancer patients, 32% to 50.7% were shown to be significantly burdened.^{22,23} Several studies found an adverse effect of CB on mental health during caregiving.²⁴⁻²⁷ However, only few studies have focused on the long-term effects on bereavement adjustment.

There are 2 competing hypotheses about the impact of CB on mental health after bereavement. The *stress reduction perspective* focuses on how bereavement ends the stressful obligations of caregiving and frees resources for the grieving process.^{28,29} According to this rationale, the loss of the caregiver role should result in improved mental health, especially in those who experienced high CB before the loss. The *cumulative stress perspective* asserts that high CB leads to impaired bereavement adjustment, facilitated by an accumulation of stressors over time, depletion of resources, and hindering of preparation for the death.^{28,29} According to the latter model, prevention and interventions targeted at reducing CB may help facilitate bereavement adjustment.

Developing such methods of prevention and intervention first requires examining the long-term repercussions of CB after bereavement. To our knowledge, there is no previously existing synthesis of study results concerning the impact of perceived CB on postbereavement mental health published in the English language.

The current systematic review aims to synthesize findings on the effect of perceived CB on postbereavement mental health in bereaved caregivers of cancer patients to provide a basis for further research in developing and evaluating prevention and intervention. A more comprehensive understanding of the current state of research shall be accomplished in 2 steps: (1) an overview of the operationalizations of CB used in this field of research will be provided and (2) the impact of CB on outcome measures reflecting postbereavement mental health will be examined.

2 | METHOD

2.1 | Search procedure

A systematic search of the electronic databases PubMed, Web of Science, and PsycINFO was conducted with the following search string in April 2017 for papers published from inception to date:

"(caregiv*) AND (burden OR strain OR *stress) AND (bereave* OR grie* OR mourn* OR loss) AND (cancer OR oncol*)"

The search results were screened as follows: (1) Duplicates were removed using the literature software Zotero. (2) The first 2 authors independently screened titles and abstracts for inclusion criteria and (3) performed a full-text screening of all articles, which could not be excluded with certainty in the preceding step. Disagreements were resolved through discussion with the last author. (4) Additional publications were acquired by scanning the references of all selected papers using the same procedure.

2.2 | Study selection and analysis

The inclusion criteria for publications were (1) publication in a peer-reviewed journal, (2) report on data from a quantitative empirical study

design, (3) sample consisting of bereaved adult caregivers, (4) cancer as the cause of bereavement in at least 75% of the cases, (5) measurement of perceived prebereavement CB and postbereavement mental health or psychopathology, and (6) examination of the association between both. Articles were excluded if they were (1) not written in English, or (2) reviews, case studies, conference abstracts, expert opinions, or clinical guidelines.

Data from all studies matching the criteria were extracted by the first author and independently checked for accuracy by the second author with the help of a data extraction sheet containing the following variables: source (author, year, and country), characteristics of the sample (N, gender, age, and relation to patient), study design, measures used as independent variable (CB) and dependent variable (eg, complicated grief, depression, and general mental health [GMH]), and results (prevalence of postbereavement mental health problems and association of prebereavement CB with postbereavement mental health).

3 | RESULTS

The literature search described above yielded a total of 699 articles, 220 of which were removed as duplicates. After titles and abstracts of the remaining 479 articles were screened, 60 publications remained for full-text screening. Of those, 17 met the eligibility criteria. Three articles were added after screening the references of relevant papers. Ultimately, 20 articles were included in this systematic review. The procedure is summarized in Figure 1.

3.1 | Study characteristics

To our knowledge, the 20 articles were based on 14 studies. Six studies were conducted in the United States,³¹⁻⁴⁰ and 1 in each of the following countries: Australia,⁴¹ Canada,⁴² Denmark,⁴³ Israel,⁴⁴ Italy,⁴⁵ Korea,⁴⁶ Taiwan,⁴⁷⁻⁴⁹ the United Kingdom.⁵⁰ An overview of all chosen articles can be found in Table 1.

Four projects were reported on by several different papers, which respectively concentrated on (1) different time frames,^{31,37} (2) different outcome measures as well as time frames,^{35,36,40} and (3) grouping of the sample.^{32,33} (4) One paper⁴⁹ reported on joint samples from 2 other articles.^{47,48}

Eleven of the studies (featured in 17 of the papers) used a prospective design. Caregiver burden was assessed before or up to 1 month after bereavement, and mental health was assessed in a time range of 1 month to 3.6 years after bereavement. The remaining 3 papers (3 studies) were cross-sectional studies that measured CB retrospectively.

Seven papers reported on GMH as an outcome,^{34,36,40,42,44,46,50} 4 on complicated grief,^{41,43,45,48} and 11 on depression.^{31-33,35,37-39,43,46,47,49} No articles were found that considered other mental illnesses such as anxiety, somatization, or posttraumatic stress disorder as an outcome.

Sample sizes ranged from 50 to 1989. Gilbar and Ben-Zur,⁴⁴ Kim et al,^{35,36,40} and Song et al⁴⁶ sampled cancer patients identified by state registries; Nielsen et al⁴³ sampled patients registered with drug reimbursement. Two studies^{43,46} achieved a representative sample.

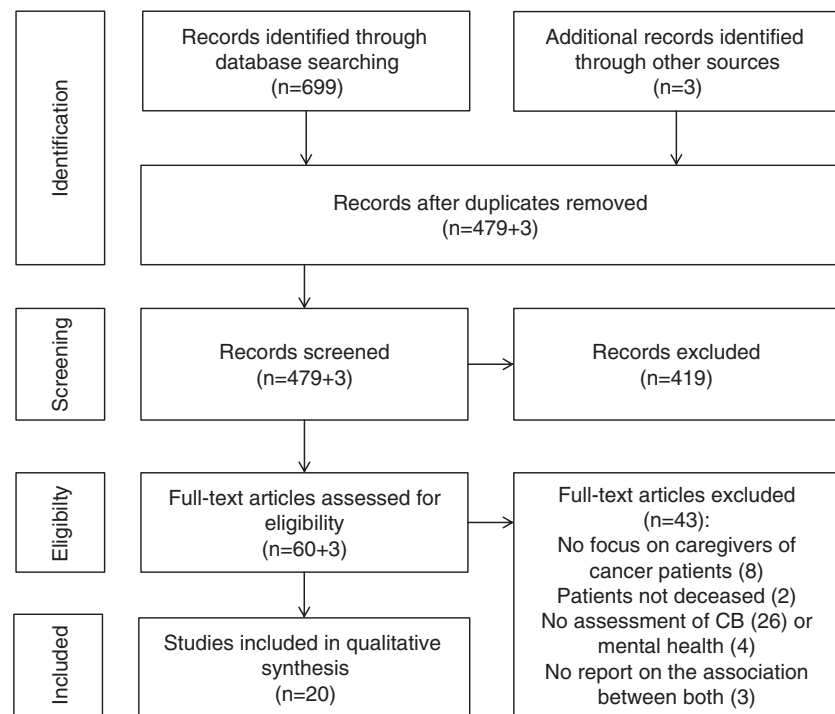


FIGURE 1 Adapted preferred reporting items for systematic reviews and meta-analyses (PRISMA) flowchart³⁰

All other studies used convenience samples from one or more treatment or care institutions. Francis et al used data derived from a randomized controlled trial,^{32,33} which was based on a convenience sample. All caregivers were identified through their ill relatives or medical staff.

Most studies exclusively addressed caregivers whose relatives died of cancer, with the exception of 3 studies by Kapari et al,⁵⁰ Nielsen et al,⁴³ and Brazil et al,⁴² where cancer patients accounted for 96%, 90%, and 82% of the samples, respectively. Two of those studies controlled for diagnosis and found no significant association with the respective outcome measures.^{42,50}

All but one study exclusively reported analyses of data concerning bereaved caregivers. Only Kim et al^{35,36} assessed bereaved and nonbereaved caregivers and included “caregiver status” as a covariate in the analyses.

3.2 | Assessment and definition of CB

The included papers assessed a multitude of substantially differing concepts of CB. For the purpose of the following analysis, measurements have been divided into *personal strain* and *role strain* (Table 1):

Personal Strain was assessed using own questions by some authors as either a feeling of being burdened or stressed by caregiving, emphasizing the emotional response (3 papers^{34,35,44}) or “satisfaction with caregiving abilities,” emphasizing the impact on the self (one paper³⁹). Emotional responses were measured by the Burden Scale for Family Caregivers⁵² (one study⁴³) and the following subscales: “stress overload” from the Pearlin Stress Scale¹⁶ (one study^{35,36,40}); “emotional burden,” “need to know about the disease,” and “thoughts about death” from the Family Strain Questionnaire⁵⁵ (one study⁴⁵); and “mental burden” from the Caregiving Consequences Inventory⁵³ (one study⁴⁶). The Caregiver Reaction

Assessment (CRA)⁵⁴ subscale “self-esteem” assessed the impact of caregiving on the self (5 studies^{35,36,38,40-42,47-49}).

Role Strain was assessed by most subscales of the CRA (“health burden,” “schedule burden,” “financial burden,” and “family abandonment”; 5 studies^{32,33,38,41,42,47-49}), the burden domain of the Caregiving Consequences Inventory (“physical burden,” “financial burden,” “schedule burden”; one study⁴⁶), and the Family Strain Questionnaire subscale “problems in social involvement” (one study⁴⁵). The Work and Social Adjustment Scale⁵⁶ measures impairments in work, home management, leisure activities, and relationships due to caregiving (one study⁵⁰).

The Zarit Interview⁵⁷ was classified as a measure of overall CB because it assesses caregivers' mental and physical well-being, finances, social life, and the relationship between the caregiver and the impaired person without distinguishing between the 2 aforementioned dimensions (2 studies^{31,37,50}).

When a paper only elaborated on total scores of a measurement tool that mainly assessed 1 of the 2 dimensions (eg, CRA measures mostly role strain), the results were allocated to the dominant dimension.

3.3 | Caregiver burden and GMH

3.3.1 | Measurement of GMH and impact of caregiving

Of the 7 papers assessing GMH, 3 used the 12- and 36-Item Short-Form Health Survey,^{65,66} and 1 used the EuroQol 5 dimensions questionnaire.⁶¹ Nonspecific psychological symptoms were assessed using the Brief Symptom Inventory,⁵⁸ the Short Form of the Profile of Mood States,⁶³ and the Revised Clinical Interview Schedule⁶⁰ by one study, respectively. Garrido and Prigerson³⁴ assessed the incidence of depression/anxiety with the Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) Axis 1⁶⁴

TABLE 1 Impact of caregiver burden on bereavement adjustment

Author, Year, Country	Sample (N; mean age; gender; relation to patient)	Prospective Design	Time of Postbereavement Assessment	CB Measure	Outcome Measure	Association of Outcome with CB		Prevalence of/Group Differences in Outcome Measure
						Personal Strain	Role Strain	
Brazil et al. (2002), Canada ⁴²	N = 151; 61 y; 87.8% female; 65.6% spouse, 30.4% child	No	10 mo	CRA	SF-12	Outcome: GMH No association between mental burden and postbereavement GMH.	Impact on health and sense of family abandonment, but no other dimensions of role strain predicted poorer GMH scores in univariate and multivariate regression models.	SF-12: Scores were significantly below the population norm.
Garrido & Prigerson (2014), USA ³⁴	N = 245; 51.96 y; 75.9% female; 56% spouse	Yes	6 mo	Author's own: Burden of providing emotional support	SF-36 SCID	High burden correlated with improvement in GMH scores on the borderline of significance ($P = .06$), but also predicted the incidence of depression or anxiety. No effect was found in a multiple linear regression.	-	Depression/anxiety: 6 mo: 12.62%
Gilbar & Ben-Zur (2002), Israel ⁴⁴	N = 69; 61.14 y; 63.8% female; 100% spouse	No	3 mo to 1 y	Author's own: Feeling burdened	BSI	No significant correlation between burden and GMH scores. High burden predicted poorer GMH scores in multiple regression.	-	BSI: All subscales were above the norm, depression highest.
Kapari et al. (2010), UK ⁵⁰	N = 50; 65.3 y; 75% female; 85% spouse/partner	Yes	3 mo, 6 mo	ZI WSAS	CIS-R	-	No significant association between WSAS scores and general GMH at either time point in multiple regression.	"Common Mental Disorder" 3 mo: 32.6% 6 mo: 22%
Kim et al. (2012), USA ⁴⁰	N = 1218 (144 bereaved); 59.9 y; 78.5% female; 63.2% spouse	Yes	0-3 y	PSS CRA (only esteem scale)	POMS-SF SF-36	Caregiving stress (PSS) predicted psychological distress (POMS-SF) and mental health (SF-36). Caregiver esteem predicted neither.	-	SF-36 and POMS-SF: Bereaved caregivers mental health was comparable to the general population, psychological distress was higher.
Kim et al. (2016), USA ³⁶	N = 1087 (230 bereaved); 57.2 y; 75.8% female; 60.3% spouse	Yes	3.6 y (SD = 2.4)	PSS CRA (only esteem scale)	POMS-SF SF-36	Caregiving stress (PSS) predicted psychological distress (POMS-SF) but not mental health (SF-36). Caregiver esteem predicted neither.	-	SF-36 and POMS-SF: Bereaved caregivers had worse GMH than those whose patients were in remission
Song et al. (2012), Korea ⁴⁶	N = 501; 53.2 y; 58.5% female; 46% spouse	No	2-6 mo	CCI	EQ-5D	Additional information: The regression included bereaved and nonbereaved caregivers.	High schedule burden, but no other dimension of role strain predicted worse postbereavement GMH.	EQ-5D: Caregivers scored lower than controls in self-care, usual activities and anxiety/depression.
Nielsen et al. (2017), Denmark ⁴³	N = 1989 62.0 y; 70% female; 64% spouse;	Yes	6 mo	BSFC	PG-13	Outcome: Complicated grief CB had no impact on complicated grief in a multivariate logistic regression.	-	6 mo: 7.6%

(Continues)

TABLE 1 (Continued)

Author, Year, Country	Sample (N; mean age; gender; relation to patient)	Prospective Design	Time of Postbereavement Assessment	CB Measure	Outcome Measure	Association of Outcome with CB		Prevalence of/Group Differences in Outcome Measure
						Personal Strain	Role Strain	
Rossi Ferrario et al. (2004), Italy ⁴⁵	N = 93; 56.2 y; 70.97% female; 42% spouse, 37% child	Yes	3 mo, 6 mo, 12 mo	FSQ	Author's own; CMQ	Emotional burden, need to know about the disease and thoughts about death correlated positively with bereavement maladjustment scores. In a multiple linear (logistic) regression only emotional burden predicted the bereavement maladjustment score (incidence).	Problems in social involvement correlated positively with bereavement maladjustment. No association in multiple linear & logistic regressions.	n.a.
Thomas et al. (2014), Australia ⁴¹	N = 134; 56.2 y; 76.7% female; 47.8% spouse, 37.2% child	Yes	6 mo, 13 mo	CRA	PG-13	Caregiver esteem did not predict complicated grief symptom scores.	In a multiple regression, only schedule burden predicted complicated grief symptom scores 13 but not 6 months after bereavement.	6 mo: 6.7% 13 mo: 11.3%
Tsai et al. (2016), Taiwan ⁴⁸	N = 493; 50.67 y; 64.7% female; 50% spouse, 33% child	Yes	1 mo, 3 mo, 6 mo, 13 mo, 18 mo, 24 mo	CRA, objective caregiving demands,	PG-13		High subjective CB predicted a lower incidence of complicated grief. Objective CB had no significant influence.	6 mo: 7.37% 13 mo: 1.8% 18 mo: 2.49% 24 mo: 1.85%
Bradley et al. (2004), USA ³¹	N = 174; 57.0 y; 72.4% female	Yes	6 mo	ZI (short form)	SCID			6 mo: 11.5%
Francis et al. (2015, 2016), ^a USA ^{32,33}	N = 199/186; 54.8/54.6 y; 81.4/83.2% female; 41.2/59.6% live with patient	Yes	2-5 mo (average 3 mo)	CRA (without esteem scale)	POMS-SF (depression-dejection)		Schedule burden directly predicted a decrease in depression scores (total sample and both patient age groups: middle aged and older patients). Health burden predicted higher depression scores (total sample, both patient age groups). Family abandonment directly predicted increased (decreased) depression scores in caregivers of middle-aged (older) patients.	No difference in depressive symptoms between patient age groups
Kim et al. (2014), USA ³⁵	N = 416 (62 bereaved); 57.7 y; 83.9% female; 54.8% spouse	Yes	2.4 y (SD = 0.8)	PSS CRA (only esteem scale)	CES-D	Caregiving stress predicted higher depression scores and incidence. No association between caregiver esteem and depression scores or incidence.		2.4 y: 46.8%

Outcome: Depression

Overall CB:
CB did not predict the incidence depression significantly in a multiple logistic regression model.

Additional information:
The regression included bereaved and nonbereaved caregivers. Bereavement status had no significant impact on depression scores or incidence.

(Continues)

TABLE 1 (Continued)

Author, Year, Country	Sample (N; mean age; gender; relation to patient)	Prospective Design	Time of Postbereavement Assessment	CB Measure	Outcome Measure	Association of Outcome with CB		Prevalence of/Group Differences in Outcome Measure
						Personal Strain	Role Strain	
Kris et al. (2006), USA ³⁷	N = 175; 56 y; 74.9% female; 52% child, 30.2% spouse;	Yes	6 mo, 13 mo	ZI (short form)	SCID	Overall CB: Higher CB predicted the incidence of depression 13 mo post-death.		13 mo: 6.9%
Kuo et al. (2017), Taiwan ⁴⁹	N = 285; 48.33 y; 61.8% female; 25.6% spouse	Yes	1 mo, 3 mo, 6 mo, 13 mo, 18 mo, 24 mo	CRA, objective caregiving demands	CES-D	—	Perceived CB had no influence on the incidence of depression; objective CB predicted a higher incidence.	1 mo: 73.3% 3 mo: 49.6% 6 mo: 37.9% 13 mo: 23.0% 18 mo: 17.9% 24 mo: 15.2%
Kurtz et al. (1997), USA ³⁸	N = 114; Age n.a.; 75% female; 78% spouses,	Yes	3 mo	CRA (without impact on health)	CES-D	Caregiver esteem did not predict depressive symptom scores. In the spouse subsample, depressive symptoms were more likely to improve in those with low caregiver esteem.	No dimension of role strain had a significant impact on postbereavement depression.	n.a.
Ling et al. (2013), Taiwan ⁴⁷	N = 186; 47.14 y; 74% female; 45.7% spouse 37.6% child	Yes	1 mo, 3 mo, 6 mo, 13 mo	CRA, objective caregiving demands	CES-D	—	Higher perceived CB predicted a lower depressive symptom score. Objective CB had no significant influence.	1 mo: 59% 3 mo: 47% 6 mo: 42% 13 mo: 39%
McHorney & Mor (1988), USA ³⁹	N = 1447; 58 y; 72% female; 54% spouse; 28% child;	Yes	3-4 mo	Author's own: Satisfaction with caregiving abilities	Clayton's measure of positive symptom complex	Dissatisfaction with caregiving abilities almost doubled the incidence of depression.	—	3-4 mo: 19.7%
Nielsen et al. (2017), Denmark ⁴³	N = 1989 62.0 y; 70% female; 64% spouse;	Yes	6 mo	BSFC	BDI-II	CB had no impact on depression in a multivariate logistic regression.	—	6 mo: 12.1% (moderate to severe depression)
Song et al. (2012), Korea ⁴⁶	N = 501; 53.2 years; 58.5% female; 46% spouse	No	2-6 mo	CCI	Author's own: depressive symptoms, suicidal thoughts	High mental burden of caregiving predicted depressive mood and suicidal ideation 2-6 mo after bereavement.	No dimensions of role strain had a significant impact.	2-6 mo: 33.1% "depressive moods" 31.4% suicidal thoughts

Abbreviations: CB = caregiver burden; GMH = general mental health; M = months; Y = years; SD = standard deviation; n.a. = not available; **CB Measures:** BDI-II = Beck Depression Inventory-II⁵¹; BSFC = Burden Scale for Family Caregivers⁵²; CCI = Caregiving Consequences Inventory⁵³; CRA = Caregiver Reaction Assessment⁵⁴; FSQ = Family Strain Questionnaire⁵⁵; PSS = Pearlin Stress Scale⁵⁶; WSAS = Work and Social Adjustment Scale⁵⁶; ZI = Zarit Interview⁵⁷; **Outcome Measures:** BSI = Brief Symptom Inventory⁵⁸; CES-D = Center for Epidemiologic Studies Depression Scale⁵⁹; CIS-R = Revised Clinical Interview Schedule⁶⁰; CMQ = Caregiver Mourning Questionnaire⁴⁵; EQ-5D = EuroQol 5 dimensions questionnaire by one study⁶¹; PG-13 = Prolonged Grief Scale⁶²; POMS-S = Profile of Mood States (Short Form)⁶³; SCID = Structured Clinical Interview for DSM-IV⁶⁴

[†]The 2 papers have been conflated because they are based on a common sample and examine the same outcome measure. However, the 2016 paper further examined a large proportion of the original sample by distinguishing 2 patient age groups. Numbers in the sample description are ordered (2015/2016), respectively.

without distinguishing between the 2 diagnoses. Therefore, the corresponding results were also grouped here as GMH assessments.

Bereaved caregivers had GMH scores significantly below the population norm in most studies.^{36,42,44,46} Kim et al³⁶ included current caregivers and those who were no longer caregiving. Changing out of the caregiver role due to bereavement as opposed to remission predicted worse mental health. Kapari et al⁵⁰ found a 36.6% (22%) prevalence of "common mental disorder" 3(6) months after bereavement, which encompasses depressive symptoms, anxiety, and somatic symptoms⁶⁷; Garrido and Prigerson³⁴ found a 12.62% prevalence of depression/anxiety 6 months after bereavement.

3.3.2 | Impact of CB on GMH

The overall measure of CB had no impact on GMH in one study.⁵⁰

Personal Strain: One study found a significant negative effect of perceived burden (assessed retrospectively) on GMH in a multiple regression,⁴⁴ whereas another found a high "burden of providing emotional support" to predict improvement in mental health on the borderline of significance ($P = .06$), but also a contradicting significant effect indicating that those more burdened have slightly higher odds of developing anxiety/depression.³⁴ Two cross-sectional studies found no effect of esteem or mental burden on postbereavement GMH.^{42,46} Controlling for bereavement status, Kim et al^{36,40} found *personal strain* to partially predict impaired mental health: stress overload predicted both postbereavement distressed mood (both papers) and mental health (one paper). Caregiver esteem predicted neither.

Role strain: One study found no association,⁵⁰ whereas two (one cross sectional) found evidence for a negative effect of some aspects of role strain (schedule and health burden, family abandonment) on GMH.^{42,46}

Overall, there is weak evidence indicating an adverse effect of *personal strain* and *role strain* on postbereavement GMH.

3.4 | Caregiver burden and complicated grief

3.4.1 | Measurement and prevalence of complicated grief in bereaved caregivers

Of the 4 papers assessing complicated grief, 3 used the Prolonged Grief Scale (PG-13).⁶² Rossi Ferrario et al³⁵ used their own measure, the Caregiver Mourning Questionnaire.

The prevalence of complicated grief (assessed with the PG-13) varied from 1.8% to 11.3% 13 months after bereavement.^{41,48}

3.4.2 | Impact of CB on complicated grief

Personal strain: A high level of emotional burden predicted bereavement maladjustment.⁴⁵ Caregiver esteem and CB measured with the Burden Scale for Family Caregivers had no impact on complicated grief.^{41,43}

Role strain as an overall measure predicted a lower incidence of complicated grief.⁴⁸ Contradictory findings exist for some aspects of role strain: schedule burden had an adverse effect on complicated grief 13 months after bereavement.⁴¹ Problems in social involvement predicted a higher bereavement maladjustment score. This effect

vanished though when controlling for confounders such as relationship to patient or emotional burden.⁴⁵

Overall, *personal strain* seems to predict higher complicated grief scores to some extent, whereas results for *role strain* are ambiguous.

3.5 | Caregiver burden and depression

3.5.1 | Measurement and prevalence of depression in bereaved caregivers

Of the 11 papers reporting on depression, 3 used the Center for Epidemiologic Studies Depression Scale,⁵⁹ and 3 used measures derived from the DSM-IV or similar criteria: The Structured Clinical Interview for DSM-IV (2 papers) and Clayton's Measure of Positive Symptom Complex⁶⁸ (one paper). One⁴³ used the Beck Depression Inventory-II,⁵¹ and two^{32,33} the subscale "depression-dejection" from the Short Form of the Profile of Mood States. Song et al⁴⁶ used their own questions to assess depressive mood and suicidal thoughts.

The reported prevalence of postbereavement depression in caregivers varies substantially. Studies that used the Center for Epidemiologic Studies Depression Scale found a prevalence ranging from 15% to 59% within the first 2.4 years after bereavement,^{35,47,49} whereas studies using measures based on DSM-IV or similar criteria^{64,68} found a lower prevalence of 6.9% to 19.7% within the first 13 months of bereavement.^{31,37,39}

Overall, studies show a decrease in prevalence rates over time.^{31,37,41,47}

3.5.2 | Impact of CB on depression

Concerning overall CB, one study^{31,37} found results depending on time since death: CB did not predict depression at 6 months, but did at 13 months post-death.

Personal Strain: One study⁴³ found no impact of personal strain on depression incidence. Another found no association of caregiver esteem with postbereavement symptom levels, although low caregiver esteem was found to predict improvement in depressive symptoms when comparing prebereavement and postbereavement levels of spouses in the same study.³⁸ Mental burden (assessed retrospectively)⁴⁶ and dissatisfaction with caregiving abilities³⁹ were associated with increased depression scores and incidence. Kim et al³⁵ found stress overload but not caregiver esteem to positively predict depression in bereaved and current caregivers equally, indicating that the effect of CB does not change with the death of the patient.

Role strain as an overall measure predicted fewer depressive symptoms in bereavement in one paper⁴⁷ but not in a related paper based on a larger sample.⁴⁹ Contradictory findings are also reported for single dimensions of role strain: A high health burden³² predicted higher depression scores. A high impact on schedule predicted lower subsequent depression scores in one study,³² but had no effect in others.^{38,46} Impact on finances^{32,38,46} and physical burden (assessed retrospectively)⁴⁶ had no significant effect on depression. Family abandonment had differing effects depending on patient age group: adverse for caregivers of middle-aged patients (40-59 y), beneficial for those of older patients (60-79 y).³³

Overall, there is some evidence for an adverse effect of *personal strain* on postbereavement depression, whereas results for *role strain* are again ambiguous.

4 | DISCUSSION

The aim of this systematic review was to provide an overview of existing research on the association between CB and postbereavement mental health. To our knowledge, no such review exists in the English language. Overall, 20 papers were included that reported on GMH (7 papers), complicated grief (4 papers), and depression (11 papers). Because the small number and high heterogeneity of the included studies only allow for preliminary conclusions, the main implications concern suggestions for future research.

Caregiver burden was diversely conceptualized. No article elaborated on a definition, resulting in varying ways of operationalization. Six different measurement tools were used, of which the CRA is the most common (10 papers, 6 studies^{32,33,35,36,38,40-42,47-49}). Three authors preferred using their own questions to established measurement tools.^{34,39,44} The lack of a definition and the diverging operationalization methods reduce generalizability and impede synthesizing the results.

A differentiation of CB into *role strain* and *personal strain* was performed in this systematic review to ensure comparability to the greatest extent possible at the current state of research. *Role strain* refers to impairments due to caregiving in other areas of life, whereas *personal strain* comprises emotional and self-related responses to caregiving demands. Therefore, the following conclusions should be considered a preliminary overview.

Bereaved caregivers of cancer patients were shown to exhibit poorer levels of overall mental health than the general population.^{36,40,42,44,46} Yet neither the prevalence of complicated grief (1.8% to 11.3%^{41,48}) and depression (6.9% to 19.7%^{31,37,39}) among caregivers nor the long-term course of symptoms differed substantially from findings concerning the general bereaved population³⁻⁷ or caregivers of patients with other illnesses, eg, Chentsova-Dutton et al⁶⁹ This indicates that caregiving alone does not impair bereavement adjustment. The question remains whether more burdensome caregiving experiences have a differential effect.

Two competing models were introduced: The *cumulative stress perspective* predicts that high CB impairs postbereavement mental health. The *stress reduction perspective* predicts that the death of the patient results in alleviation of CB, thus freeing resources for bereavement adjustment. Evidence for both theories was found. Possible explanations will be discussed below.

One study found no effect of CB on postbereavement GMH.⁵⁰ One study reported mixed results for *personal strain*,³⁴ and 5 studies showed an adverse effect of at least some aspects of *personal* and *role strain*.^{36,40,42,44,46} However, three of the latter used cross-sectional data, which entails the risk of recall bias. Therefore, the *cumulative stress perspective* was to some extent confirmed for *personal* and *role strain*, but results have to be interpreted cautiously.

Complicated grief was differentially affected by 2 aspects of *personal strain*: “emotional burden” had an adverse effect in one study,⁴⁵ but “caregiver esteem” had none in another.⁴¹ *Role strain* decreased the incidence of complicated grief in one study,⁴⁸ whereas 2 studies reported some aspects of *role strain* to increase the incidence of complicated grief.^{41,45} One of them indicated that the effect only appears when regarding longer time frames (13 vs 6 months). Overall, some evidence supports the *cumulative stress perspective*. However, other results confirm the *stress reduction perspective* for *role strain*.

Postbereavement depression was predicted by overall CB 13 months after bereavement in one project.³⁷ *Personal strain* had no impact in one study,⁴³ predicted improvement of depressive symptoms on the within-subject level in another (comparing pre- and post-loss values),³⁸ but had an adverse effect on the between-subject level in 3 others (comparing the highly and less personally strained).^{35,39,46} However, one of these studies only used their own questions to assess depression and used a cross-sectional design, entailing the danger of recall bias.⁴⁶ Overall, *role strain*⁴⁷ or *schedule burden*^{32,33} predicted lower depression scores, whereas *health burden* predicted higher scores.^{32,33} Results for family abandonment differed by age group.^{32,33} Three studies found no influence of *role strain*.^{38,46,49} Overall, some evidence supports the *cumulative stress perspective*, yet some results exist for *role strain* that confirm the *stress reduction perspective*.

Summarizing the results across all outcome measures, *personal strain* may be seen as having an adverse effect, if any, confirming the *cumulative stress perspective*. Inconsistencies in the reported findings are attributable to a number of factors: (1) The effect might be weak, unstable, or dependent on covariates that have not been assessed in all studies. A recent review showed that several factors that influence CB in dementia caregivers⁷⁰ may also influence bereavement adjustment, eg, coping skills. If not controlled for, these factors may lead to a misjudgment of the role of CB. (2) The methods of operationalization and measurement used may have an impact on results. (3) Effects differ depending on whether self-related or emotional responses were assessed and whether comparisons were made within or between subjects. (4) Effects are influenced by limitations of the included studies such as most studies using data from convenience samples, possibly resulting in selection bias.

The conflicting results regarding *role strain* might be explainable by 3 observations: (1) 2 of 3 papers that found a beneficial effect of *role strain* stem from the same Taiwanese sample, indicating that a cultural effect might be at play. When intensive caregiving is expected, as reported for Asian countries,⁷¹ the concomitant burden may be understood as an affirmation of fulfillment of normative demands. Also, cultural expectations concerning concealment of negative emotions⁷² might have reinforced this effect. (2) The adverse effect of *health burden* may be caused by a deprivation of the corresponding resources (eg, impairments to physical health due to physical requirements of caregiving) that persists beyond bereavement.¹⁶ The less persistent nature of *schedule impairments* and the seemingly age-dependent effect of family abandonment may explain the more inconsistent findings for these dimensions. (3) Research concerning positive aspects of caregiving revealed that intensive caregiving, as

may be reflected by a high role burden, may also foster a sense of personal growth, meaningfulness, and facilitation of communication about grief,^{15,73} which in turn, might benefit bereavement adjustment.

The results allow for a cautious assumption that personal strain has an adverse effect on postbereavement mental health and that the multiple aspects of role strain have differential effects. The co-occurrence of seemingly conflicting results may also indicate that the *cumulative stress perspective* and *stress reduction perspective* do not necessarily mutually exclude each other. The presented findings are consistent with current research concerning bereavement after loss due to other illnesses, insofar as that some studies found a negative impact of CB,⁷⁴⁻⁷⁶ whereas others found none.⁷⁷ The found effects are also in line with studies examining the effect of interventions targeted at reducing CB, which found a beneficial effect on mental health during caregiving^{78,79} and after bereavement.⁸⁰ Yet the divergence of results forbids any definitive conclusions about the influence of CB on postbereavement mental health.

4.1 | Limitations

The current systematic review only included research published in peer-reviewed journals. This may result in publication bias: Papers that found no impact of CB on postbereavement mental health might not have been published. Because CB is often examined as one of many constructs predictive of postbereavement mental health, studies that examined CB as a secondary predictor but did not mention this in title or abstract may have been overlooked. Also, only English articles were included. This presumably led to most of the presented papers stemming from western countries.

Some papers only reported on total scores of a measurement tool that mainly assessed 1 of the 2 dimensions of CB. In such cases, results were allocated to the dominant dimension for comparability and readability, possibly leading to a distortion of the results.

High heterogeneity in design, sample size, types of comparisons made, and operationalization of constructs paired with a small number of studies lead to low comparability.

4.2 | Clinical implications

Although the included studies allow only cautious conclusions, there is evidence suggesting that CB negatively impacts postbereavement mental health. Emotional distress due to caregiving may especially impair bereavement adjustment. Role strain also seems to result to some extent in a depletion of resources, which complicates adjustment to the loss. Therefore, intervening and preventive approaches targeting CB may influence bereavement adjustment and have a beneficial effect lasting beyond the loss of the patient. The importance of general psychosocial attendance to relatives of cancer patients during the time of illness is hereby also underlined. Early intervention may reduce complications in bereavement and subsequent health care utilization. The concept of CB and its repercussions on caregivers should therefore be brought to the attention of palliative care staff.

5 | CONCLUSION

To our knowledge, this systematic review is the first to compare effects of CB on bereavement outcomes across studies focusing on bereaved relatives of cancer patients. To date, CB as a risk factor for bereavement maladjustment has rarely been examined and only loosely defined. The presented results differ widely between studies. Due to the lack of a precise operational definition of CB and the resulting variation in used measures, it cannot be determined whether these inconsistencies arise from methodological issues or reflect a weak overall effect of CB on postbereavement mental health. It also remains unclear which components of CB might cause difficulties in bereavement adjustment and how they interact with each other and with other influencing factors.

This systematic review shows that further examining the impact of CB on postbereavement mental health is an indispensable prerequisite for interventions that could positively influence the trajectory of caregiver distress beyond bereavement. For this purpose, CB should be thoroughly defined and examined as a multidimensional construct with established measurement tools.

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