REVIEW

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Variables associated with distress amongst informal caregivers of people with lung cancer: A systematic review of the literature

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Abstract

Objective: Informal caregivers of people with lung cancer often experience a substantial care burden and associated negative consequences due to the often-contracted course of the disease. The objective of this review was to systematically examine the evidence on the factors associated with lung cancer caregiver distress.

Methods: Five databases (MEDLINE, CINAHL, EMBASE, PsychINFO and Web of Science) were searched for studies investigating factors associated with distress amongst caregivers of people with lung cancer. Empirical studies published up to July 2020 were included if they measured distress using a valid and reliable measure and examined its association with at least one other factor, with a sample of 50 or more caregivers.

Results: Thirty publications describing 27 studies (16 cross-sectional; 6 prospective; 8 intervention) involving 3744 caregivers (primarily spouse or adult child) were included. A narrative synthesis of the findings is presented due to heterogeneity in study design, variables measured and analyses conducted. Patient variables associated with greater distress included: stage of cancer and quality of spousal relationship. Caregiver variables associated with higher distress included: social support, coping strategies and self-efficacy.

Conclusions: Several variables were associated with distress amongst lung cancer caregivers. Understanding these variables could inform the development of interventions that will enable caregivers to care effectively while maintaining their own well-being. Screening for distress among caregivers may identify those caregivers who would benefit from early intervention.

KEYWORDS
anxiety, burden, cancer, depression, distress, informal caregivers, lung cancer, oncology, psycho-oncology

1 | BACKGROUND

Lung cancer is the second most commonly diagnosed cancer worldwide (11.4% of the total cases) and the leading cause of cancer death (18.4%).[1] In spite of several advancements in treatment, international 5-year survival rates remain lower than other causes of cancer at around 17%.[2] Symptoms associated with the disease and treatment side effects include pain, dyspnoea, fatigue and anorexia. The symptom burden of people with lung cancer has been reported as greater than that experienced with other types of cancer,[3] and is associated with impaired functioning and a concomitant negative impact on quality of life.[4] In addition, lung cancer is associated with high levels of distress[5,6] and an increased suicide risk,[7] compounded by perceived stigma and shame related to smoking behaviours.[8]

As lung cancer patients are frequently investigated and treated as outpatients whenever possible,[9] informal caregivers may face considerable duties and responsibilities.[10] For example, compared to other cancer types, patients with lung cancer report long-term effects on daily functioning and higher levels of physical and daily living support needs.[11] Thus, the tasks associated with caregiving may include assisting with activities of living, co-ordinating care, monitoring treatment and managing side effects and symptoms, seeking information, and the provision of emotional, and social and spiritual support.[12,13] Caregivers frequently take on these tasks feeling ill-prepared to meet the diverse needs of the patient particularly as the disease progresses.[14,15] The care burden combined with the often contracted course of lung cancer, therefore, has been associated with negative consequences for psychological, social, and spiritual functioning for informal caregivers, leading to deteriorating psychological well-being and quality of life.[16-20] Furthermore, a European wide study indicated that the burden of caring for someone with lung cancer is associated with an increased likelihood of stress-related illness, including depression and insomnia, and may also impact work productivity and other activities potentially increasing the risk of social isolation.[21]

The caregiving burden and associated psychological distress related to the new and developing role as a caregiver[16] may, in turn lower self-efficacy and confidence in supporting the patient.[22,23] As a consequence, mitigating any distress experienced by caregivers, would not only be important for their own well-being but could also improve patient outcomes. A systematic review of psychosocial interventions for caregivers of lung cancer patients[24] argued that clinicians and health care organisations should address caregiver's need and quality of life as part of an integrated care delivery model. The review included 22 studies and concluded that overall, the interventions had positive benefits on various outcomes related to the emotional, physical and social aspects of caregiving, including alleviation of distress.[24] However, while multicomponent interventions tended to produce better results than those with a single focus, there is still be a need to identify the specific factors that are associated with caregiver distress in order to develop future models of care and meaningfully inform effective interventions for lung cancer caregivers. The current review, therefore, aimed to identify the specific variables associated with caregiver psychological distress in published research to date.

2 | METHODS

This review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement, and has been registered with Prospero (CRD42020202572).

2.1 | Search strategy

A systematic search of five databases (MEDLINE [EBSCO)], CINAHL, EMBASE, PsychINFO, and Web of Science Social Sciences Citation Index) was conducted by two authors (O. R. and S. W.), with no restrictions on date of publication. The search was limited to literature published in English, and updated July 2020. See Supporting Information Materials S1 for the MEDLINE search strategy. The authors also screened the reference lists of included articles and existing reviews to identify any additional eligible articles. All titles and abstracts of the identified articles were screened for eligibility by two authors (O. R. and S. W.) and those that were deemed irrelevant were discarded. The full texts of the remaining studies were obtained and independently reviewed by the same two authors. Any disagreement as to inclusion/exclusion was resolved by discussion and consensus, and the other authors (S. D., P. G. or A. C.) were available to resolve any disputes.

2.2 | Selection criteria

We considered studies that included people aged 18 or over identified by the person with lung cancer (small cell and non-small cell lung cancer) as the main caregiver; this included spouse/partner, adult child, other family member or friend. Distress was conceptualised as a "multifactorial unpleasant experience of a psychological (cognitive, behavioural, emotional), social, spiritual and/or physical nature that may interfere with the ability to continue to cope effectively" (National Comprehensive Cancer Network[25]). Studies were included if they had investigated the relationship between caregiver distress using a standardised measure and at least one other factor. There were no restrictions as to quantitative research design; qualitative studies were excluded. Studies were also excluded if the sample involved less than 50 caregivers as these may not be sufficiently powered to establish reliable findings. Non-English publications were excluded. Studies with mixed cancer types where the findings for the lung cancer caregivers could not be disaggregated were also excluded.

2.3 | Quality assessment

Included articles were critically appraised by two authors (O. R. and S. W.) to evaluate risk of bias using a 12-item checklist based on previous research,[26] supplemented by standard critical appraisal questions.[27] The studies were given a score of two for every criterion on the checklist which they fulfilled, a score of one where they partially fulfilled the criterion and zero where they failed to fulfil the criterion. In line with the assessment criteria associated with this assessment tool,[26] studies were rated as high quality if they scored greater than 17 out of a possible score of 24, adequate quality if they scored between 9 and 17, and low quality if they scored less than 9. If there was any disagreement between the raters, consensus was achieved through discussion.

The Cochrane risk of bias tool[28] was employed for the included intervention studies and appraised by two authors (A. C. and S. D.). This tool assesses several domains of potential bias (selection bias, reporting bias, performance bias, detection bias and attrition bias) which are judged to be at high or low risk of bias. Any disagreement was resolved through consensus.

2.4 | Data extraction and synthesis of results

The following data were extracted from eligible articles: (1) the study location; (2) aim(s); (3) design; (4) recruitment setting; (5) caregiver characteristics (age, gender, relationship to person with lung cancer); patient characteristics where available (stage of cancer, time since diagnosis); (7) psychosocial (distress) tool(s) used; (8) predictor(s) of distress assessed and tools used; (9) the specific findings determining the relationship, if any, between the measure of distress and the predictor variables.

Due to the heterogeneity of the included studies, we were unable to conduct a meta-analyses and instead adopted a narrative approach to synthesise findings.

3 | RESULTS

Figure 1 summarises the screening and selection process; searches of the electronic databases yielded 3770 studies. After removal of duplicates, titles and abstracts of 2730 articles were screened and 196 were identified as potentially relevant. Following assessment of the full text of these 196 articles, 30 articles met the inclusion criteria.

3.1 | Study characteristics

The 30 articles (describing 27 studies) included 3744 caregivers (see Tables 1 and 2). We included four articles from the one study[17,37–39] as each paper examined a different range of variables and reported the association with distress. Sample sizes ranged from 50 to 366 caregivers. The mean age of the caregivers was 58.5 years (ranged

from 47.3 to 66.1), and the majority (65.4%) were female. Nineteen of the studies recruited both patient and caregiver, and reported findings related to both. In eight studies, the caregiver was the spouse[29–35] while for the remaining studies the relationship between the patient and caregiver was primarily either spouse/partner or adult child. Sixteen of the studies[16,29–32,34,36,42,43,46–50,52,55] reported the stage of cancer and over one third (37.6%) of the patients were at stage IV at the start of the study. The time since diagnosis, where reported, ranged from 2 months to 5 years. The eligible articles included cross-sectional ($n = 16$) and prospective ($n = 6$) designs, and intervention studies ($n = 8$). The majority of the studies were conducted in the USA ($n = 21$), with four from Asia (Taiwan $n = 2$; Hong Kong $n = 1$; Korea $n = 1$), one from South America (Brazil) and one from Europe (The Netherlands).

3.2 | Quality assessment

The quality assessments of the cross sectional and prospective studies are summarised in Table 1 (with further details in Table S2); four of the studies[32,35,40,45] were rated as of 'acceptable quality' while the remaining studies were of 'high/good quality' (scoring over 17 out of a possible 24). The main areas in which articles scored poorly included failure to justify sample size and lacking description of nonresponders and nonparticipants.

Risk of bias in relation to the eight intervention studies is summarised in Table 2 (with further details in Table S2). While four of the intervention studies[48,50,51,53] were judged to be at low risk of bias overall, there was insufficient detail to make a clear judgment in some domains, particularly in relation to blinding. One further study[49] was rated as 'unclear' overall. Two of the included intervention studies were not randomised control trials and a quality assessment was conducted rather than a risk of bias. One of these studies[54] employed a sequential design and was assessed as 'high quality' overall, while the other study[52] was a secondary analysis of an RCT and was rated as 'acceptable quality'. The final study was judged to be at a moderate risk of bias overall[55] as there was some concern in relation to allocation concealment, and a lack of clarity in other domains.

3.3 | Measurement of distress

While distress was conceptualised broadly,[25] the majority of studies assessed psychological distress, that is, depression and anxiety. There was some heterogeneity in the questionnaires used to measure distress, as follows (in some studies two measures of distress were employed): Hospital Anxiety and Depression Scale (HADS; $n = 6$),[22,32,34,36,41,49] Hamilton Depression Rating Scale ($n = 3$),[29,30,32] Brief Symptom Inventory (BSI; $n = 1$ reported in four articles),[17,37–39] Center for Epidemiological Studies Depression (CESD; $n = 7$),[30,35,40,44,45,46,53] Profile of Mood States (POMS; $n = 4$),[33,47,48,55] Distress Thermometer (DT; $n = 2$),[16,54] PROMIS
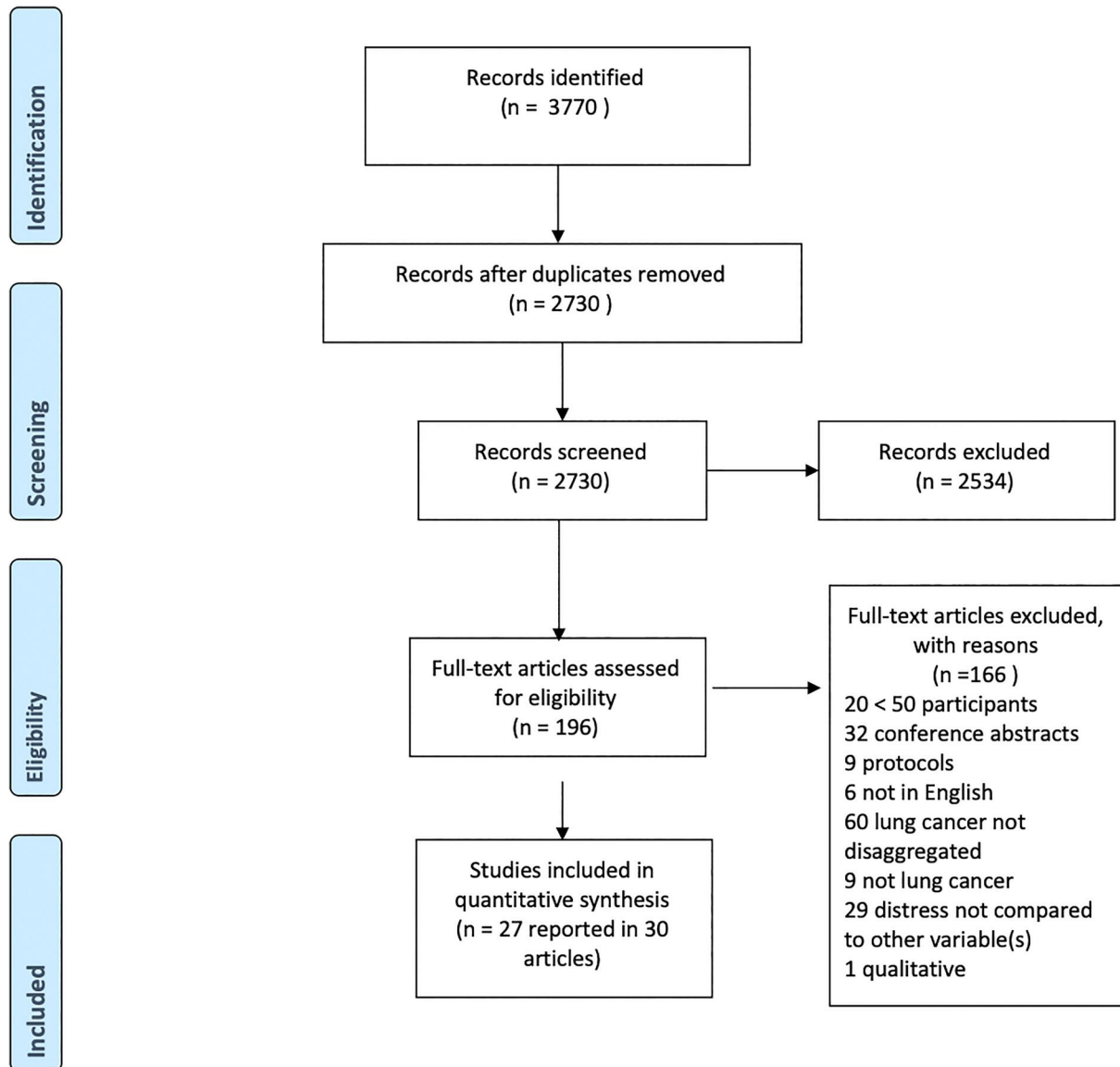
FIGURE 1 PRISMA study flow diagram. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses

Anxiety and Depression measures ($n = 1$),[51] Beck's Depression Inventory (BDI; $n = 1$),[42] Patient Health Questionnaire and Generalised Anxiety Disorders scale (PHQ GAD; $n = 2$),[50,52] Death Anxiety Scale ($n = 1$).[43]

Twelve studies reported the proportion of participants who reached clinically relevant levels of depression and/or anxiety. The first of these studies, Mosher et al.[36] recruited caregivers who had elevated distress (≥ 8 on either depression or anxiety subscales HADS); 78% continued to meet the clinical cut-off during the study. In another study,[34] 31.8% had clinically heightened levels of distress (HADS-T $\geq$ equal to 15), and in a further study[22] 50.9% of caregivers were at risk of anxiety and 32.1% at risk for depression. In an additional study by Fujinami et al.[16] 52% ($n = 85$) of the participants scored above cut-off of 4.0 for high distress using the DT. In the series of related articles[17,37–39] using the BSI, 30% met criteria for 'caseness' (BSI) at baseline, and this had decreased to 14% at the 6-

month follow-up. For three of the studies using the CESD between 22% and 30% of caregivers reached the clinical cut-off for depression (scores ≥ 16).[30,35,40] Finally, gender differences in distress were only specifically examined in two studies, and in both cases female caregivers reported higher levels of depression than men.[29,32]

There was considerable variation in the factors examined and the instruments used to measure them. All of the included observational studies demonstrated a significant relationship between distress and at least one other factor, whereas there were mixed findings with regards to the intervention studies.

3.4 | Observational studies

The factors have been categorised into three main groupings as follows: (1) patient variables; (2) relationship quality; and (3) caregiver

TABLE 1 Characteristics of included studies: Cross-sectional and prospective studies

Author (year)	Country	Study design and measurement timepoints	Sample	Clinical characteristics of patient	Distress measure	Variables assessed	Caregiver variables significantly associated with distress	Patient variables significantly associated with distress	Quality assessment measure
Abernethy et al. (2002)[29]	USA	Cross-sectional	156 spousesMean age: 63.9 SD: 9.1278% Female	Stages: I: 44%; II: 12%; III: 29%; IV: 15%Diagnosed within previous 5 years	Hamilton Depression Rating Scale	(1) Religious Coping Index; (2) Perceived Control; (3) Interpersonal and Instrumental Self Efficacy; (4) Duke Social Support Index	Social support [−] Self-efficacy [−] Perceived control [−] Religious coping [+]	Cancer stage [+]	Good
Badr et al. (2008)[37]	USA	ProspectiveT0 within 4 weeks of treatment starting; 3 and 6 months follow-up	167 dyads (all spouse) Mean age: 62.86 SD: 10.1467.1% Female	Stages: I: 16.3%; II: 14.5%; III: 32.5%; IV: 36.7%Mean time since diagnosis: 2.3 month SD: 11.08	BSI	(1) Relationship talk; (2) Dyadic Adjustment Scale	Relationship talk satisfaction [−]		Good
Badr and Carmack Taylor (2008)[38]	USA	ProspectiveT0 within 4 weeks of treatment starting; 3- and 6-month follow-up	158 dyads (all spouse)Mean age: 60.39 SD: 11.0867.1% FemaleSame sample as Badr, Acitelli and Carmack Taylor	Same sample as Badr, Acitelli and Carmack Taylor	BSI	(1) Dyadic Adjustment Scale; (2) RMSM		Positivity [−] Networks [−] Shared tasks [−]	Good
Borges et al. (2016)[41]	Brazil	Cross-sectional	91 dyads: Spouse 30% Adult Child 49%Stratified by QoL (impaired/nonimpaired) and cancer stage (early/advanced) Mean age: 47.6 SD: 13.284% Female	Adenocarcinoma: 52% locallly advanced or metastatic: 64%	HADS	(1) Caregiver Burden Scale;(2) Patient: SF36		Stage [+] QoL [−]	Good
Carmack Taylor et al. (2008)[39]	USA	Cross-sectionalT0 within 4 weeks of starting treatment	Same sample as Badr, Acitelli and Carmack Taylor	Same sample as Badr, Acitelli and Carmack Taylor	BSI	(1) COPE(2) CAGE (3) MOS Social Support (4) Blame (2-items)	Behavioural disengagement [+] Substance use [+] Blame [+]	Behavioural disengagement [+]	Good

TABLE 1 (Continued)

Author (year)	Country	Study design and measurement timepoints	Sample	Clinical characteristics of patient	Distress measure	Variables assessed	Caregiver variables significantly associated with distress	Patient variables significantly associated with distress	Quality assessment measure
Fujinami et al. (2015)[16]	USA	Cross-sectional	163 Caregivers, 68% spouses. 20.3% Adult Child Mean age: 57.23SD: 13.1664% Female	NSCLC Stage: I and II: 21%; III: 23%; IV: 56%	Distress thermometer	(1) City of Hope QoL Scale—Family version; (2) Caregiver Burden Scale; (3) Preparedness for Caregiving Scale	Self-care [-] Preparedness and subjective demand burden [-] subjective stress burden [+]		Good
Hsieh et al. (2019)[42]	Taiwan	Cross-sectional	72 dyads, 72% Partners 21% Adult Child Mean age: 50.69 SD: 11.4652.78% Female	Stage I-IIIa: 48.6%; IV: 51.39%	Beck Depression Inventory	(1) Kingston Caregiver Stress Scale, (2) FFMQ, (3) Compassion for Self and Others subscales from the Compassion Engagement and Action Scale	Stress [+] dispositional mindfulness [-] self-compassion [-]	Dispositional mindfulness [-]	Good
Kim et al. (2005)[30]	USA	Cross-sectional	120 spouses Mean age: 63.1 SD: 1066% Female	Stage I: 47%; II: 25%; III: 25%; IV: 16% Majority had completed treatment	CESD; Hamilton Depression Scale	(1) Neo-5; (2) Self-efficacy Scale, (3) Duke Social Support Index, (4) Burden Inventory	Neuroticism [+] Self-efficacy [-] Mediated by burden and social support		Good
Kim et al. (2015)[44]	USA	Prospective Caregivers: Patients T1 4 months T2 12 months postdiagnosis	186 dyads (212 colorectal)Age/gender not reported separately for LC	Not reported 5-month postdiagnosis	CESD	SF-12	Physical QoL [-] Mental QoL [-]	Patients depression [-] effect on caregivers physical QoL	Good
Lau et al. (2018)[43]	Hong Kong	Cross-sectional Baseline data from RCT	173 dyads 66.5% spouses Mean age: 53.2 SD: 12.653.8% Female	Stage I: 2.3%; II: 6.4%; III: 19.1%; IV: 62.4%	Anxiety (Death Anxiety Scale)	Dysfunctional Attitudes Scale, Caregiver QoL Index-cancer	Achievement [-] Dependency [-] Self-control [-] QoL [-]		Good
Lee et al. (2013)[22]	Taiwan	Cross-sectional	106 dyads 42.4% spouses, adult children 38.7% Mean age: 47.3 SD: 14.167% Female	Stage IIIb or IV	Depression and Anxiety (HADS)	Self-efficacy scale	Age [-] Self-efficacy [-] Pain [+] Caring for another sick family member [+]	Higher OR for depression if spouse	Good

(Continues)

TABLE 1 (Continued)

Author (year)	Country	Study design and measurement timepoints	Sample	Clinical characteristics of patient	Distress measure	Variables assessed	Caregiver variables significantly associated with distress	Patient variables significantly associated with distress	Quality assessment measure
Lyons et al. (2014)[31]	USA	Prospective baseline, 3, 6, 9 and 12 months	77 dyads (spouse) Mean 66.1 SD: 11.369% Female	Stage IV 36%	Depression (CESD)	Relationship Quality Mutuality Scale	Relationship quality [−]	Physical function [−] Pain [+] Age [−] Relationship quality [−]	Good
Milbury et al. (2013)[17]	USA	ProspectiveT1 within 4 weeks of treatment starting T2 3 and T3 6 months follow-up	Same sample as Badr, Acitelli and Carmack Taylor		Distress (BSI)	(1) Caregiver Reaction Assessment (2) Dyadic Adjustment Scale	Caregiving burden [+] Esteem [−] Financial strain [+] Health problems [+]		Good
Mosher et al. (2013)[36]	USA	Cross-sectional Within 12 weeks of first visit to oncology	83 caregivers; spouse 62%, adult children 27%Mean age: 55 SD: 1277% Female	NSCLC (SCLC n = 5) Stage I: 22%; II: 14%; III: 28%; IV: 33%	Depression and Anxiety (HADS: above clinical cut-off at recruitment)	Covinsky Family Impact Survey, Caregiving Burden−help with IADLs	Loss of major source of income [+] Loss of involvement in social activities [+]		Good
Pinquart and Duberstein (2005)[32]	USA	ProspectiveTI baseline T2 I year	138 dyads (spouse) Mean age: 63.19 SD: 10.2165.2% Female	Stage I: 43.5%; II: 13.8%; III 27.5%; IV: 15.2%	Depression and Anxiety (HADS, Hamilton Depression Scale)	Life Orientation Test	Pessimism [+]	Depression [+] T1 Advanced stage [+]	Acceptable
Porter et al. (2012)[33]	USA	Cross-sectionalTime since diagnosis 18.4 months	127 dyads (spouse) Mean age: 62.8 SD: 10.562.2% Female	Majority (n = 123) stages I–III(SCLC n = 4)	Psychological distress (profile of Mood States)	Experience in close relationships	High avoidant [+] Anxious Avoidant [+]		Good
Porter et al. (2008)[47]	USA	Cross-sectional	152 dyads spouse 76%, adult children 14% Mean age: 60 SD: 13.266.4% Female	Stage I: 53.5%; II: 14.5%; III: 28.9%; IV: 2.6%	Psychological distress (profile of Mood States)	Self-efficacy Scale	Self-efficacy [−]		Acceptable
Sarna et al. (2006)[45]	USA	Cross-sectional	51 dyad (female patients) Spouse 57%, adult children 28% Mean age: 59 SD: 1435% Female	Stage not reported 80% surgery Mean time since diagnosis 22 months	CESD	SF-36	MCS [−]		Good

TABLE 1 (Continued)

Author (year)	Country	Study design and measurement timepoints	Sample	Clinical characteristics of patient	Distress measure	Variables assessed	Caregiver variables significantly associated with distress	Patient variables significantly associated with distress	Quality assessment measure
Schellekens et al. (2017)[34]	The Netherlands	Cross-sectional	88 dyads (spouse) Mean age: 61.6 SD: 8.4 Female: 68%	Stage I: 28%; II: 17%; IIIa: 18%; IIIb: 13%; IV: 24%	Depression and Anxiety (HADS)	Five Facit Mindfulness Questionnaire	Mindfulness [−] Self-compassion [−]		Good
Seo and Park (2019)[46]	South Korea	Cross-sectional	107 caregivers Spouse 62.6% Adult Child 30.8% Mean age: 60.25 SD: 11.4275.7% Female	Stage I: 25.2%; II: 9.3%; III: 7.5%; IV: 45.8%	CESD	Zarit Burden Interview Social Support Scale.	Burden [+] Social support [−]		Acceptable
Siminoff et al. (2010)[40]	USA	Cross-sectional	190 dyads Spouse 54.7% Adult Child 26% Mean age: 55 SD: 13.475% Female	Stage not reported Receiving treatment (65.5%) or recently completed (22.5%)	Depression (CESD)	Family Environment Scale Physical Health (4 items from SF20)	Age [−] blaming patient [+] spouse [+] Familial cohesion [+]Physical health [+]	Familial expressiveness [+] Familial conflict [+]	Acceptable
Thielmann and Conner (2009)[35]	USA	Cross-sectional	164 dyads (spouse) Mean age: 61.9 SD: 10.8 Female 60.4%	Stage I–IV diagnosed at least 3 months prior to inclusion	Depression (CESD)	Caregiver Demands Scale, Modified Interpersonal Support Evaluation List	Demands [+] Social support [−]		

Note: [+] and [−] indicate the direction of impact on distress.

Abbreviations: BSI, Brief Symptom Inventory; CESD, Center for Epidemiological Studies Depression; FFMQ, Five Facet Mindfulness Questionnaire; HADS, Hospital Anxiety and Depression Scale; MCS, Mental Component Score; MOS, medical outcomes study; RMSM, relationship maintenance strategies measure; SCNS-P&C, Supportive Care Needs Survey-Partners and Caregivers.

TABLE 2 Characteristics of included studies: Interventions

Author (year)	Country	Sample	Clinical characteristics of patients	Distress outcome measure	Intervention components	Duration and assessment timepoints	Main findings	RoB assessment
DuBenske et al. (2014)[55]	USA	285 caregiversSpouse 72% Mean age: 55.66 SD68% Female	Stage IV 66.4% anticipated survival of at least 4 months	Short POMs	Intervention: Comprehensive health Enhancement System (CHESS) plus standard care and InternetControl: Internet plus standard care	Baseline and 6 months follow-up	Intervention group less negative mood than Internet only	Moderate
Milbury et al. (2020)[53]	USA	75 dyads (spouse/partner) Mean age 63.9 SD 10.351% Female	One year post diagnosis	CESD	Intervention: a. Couple based mediation (CBM; mindfulness support) b. Social support Control: standard care	One session per week for 4 weeksBaseline and 1 and 3 months follow-up	CESD difference bet CBM and UC no other sig main or interaction effects	Low
Mosher et al. (2016)[50]	USA	106 dyadsSpouse 63% Mean age 56.54SD 13.9573% Female	Stage I: 28.98%; II: 13.01; III: 17%; IV: 40.45%	PHQ-8 & GAD-7	Intervention: a. Telephone symptom management b. Education/support	4 weekly 45 min telephone sessions	No main or interaction effects for anxiety and depression symptoms	Low
Mosher et al. (2019)[51]	USA	50 dyads spouse 72%Mean age 57.02 SD 14.8184% Female	Stage III or IV NSCLC diagnosed at least 3 weeks before enrolment	PROMIS anxiety and depression	Intervention: a. Telephone-based ACT b. Education/support	Six sessions2 and 6 weeks follow-up	No main or interaction effectsNo meaningful change in any outcomes	Low
Porter et al. (2011)[48]	USA	233 dyadsMean age 59.3 SD 12.369% Female	Stage I: 52.6%; II:15.9%; IIIa: 25.9%SCLC; 4.3% Median days since diagnosis 207.5 (IQR 668) with previous 6 mths.	POMS-B,	Intervention: a. Coping skills training b. Education/Support	14 telephone sessions4 months follow-upPre-test, post-test and 4 months follow-up	Caregivers in both groups showed improvements anxiety	Low
Sun et al. (2015)[54]	USA	366 dyads (relationship not reported)Mean Age: 57.39 SD: 13.73762% Female	Stage I – IV NSCLC	DT	Intervention: Tailored QoL palliative care plan presented to MDT who offered recommendations to dyads plus 4 educational QoL sessions for caregivers, with tailored self-care planControl: Standard care	Baseline and 7 and 12 weeks follow-up	Intervention group lower psychological distress regardless of disease st; age.	Good quality*

TABLE 2 (Continued)

Author (year)	Country	Sample	Clinical characteristics of patients	Distress outcome measure	Intervention components	Duration and assessment timepoints	Main findings	RoB assessment
Winger et al. (2018)[52]	USA	51 dyads 62.75% spouse Adult Child 17.65% Mean Age 56.33 SD 14.0972.55% Female	Stage I -III 49.02%; IV 37.25%SCLC 13.6%	PHQ Generalised Anxiety Disorders Scale	Secondary analysis of Intervention: Telephone symptom management - Skills practice	4 weekly sessions6 weeks follow-up	Practice of guided imagery associated with less psychological distress	Adequate quality*
Xiu et al. (2020)[49]	Honk Kong	157 dyadsSpouse 69.4% Adult Child 17.2%Mean Age 53.9 SD 12.1852.2% Female	Stage I: 2.5%; II 6.4%; III 19.7%; IV: 63.7%	HADS,	Intervention: a. CBTb. Integrative body-mind-spirit		Both groups improved – no interaction effects	Unclear

Note: * non RCTs so quality assessment tool used [+] and [–] indicate the direction of impact on distress.

Abbreviations: CBT, cognitive behavioural therapy; CESD, Center for Epidemiological Studies Depression; Dt, Distress Thermometer; GAD, Generalised Anxiety Disorder; PHQ, Patient Health Questionnaire; POMS, profile of mood states; PROMIS, patient reported outcomes Measurement Information System.

variables. In some instances, studies reported findings relevant to more than one category. The findings of the multiple regression models reported in the articles are used in this review to determine the relationships between distress and variables, wherever available, otherwise we used the correlational analyses as reported.

3.5 | Patient variables

Patient variables were associated with caregiver distress in four studies.[29,31,32,41] Three studies[29,32,41] reported a relationship between the stage of cancer and depression and/or anxiety; in each case, more advanced cancer was associated with higher levels of distress amongst the caregivers. In one study,[31] caregivers experienced higher mean depression scores when the patient was younger ($p < 0.01$), and depressive symptoms increased as the patients' physical function declined ($\gamma_{70} = -0.05$, $p < 0.05$). Similarly, in another study,[41] impaired quality of life of patients was associated with higher levels of depression and anxiety for the caregiver ($p = 0.012$). Finally, Pinquart and Duberstein[32] reported that higher depression scores of the patient were associated with caregiver depression ($b = 0.72$, $p < 0.001$).

3.6 | Relationship between patient and caregiver

Variables concerned with the relationship between the person with lung cancer and their caregiver associated with distress were reported in five studies. One study reported in four articles[17,37–39] examined the effects of marital adjustment on the psychosocial adaptation to lung cancer; the Global Severity Index of the BSI was used to measure distress. Satisfaction with relationship talk (discussion between patient and spouse following cancer diagnosis) was associated with a decrease in distress for the caregiver spouse over the 6 months of follow-up[37] ($r = -0.21$ to -0.37, $p < 0.001$). Patient engagement in strategies that helped to maintain relationships was associated with lower levels of caregiver distress ($r = -0.06$ to -0.07, $p < 0.05$); in addition, caregivers reported less distress when the patient relied more on common social networks[38] ($b = -0.05$).

Lyons et al.[31] also reported on relationship quality; depressive symptoms were significantly lower for caregiver spouses who reported higher levels of relationship quality ($p \leq 0.01$). A further study[33] examined the attachment style of the patient and spouse caregiver. The findings, after controlling for demographic and medical variables, indicated that spouses high in avoidant attachment reported significantly lower levels of marital quality ($b = -0.64$, $SE = 0.1$, $p < 0.0001$) and higher levels of depression ($b = -0.67$, $SE = 0.34$, $p < 0.05$) compared to other attachment styles; spouses high in anxious attachment reported significantly higher levels of anxiety ($b = 0.74$, $SE = 0.40$, $p < 0.05$).

Two studies[22,40] with both spouse and adult child caregivers, examined the association between these different relationships and caregiver depression. Lee et al.[22] indicated that, in family caregivers

of newly diagnosed patients, the odds for depression were higher if a caregiver was the patient's spouse, rather than having another relationship with the patient (odds ratio [OR]: 14.21, 95% confidence interval [CI]: 3.18–63.52, $p < 0.001$). Similarly, Siminoff et al.[40] also reported that there was an increase of depressive symptoms among caregivers if the caregiver was the spouse rather than offspring of patients who were undergoing treatment, or who had recently completed treatment ($b = 2.1$, $p < 0.05$). In addition, both patient and caregiver reports of lower family cohesion and family conflict were associated with higher caregiver depression in the same study[40] ($b = 0.58$, $SE = 0.16$, $p < 0.001$; $b = 0.59$, $SE = 0.15$, $p < 0.001$, respectively).

3.7 | Caregiver variables

A range of caregiver variables were associated with distress, including age, personality, attitudes, coping, caregiver burden and self-efficacy. The age of the caregiver was associated with distress in two studies. Siminoff et al.[40] reported that lower caregiver age was associated with higher depressive symptoms ($b = -0.10$, $SE = 0.02$, $p < 0.01$); in a different study,[22] with newly diagnosed patients, the odds ratio for anxiety and depression was less if the family caregivers were older (OR: 0.95, 95% CI: 0.91–0.99, $p < 0.007$; OR: 0.92, 95% CI: 0.87–0.97, $p < 0.002$, respectively).

Personality. Two studies examined aspects of caregiver personality.[30,32] One study[30] demonstrated that high levels of neuroticism among caregivers were positively associated with both self-report and observer-rated depression ($\beta = 0.78$; $\beta = 0.91$). The relationship between caregiver personality and depression was mediated by both social support ($\beta = -0.18$, $p < 0.01$); and indirectly caregiving burden.[30] The second study[32] indicated that higher levels of pessimism were associated with higher depressive symptoms ($b = 0.66$, $p < 0.001$). In the same study, depression levels decreased slightly over time (1 year), regardless of stage of cancer, but no significant relationship with either optimism or pessimism and the change in depression was found.

Attitudes. Two studies compared the relationship between mindfulness and caregiver distress. The findings of one study[42] indicated that dispositional mindfulness (defined as a trait where an individual tends to pay attention to the present moment, non-judgementally and with acceptance[42]) buffered the association between caregivers' stress and depressive symptoms ($\beta = -0.02$, $p < 0.05$); higher levels of caregivers' stress were associated with high levels of symptoms of depression only in those with relatively low dispositional mindfulness scores. Similarly, Schellekens et al.[34] found that higher mindfulness (using the same measure as the previous study) ($\beta = 0.19$, $p < 0.002$) and self-compassion ($\beta = -0.45$, $p < 0.001$) were related to lower caregiver distress.

Lau et al.[43] examined anxiety related to death and dysfunctional attitudes amongst caregivers; higher levels of death anxiety were positively related to dependency (seeking approval from others; $r = 0.38$, $p < 0.001$) and achievement (the belief that oneself is worthless unless productive; $r = 0.28$, $p < 0.001$), whereas death anxiety was negatively associated with self-control ($r = -0.24$, $p < 0.01$). Two studies[39,40] examined caregiver attitudes towards the cause of the disease using the construct of blame; in both cases blaming the patient for causing the cancer was associated with higher depressive symptoms of the caregiver ($\beta = 0.21$, $p = 0.025$[39]; $b = 1.2$, $SE = 0.48$, $p < 0.05$[40]).

Coping. Two studies[29,39] reported the coping strategies employed by the caregivers. The use of behavioural disengagement as a coping strategy by both the patient and spouse caregiver predicted higher levels of distress in the first month after treatment initiation[39] ($\beta = 0.26$, $p = 0.004$; $\beta = 0.33$, $p < 0.0001$, respectively). In the same study, more use of substances as a coping strategy was also a predictor of greater distress in spousal caregivers ($\beta = 0.21$, $p = 0.021$). More positively, in a different study[29] spouses who used moderate levels of religious coping were less depressed than those who used lower or higher levels (change in $R^2 = 0.04$, $p < 0.05$).

Quality of Life and Caregiver Burden. Three studies indicated that distress symptoms were related to poorer quality of life of the caregivers.[43–45] Health problems of the caregiver was also associated with higher levels of distress in three studies.[17,22,40] Fujinami et al.[16] examined how distress (using the DT) in family caregivers was related to quality of life (using the City of Hope Quality of Life—family version) and aspects of caregiving burden; disruption to quality of life, such as not being able to participate in usual social activities, and the emotional and physical demands of caregiving were all associated with higher distress (all p's < 0.05). Related to the burden of caregiving, Lee et al.,[22] reported that caring for another sick family member as well as the lung cancer patient increased the likelihood of both depression and anxiety (OR: 15.66, 95% CI: 2.7–90.87, $p < 0.002$; OR: 7.34, 95% CI: 1.80–29.94, $p < 0.005$, respectively).

The relationship between caregiving burden, social support and depression were examined in five further studies. Social support was found to partially mediate between caregiving demands and depression in one study[35]; that is, effective support systems may help to reduce the burden of caregiving and in turn reduce depression ($\beta = 0.322$, $p < 0.001$). In a second study,[46] depression in the family caregivers was negatively correlated with social support ($r = -0.32$, $p < 0.001$) and positively correlated with caregiving burden ($r = 0.57$, $p < .001$).[46] Perceived social support was also negatively correlated with observer rated depression in Abernethy et al.[29] ($r = -0.28$, $p < 0.01$). The findings of Kim et al.[30] suggest that caregivers who reported lower levels of social support were more likely to experience greater caregiving burden, which in turn led to higher levels of depressive symptoms among them. A further study indicated that caregivers who reported a greater degree of financial strain at baseline experience more distress at a 6-months follow-up[17] ($t = 2.53$, $p = 0.01$). In the final study,[36] the loss of income ($r = 0.31$, $p < 0.01$) and reduced involvement in social activities ($r = 0.56$, $p < 0.001$), linked to the caregiving role, were associated with higher levels of depression and anxiety in a cohort of caregivers who scored above the clinical cut-off (HADS) at recruitment.

Self-efficacy. Five studies[17,22,29,30,47] examined the relationship between self-efficacy and caregiver distress. In all cases, greater levels of self-efficacy were associated with lower distress. Perceived control and interpersonal self-efficacy contributed significantly to variance in depression in one study[29] (change in $R^2 = 0.12$, $p < 0.01$). Kim et al.[30] reported that caregivers who scored high on interpersonal self-efficacy tended to report lower levels of depressive symptoms, mediated by caregiver burden ($\beta = -0.26$, $p < 0.001$). Similarly, caregivers with higher self-efficacy in managing symptoms had a lower risk of both depression and anxiety in Lee et al.,[22] (OR: 0.95, CI: 0.93–0.98, $p < 0.001$; OR: 0.97, 95% CI: 0.95–0.99, $p = 0.006$, respectively) and lower levels of mood disturbance in Porter et al.[47] Finally, in one study,[17] caregiver esteem (subscale of the Caregiver Reaction Assessment) was not associated with distress scores at baseline but was negatively associated in the follow-up assessments at 3 ($r = 1.22$, $p < 0.05$) and 6 months ($r = -0.26$, $p < 0.001$).

3.8 | Intervention studies

Eight intervention studies were included in this review with mixed findings (see Table 2). Two studies, each with two active arms, showed an improvement in distress following an intervention. Specifically, in one of the studies[48] caregivers who received either 14 sessions of telephone assisted coping skills training (CST) or education/support intervention reported decreases in anxiety ($b = -0.21$, $SE = 0.21$, $p = 0.02$). Further analyses suggested that the CST was more beneficial to caregivers with patients in stages II and III, whereas the education/support intervention was more beneficial when the caregiver was supporting someone with stage I cancer. In the second study with two active arms[49] (dyadic cognitive behaviour therapy vs. an integrative mind-body-spirit intervention), both groups showed reduced severity of stress and anxiety at 8- and 16-week follow-ups (stress: effect sizes: 0.28–0.42 anxiety: effects sizes 0.33–0.38), but there was no effect for either group on depression scores.

Two further studies[50,51] with two active arms reported no effects on symptoms of distress. Specifically, Mosher et al.[50] compared a multicomponent telephone symptom management intervention with an education support group and found no effect on anxiety and depression measures for either condition. Secondary analysis[52] of Mosher et al.[50] revealed that greater practice of guided imagery (as part of a relaxation component of telephone symptom management) was associated with reduced psychological distress in caregivers ($\beta = -0.30$, $p = 0.01$). The second study[51] compared six sessions of telephone Acceptance and Commitment Therapy with an education support condition for caregivers of people with advanced lung cancer; there were no main or interaction effects for any of the distress related outcomes.

In a further three-arm study[53] (mindfulness based intervention vs. social support vs. usual care), depression was reduced in the mindfulness group compared to usual care only ($F = 7.39$, $p < 0.01$,

$d = 0.74$). A further study[54] reported that psychological distress was reduced for caregivers who followed a tailored palliative care plan, selfcare plan and educational sessions compared to those receiving usual care ($p \leq 0.01$). Finally, DuBenske et al.[55] found that an Internet-based support network group reported lower negative mood at the 6-month follow-up compared to the group with Internet access (with recommended websites) only ($p < 0.006$).

4 | DISCUSSION

To our knowledge, this is the first review to systematically identify the variables associated with psychological distress among lung cancer caregivers. The findings point towards a range of variables associated with distress in this population. Understanding the specific issues that contribute to caregiver distress is an important step in developing appropriate and effective supports for this population.

There were high levels of distress amongst the caregivers in the included studies and, where reported, between a quarter and three quarters of the caregivers met criteria for depression and/or anxiety that would warrant further assessment and management. These findings are in line with those reported in an earlier review on the effects of caring for a patient with cancer more generally,[56] indicating that caregivers experience higher levels of depression and anxiety than noncaregivers. Furthermore, these findings are also congruent with a Europe wide study that has revealed that lung cancer caregivers are more likely to be diagnosed with depression than noncaregivers.[21] Elevated levels of depression and anxiety are likely to interfere with the ability to carry out the duties associated with the caregiving role, as well as impact on the caregiver's own physical health and quality of life. These findings emphasise the need to screen and identify caregivers at risk who may benefit from formal psychological support.[57]

The findings of this review highlight the diversity of factors associated with distress experienced by this group. Based on the cross-sectional and prospective data, the factors implicated in caregiver distress can be categorised into (1) patient variables; (2) relationship quality; and (3) caregiver variables. Patient illness-related factors that were associated with increased distress included advanced stage of cancer and poorer functional status, both of which are likely to increase demands on the caregiver. In terms of relationship quality, while there was some evidence to suggest that the spouse of the person with lung cancer seem to be particularly vulnerable to distress,[22,40] strategies that enhance the marital relationship may help to mitigate this. Finally, caregiver variables such as social support, perceptions of burden and self-efficacy in managing the caregiver role were all related to caregiver distress.

As already mentioned, spousal caregivers in the current review appear to be at greater risk of distress[22,40] compared to other informal caregivers. The experience of caring is likely to be different for spouses versus offspring or friends of the patient as their caring role is more likely to be full-time and more intimate compared to other relationships.[59] It has been suggested that a shared identity as

a couple and viewing the illness as a shared problem may help to minimise some of the negative effects of caregiving.[60] Thus, the quality of the spousal relationship may be an important determinant of distress[17,31,37–39]; in the current review couples who expressed greater satisfaction and less conflict within the relationship exhibited lower levels of depression and anxiety. Nineteen of the included studies in this review recruited the patient as well as the caregiver, reflecting the increasing emphasis on the caregiver-patient as a dyad rather than considering the caregiver as an individual.[61] The caregiver and patient may experience distress differently and have different perspectives,[62] nevertheless their individual responses may influence how they manage the challenges associated with the disease.[61] While outside of the scope of this review, the dyadic approach to analysis provides an opportunity to understand the reciprocal and interdependent processes that people engage in that may impact on important health outcomes for both patient and caregiver.[59,61] For example, caregiver exhaustion may influence patient distress because the caregiver is too tired to meet their needs, while the patient may be too distressed to recognise the burden and distress experienced by the caregiver.[17]

The findings of this review suggested a number of potential mediators or moderators of distress. Two important mediators that were identified were social support and self-efficacy, both of which appear to buffer the effects of caregiver burden. This is particularly relevant as social support and self-efficacy are potentially modifiable though targeted interventions[24]; enhancing self-efficacy, for example, would help caregivers feel more prepared for their role and reduce the perceptions of caregiver burden and thus decrease distress and improve the overall quality of life of both caregiver and patient.[58]

Intervention studies were included in this review to examine components that have the potential to reduce caregiver distress; for example, to answer the question whether the provision of coping skills training or cognitive behaviour therapy help to reduce distress? There were mixed findings in relation to the interventions, with some studies showing no effect on distress, and it was not always possible to determine the process of change for the studies that did report a significant improvement in mood. As multicomponent, rather than single component, interventions tend to produce better results for caregivers,[24] it seems likely that any effect on distress may be indirect due to the interaction between the components included in such interventions. For example, DuBenske et al.[55] speculated that the reduction in negative mood following the multicomponent CHESS intervention may have occurred through a variety of mechanisms that support coping. The possible interaction between components in an intervention is reflected in the findings of the current review; specifically, a lack of social support may increase perceptions of burden and, in turn, levels of depression,[30,35,46] while higher self-efficacy in managing symptoms may reduce burden and lower feelings of distress[22,30,47]

Three of the prospective studies suggested that distress may decrease slightly over time for caregivers[17,32,37] but as the follow-up periods differed across the studies (from 3 months to 1 year), it is difficult to draw firm conclusions as to any possible dynamic changes in distress. The majority of the studies included in this review were cross-sectional in design and recruited caregivers who were caring for patients at various stages of the disease trajectory from a few months since diagnosis to those who had completed treatment. The caregiving context and associated (di)stress may fluctuate during transitional periods of disease management, such as the time of diagnosis, the start of a new treatment and between treatment modalities.[61] These periods of change may create uncertainty and heightened anxiety for caregivers, thus there remains a need for longitudinal studies focussing on assessment of distress and other aspects of caregiving to identify the critical periods so that the provision of appropriate support can be developed.

4.1 | Study limitations

There are a number of limitations to this review that should be noted. First, the review was limited to studies published in the English language, and there may be relevant research in other languages that we have missed. In addition, we did not include a number of studies that recruited participants caring for people with other cancer types as well as lung cancer unless the results were disaggregated in the article. The included studies employed a range of measures to assess distress, which may not be directly comparable to each other. Furthermore, several tools were used to assess depression and anxiety, each with different methods of conceptualising clinical relevance, making it difficult to draw firm conclusions regarding levels of distress amongst the caregivers. There was also considerable diversity in the variables assessed and tools used precluding any statistical meta-analysis. Finally, the studies were predominately conducted in developed countries limiting generalisability to developing countries where the variables associated with distress might be different due to variation in cultural and socioeconomic factors.

4.2 | Clinical implications

The overall findings of this review have a number of implications for supporting caregivers of people with lung cancer. First, the high levels of depression and anxiety reported in the studies suggest that there is a need for health professional to consider screening for distress amongst caregivers. The DT is an effective screening tool and had been used for both patients and caregivers[62]; its brevity may mean that it can be useful in busy clinics where time constraints or other demands may be a barrier to the use of other, longer tools.[63] As some of the studies indicated that a proportion of caregivers met clinically relevant levels of depression and/or anxiety, research is needed to identify the risk factors that may predispose caregivers to ongoing mental health problems including major depressive episodes and/or generalised anxiety disorder.[57] Second, as transitions in care, such as changes in treatment or the appearance of new symptoms

are likely to increase the risk of distress in caregivers, longitudinal research designs are needed to identify the critical periods for caregivers in the cancer trajectory so that appropriate supports can be introduced in a timely manner. These supports include the provision of information needed by caregivers to feel prepared in their role and promote feelings of self-efficacy. Information needs are likely to change over time and therefore need to be tailored to specific transitions; for example, caregivers may need disease specific information at the time of diagnosis, information about side effects during treatment and practical skills once the patient is discharged home.[64]

Importantly, some of the variables associated with distress in the current review may be modifiable in targeted interventions, for example, by developing self-efficacy, effective coping strategies and support networks amongst caregivers. However, there were mixed findings in the intervention studies included in this review and it was not possible to determine the most effective processes that may reduce distress. There, is therefore, scope for further rigorous, well-designed research to determine the important active components to include in targeted interventions aiming to reduce distress in caregivers and to identify the most clinically meaningful measures of distress for this population.[65]

5 | CONCLUSION

This review underlines the high levels of distress experiences by caregivers, highlighting the need to screen caregivers and identify those who may benefit from psychological support. The provision of well-designed interventions targeting modifiable variables such as self-efficacy, effective coping strategies and support networks may help to reduce distress. There is, therefore, a need for further longitudinal research to fully understand the precursors to distress in order to mitigate against them.

CONFLICT OF INTEREST STATEMENT
The authors declare no potential conflicts of interest.

DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.