


REVIEW

Supportive interventions for family caregivers of patients with advanced cancer: A systematic review

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Abstract

Objective: Family caregivers are often intensively involved in palliative and end-of-life cancer care. A variety of interventions to support family caregivers have been developed, differing in target population, modality, and components. We aimed to systematically examine characteristics and the effectiveness of interventions to support family caregivers of patients with advanced cancer.

Methods: A systematic review was conducted using Embase, Medline Ovid, Web of Science, Cochrane, Google Scholar, and Cinahl. This review included quantitative studies published from January 2004 until January 2020 reporting on interventions to support family caregivers of patients with advanced cancer in all care settings.

Results: Out of 7957 titles, 32 studies were included. Twenty-two studies were randomized controlled trials. Interventions were delivered to four target populations: individual family caregivers ($n = 15$), family caregiver-patient dyads ($n = 11$), families ($n = 2$) and peer groups ($n = 4$). Most interventions ($n = 26$) were delivered face-to-face or by phone, two were delivered online. Most interventions included multiple components and were primarily aimed at supporting family caregivers' self-care. Twenty-nine interventions were shown to have beneficial effects on family caregiver outcomes, mostly in the psycho-emotional ($n = 24$), daily functioning ($n = 13$) and social dimension ($n = 6$). Individual interventions were mainly effective in the psycho-emotional dimension, dyad and family interventions in the psycho-emotional and social domain, and group interventions mainly had an effect on daily functioning.

Conclusions: Interventions to support family caregivers in advanced cancer care vary widely. Most intervention studies reported beneficial effects for the wellbeing of family caregivers. There is evidence that the target group is associated with beneficial effects on different outcome dimensions.

Yvonne N. Becqué and Maaïke van der Wel should be considered joint first author.

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KEYWORDS

cancer, caregiver, family, intervention, oncology, palliative care, psycho-oncology, psychosocial support, review

1 | BACKGROUND

In 2020, 4 million new cases of cancer were registered and 1.9 million people died from cancer in Europe.¹ By 2040, cancer incidence is expected to double.² Every cancer diagnosis has an impact on not only the patient, but also on their family and friends, who often provide informal care. These “family caregivers” are often intensively involved, especially when caring for patients with advanced cancer.^{3,4} They support patients with activities of daily living (e.g. bathing, meal preparation), medical care (e.g. medication support, involvement in treatment decisions), household tasks (housekeeping, caring for other family members), financial administration, psychosocial care (e.g. companionship, communication with family and friends), and advocacy (e.g. when navigating through healthcare and when dealing with insurance issues).^{4–6}

Providing care and support is physically and psychologically demanding. Grande et al.⁷ found that family caregivers during end-of-life caregiving have a worse psychological and general health compared to the general population. A significant proportion (11%) of family caregivers of patients with advanced cancer experience a high caregiver burden.⁸ The psychological burden of having cancer may be even greater for family caregivers than for the patient,⁹ especially when the disease progresses. Although family caregivers take care of many aspects of patient care, their own social, cognitive, and psychological needs often remain unmet.¹⁰ Family caregivers have been found to often put their own needs aside.¹¹ These findings indicate a high need of support for family caregivers.¹² The World Health Organization underlines the importance of supportive care for family caregivers.²

Many interventions have been developed to support family caregivers of patients with advanced cancer. These interventions differ in terms of target population, modality and components.^{13,14} Research has shown that several interventions resulted in improved wellbeing of family caregivers.^{15,16} However, there is a lack of systematic synthesis of current knowledge about the characteristics and effects of supportive interventions.^{17,18} Therefore, we aimed to:

1. systematically examine characteristics of supportive interventions for family caregivers of patients with advanced cancer;
2. systematically examine the evidence on the effectiveness of these interventions on different outcome dimensions;
3. assess whether characteristics of supportive interventions are associated with family caregivers' outcomes.

This knowledge is important for clinical practice and could inform healthcare professionals and healthcare organizations on how to

provide support for family caregivers and improve family caregivers' wellbeing.

2 | METHODS

We conducted a systematic review, including a systematic search and a quality appraisal.

2.1 | Registration of the review

This systematic review was registered at the PROSPERO register (registration number: CRD42020166661).

2.2 | Eligibility criteria

Several criteria were used to select eligible studies: (1) English-language articles published over a 15-year period (from January 2004 until January 2020) which reported on studies on interventions to support adult family caregivers providing care to patients with advanced cancer; (2) quantitative studies with outcome measures related to the well-being of family caregivers.

We excluded: (1) articles on interventions which were patient-focused rather than caregiver focused; (2) articles on interventions designed to specifically support family caregivers in bereavement; (3) studies involving pediatric cancer patients or patients with mental co-morbidity or cognitive impairments such as dementia; (4) conference abstracts; (5) pilot and feasibility studies.

2.3 | Information sources and search strategy

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist was used as the underlying structure for this article.

In July 2017, a systematic electronic search was conducted with the help of a Biomedical Information Specialist from the Medical Library of Erasmus MC, University Medical Center Rotterdam. In May 2020 we updated the search. The following databases were searched: Embase, Medline Ovid, Web of Science, Cochrane Central, CINAHL, and Google Scholar. To identify relevant studies, a broad search strategy was used, built on the PI(C)O model: Population: family caregivers of advanced cancer patients; Intervention: supportive interventions for family caregivers; Outcome: any outcome related to family caregivers' wellbeing. The following search/key terms were

used: ("advanced cancer" OR palliat* OR hospice* OR (terminal* OR serious* OR critical*) disease OR ill* OR "end-of-life") AND (relative OR relatives OR "informal* care" OR caregiv* OR spouse OR husband OR wife) AND (support* OR intervention* OR program* OR counsel* OR psychotherap*) AND (participat* OR coping OR wellbeing OR burden). Terms like NOT (child OR congresses OR abstracts) were used to exclude studies on pediatric cancer as well as research abstracts (See Supporting Information S1 for an exemplary search strategy).

2.4 | Study selection

Retrieved records were imported into a reference management program (EndNote®). After removing duplicates, one author (Muzeyyen Aktan-Arslan) screened the titles and abstracts for eligibility. A second author (Erica Witkamp) independently checked 20% of these titles and abstracts. They were in total agreement. Then the full text of selected articles was retrieved for further evaluation. Full text articles were read and screened by at least 2 members of the research team (Yvonne N. Becqué, Muzeyyen Aktan-Arslan, Maaïke van der Wel, Anne Geert van Driel). In case it was unclear whether a paper met the inclusion criteria, it was discussed in the research team until consensus was reached.

2.5 | Data extraction

Each included article was analyzed by at least two authors (Yvonne N. Becqué, Muzeyyen Aktan-Arslan, Maaïke van der Wel, Anne Geert van Driel). Disagreements were discussed and resolved through consensus.

A data extraction form was used to summarize the characteristics of each study and intervention. The following information was obtained on family caregivers and patients: sample size, gender, age, the relationship between the family caregiver and patient, and (for patients only) advanced cancer type. Furthermore, information was extracted on: study design, study setting, intervention characteristics (including theoretical framework, provider, content, modality, period, and dosage) and significant effects of interventions on family caregiver outcomes.

The content of the interventions was analyzed for three components, as described by Northouse et al.¹⁹: (1) patient caregiving; (2) family caregiver self-care; (3) family care. Patient caregiving refers to the intervention addressing information or skills related to caregiving tasks. Family caregiver self-care refers to information and skills related to family caregivers' self-management of stress related to caregiving and of their health in general. Family care refers to information and skills to help family caregivers or couples to manage family or marital concerns.¹⁹ In addition, we also examined whether the intervention targeted the family caregiver as an individual and included for example, a needs assessment or problem inventory to explore and meet their personal needs, problems or preferences.

The outcomes measured for family caregivers were classified into six dimensions: physical, psycho-emotional, social, spiritual, daily functioning, and quality of life. Four of the dimensions were determined by the dimensions of palliative care.²⁰ (1) Physical refers to physical symptoms; (2) psycho-emotional refers to psychological and emotional wellbeing, and self-esteem; (3) social refers to social wellbeing and marital functioning; (4) spiritual refers to seeking and expressing meaning and purpose. The remaining two dimensions were (5) daily functioning, which included preparedness, self-efficacy, and competence for caregiving, and (6) quality of life. This sixth dimension was based on the outcomes of the studies included. If quality of life was measured as overall quality of life, and not as a subdimension of quality of life, the outcome was classified as quality of life.

2.6 | Quality appraisal

The included studies were critically appraised by four authors (Yvonne N. Becqué, Muzeyyen Aktan-Arslan, Maaïke van der Wel, Anne Geert van Driel) for validity and risk of bias using the method of Hawker et al.²¹ This method was developed to assess the quality of a diversity of studies. It contains nine questions, each of which can be answered with "good" (4 points), "fair" (3 points), "poor" (2 points), and "very poor" (1 point). A total score was calculated for each study, with a minimum of 9 and a maximum of 36.²¹ 20% of the articles were assessed by two authors and scores were compared. Any disagreements were resolved through discussion.

3 | RESULTS

A total of 16,713 potentially relevant articles were identified. After removing duplicates, 7957 articles remained. After screening titles and abstracts and reading the full-text of 87 publications for eligibility, 35 articles reporting on 32 studies met the criteria.^{22–56} Three articles were pooled since they reported on the same intervention study.^{34,35,52–55} Two main reasons for the exclusion of the remaining 52 articles were that the study did not include caregiver outcomes ($n = 17$) or that the study designs did not meet the inclusion criteria, for example, as in pilot or feasibility studies ($n = 9$). Figure 1 shows the flow chart of the selection process.

3.1 | Characteristics of the studies

Table 1 shows the characteristics of the included studies. Twenty-two studies concerned randomized controlled trials (RCTs) (four three-armed RCTs, one wait control design, one parallel design, one pooled design, and one cluster randomized trial),^{22,25–27,29–32,34,35,37,38,41–47,50,51,54–56} one a quasi-experimental study,^{52,53} one a stepped-wedge cluster non-randomized trial,²³ five had single group pre-post intervention designs,^{24,33,36,40,49} and three had other quantitative designs.^{28,39,48}

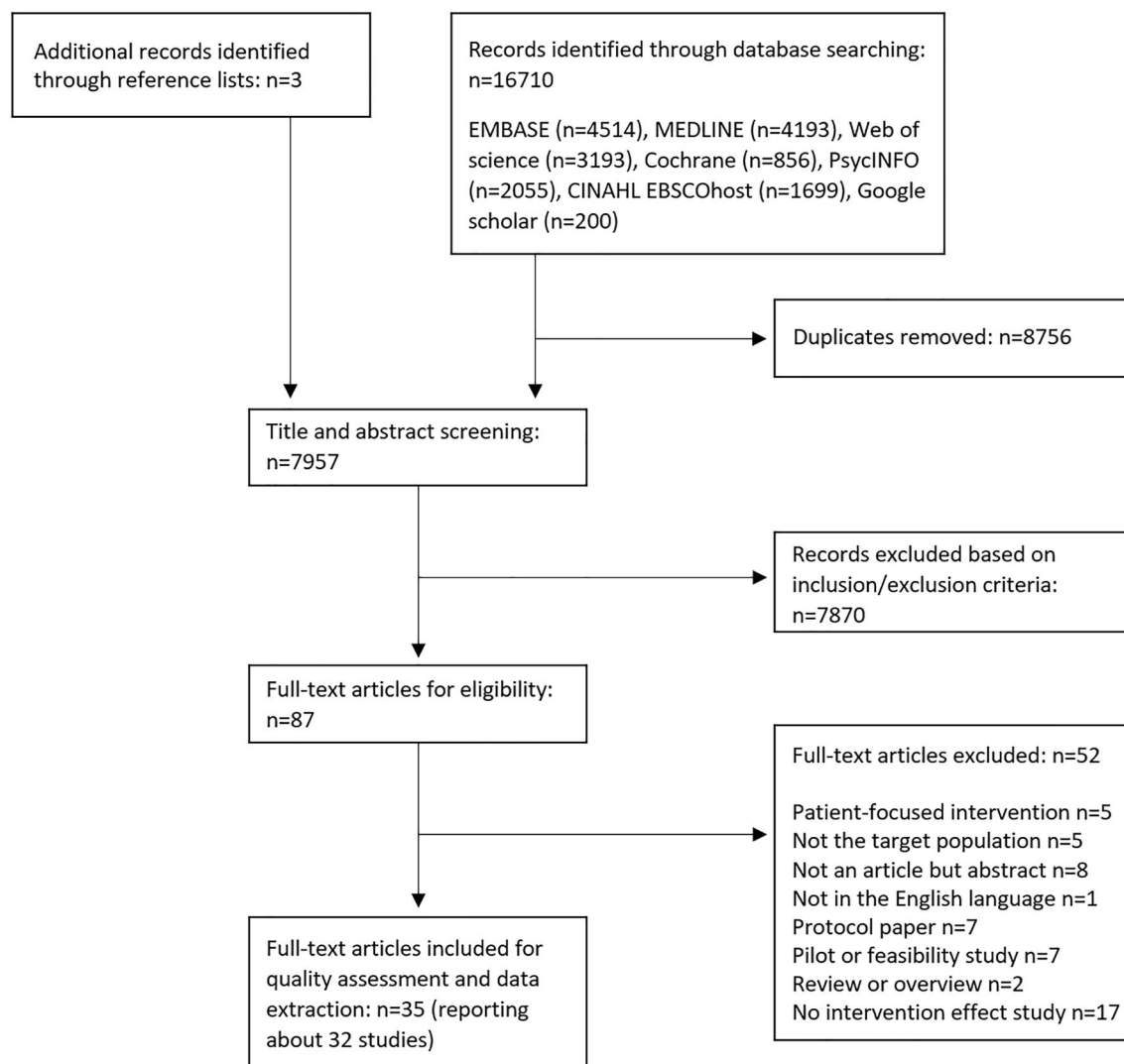


FIGURE 1 Selection of the 35 articles (reporting on 32 studies).

Seven articles were published in 2004–2008, fourteen in 2011–2015 and eleven in 2016–2019. Twelve studies were conducted in the USA,^{25,27,29,30,38,42,43,45–47,51–53} seven in Australia,^{23,32–37,44} and five in Scandinavia.^{22,31,49,50,54,55} The remaining studies were conducted in Canada,^{24,28,41} Asia^{39,40,48} and the United Kingdom.^{26,56}

The number of participants in the 32 studies ranged from 34 to 490 family caregivers. The mean age of the family caregivers ranged from 34 to 66 years. Caregiver characteristics are reported in Table 1. In 29 studies, patients had various cancer diagnoses. Three studies focused on patients with lung cancer^{27,52,53} or breast cancer.⁴⁶ The most common patient-family caregiver relation was spousal, with the proportion ranging from 40% to 100%. In addition, adult children, parents and other family members were involved as a family caregiver. Two studies focused only on spouses,^{40,41} and in two the relationship was unknown.^{42,52,53} In most studies, more than half of the family caregivers were female and one study 100% were female.²⁸ Gender was unknown in two studies.^{38,46}

A wide range of measuring instruments was used. The Hospital Anxiety and Depression Scale was used for multiple

studies.^{22,29,31,32,40,44} Other instruments are reported in Supporting Information S2.

3.2 | Quality assessment

The average score on the Hawker Quality Assessment Tool was 28.4 on a scale of 9–36, with scores ranging from 22 to 33. Ethical issues were hardly reported in the studies. The quality assessment scores can be found in Table 2.

3.3 | Characteristics of the interventions

3.3.1 | Target population

Almost half of the interventions were developed for individual family caregivers ($n = 15$) (*individual interventions*). One third of the interventions were developed for dyads ($n = 11$) (*dyadic interventions*):

TABLE 1 Characteristics of study and sample.

No	Author(s), year of publication, country	Design	Quality total score	Setting of the intervention	Sample characteristics of caregivers (N, gender, and mean age, standard deviation)	Relation to patient	Sample characteristics of patient (N, gender, mean age, advanced cancer type)
Individual							
1.	Aoun et al. (2015), Australia	Stepped-wedge cluster non-randomized trial	31	Home (visits)	N = 322 I = 233, 70% female, mean age 62 (12) C = 89, 80% female, mean age 66 (13)	Spouse (I 67%, C 71%) Child (I 22%, C 18%) Parent (I 2%, C 3%) Other (I 7%, C 8%)	N = 322 I: 92% advanced cancer, 8% other diagnoses C: 83% advanced cancer, 17% other diagnoses
2.	Cameron et al. (2004), Canada	One-sample pretest, posttest design	25	Hospital	N = 34 68% female, mean age 54 (16)	Spouse 74%	N = 34 41% female, mean age 63 (13) 44% gastrointestinal, 29% lung and 27% other cancers
3.	Chih et al. (2013), USA	Two RCT's (pooled)	33	Home (eHealth)	N = 217 64% female, mean age 56 I1 (CHESS) = 107, 66% female, mean age 56 (13) I2 (CHESS + CR) = 110, 63% female, mean age 56 (13)	Spouse 69% CHESS: Spouse 73% CHESS + CR: Spouse 68%	N = 217 56% female, mean age 63 41% breast, 29% lung and 29% prostate cancer
4.	Dionne et al. (2015), UK	RCT (wait-control design)	30	Home	N = 122 79% female, mean age 60 I (Early) = 61, 77% female, mean age 61 C (Delayed) = 61, 80% female, mean age 58	Spouse (I 79%, C 72%) Child (I 7%, C 16%) Parent (I 7%, C 5%) Other (I 7%, C 7%)	N = 207 46% lung (I 46%, C 41%), gastrointestinal (I 23%, C 28%), genitourinary (I 8%, C 8%), breast (I 8%, C 8%), hematologic (I 5%, C 7%) and other cancers (I 10%, C 8%)
5.	DuBenske et al. (2014), USA	RCT	28	Home (eHealth)	N = 246 received intervention 68% female, mean age 56 (18–84). I (CHESS) = 124, 66% female, mean age 57 (13) C (Internet) = 122, 71% female, mean age 55 (12)	Spouse 72% I CHESS: Spouse 73% Internet: Spouse 71%	N = 246 Lung cancer stage III–IV

(Continues)

TABLE 1 (Continued)

No	Author(s), year of publication, country	Design	Quality total score	Setting of the intervention	Sample characteristics of caregivers (N, gender, and mean age, standard deviation)	Relation to patient	Sample characteristics of patient (N, gender, mean age, advanced cancer type)
6.	Duggleby et al. (2013), Canada	Time series/Mixed method design	27	Home (activity)	N = 36 100% female (rural woman), mean age 59 (12)	Spouse 86% Child 8% Other 6%	N = 36, 6% female, mean age 65 (11) Variety of cancer diagnoses.
7.	Ferrell et al. (2019), USA	RCT	22	Clinical setting (in person or phone calls)	N = 240 81% female, financially strained, mean age 55 I = 123 C = 117	Spouse 64% Child 20% Parent 3% Other 12%	N = 240 55% genitourinary, 27% gastrointestinal and 19% gynecologic cancer, stage III-IV
8.	Hudson et al. (2005), Australia	RCT	30	Home (home visits and phone call)	N = 106 65% female, mean age 61 (14) I = 54 C = 52	Spouse 67% Child 16% Parent 8%	N = 106 54% female, mean age 69 (13) Advanced cancer
9.	Hudson et al. (2013; 2015), Australia	RCT (three-armed)	31	Home (home visits and phone calls)	N = 298 71% female, mean age 59 (14) I1 (one visit) = 57 I2 (two visits) = 93 C = 148	Spouse 54% Child 24% Parent 13% Friend 14% Other 16%	Advanced cancer
10.	Lee et al. (2016), Taiwan	Two-group comparative design with repeated measures	23	Hospital	N = 81 63% female, mean age 51 (15). I = 40, 62% female, mean age 50 (14). C = 41, 63% female, mean age 51 (16)	Spouse (I 55%, C 61%) Child (I 28%, C 27%) Other (I 18%, C 12%)	N = 81 49% female, mean age 57 (13) 36% gastrointestinal, 21% breast and 43% other cancers
11.	McMillan et al. (2006), USA	RCT (three-armed)	33	Hospice	N = 329 I1 (Stand. care + COPE) = 111, 77% female, mean age 63 (14) I2 (Stand. care + support) = 109, 99% female, mean age 62 (15) C = 109, 81% female, mean age 60 (15)	No information	N = 329 40% female, mean age 71 Advanced cancer
12.	Mitchell et al. (2013), Australia	RCT	32	GP consultation	N = 392 I = 161: 68% female, mean age 58 (13) C = 168: 65% female, mean age 57 (13)	Spouse (I 68%, C 68%) Child (I 17%, C 13%) Parent (I 8%, C 10%) Other (I 10%, C 9%)	Advanced cancer

TABLE 1 (Continued)

No	Author(s), year of publication, country	Design	Historical control study	Quality total score	Setting of the intervention	Sample characteristics of caregivers (N, gender, and mean age, standard deviation)	Relation to patient	Sample characteristics of patient (N, gender, mean age, advanced cancer type)
13.	Otani et al. (2014), Japan	Historical control study		27	Palliative (home) care institutions Three palliative units, 1 palliative care team and 3 specialized home care team.	N = 355 I = 113, 73% female, mean age 57 (12) C = 242, 75% female, mean age 58 (13)	Spouse (I 42%, C 55%) Child (I 36%, C 30%) Parent (I 5%, C 2%) Other (I 9%, C 13%)	Advanced cancer and delirium
14.	Sherwood et al. (2012), USA	RCT		32	Home (telephone contacts)	N = 225 I (Nurse arm) = 112, 58% female, mean age 54 (13) C (Coach arm) = 113, 42% female, mean age 56 (13)	Spouse (I 75%, C 67%)	N = 225 Advanced cancer, stage III or IV, solid tumor, receiving chemotherapy.
15.	Walsh et al. (2007), UK	RCT (parallel)		23	Home (visits or phone calls)	N = 271: 79% female, mean age 56 (14) I = 137, 79% female, mean age 56 (15) C = 134, 80% female, mean age 56 (13)	Spouse 64% (I 68%, C 60%) Child (I 21%, C 28%) Other (I 12%, C 12%)	29% lung, 20% gastrointestinal, 15% genitourinary, 9% head and neck, 7% Breast and 20% other cancers
Dyad								
1.	Ammari et al. (2018), Denmark.	RCT		30	Home (visits)	N = 57 I = 28: 79% female, mean age 63 C = 29: 63% female, mean age 61	Spouse (I 86%, C 76%)	N = 57 32% Female, mean age 67 33% prostate, 25% lung, 19% lower gastrointestinal cancer and other
2.	El-Jawahri et al. (2017), USA	RCT		28	Unknown (visits or phonecall)	N = 275 I = 137, 94%, mean age 57.5 (14.7) C = 138, 96%, mean age 57.2 (12.5)	Spouse (I 67%, C 67%) Child (I 21%, C 16%) Parent (I 0%, C 4%) Other (I 11%, C 13%)	N = 275 lung and non-colorectal gastrointestinal cancers

(Continues)

TABLE 1 (Continued)

No	Author(s), year of publication, country	Design	Quality total score	Setting of the intervention	Sample characteristics of caregivers (N, gender, and mean age, standard deviation)	Relation to patient	Sample characteristics of patient (N, gender, mean age, advanced cancer type)
3.	Lapid et al. (2016), USA	RCT	25	Unknown (sessions and phone calls)	N = 131 I = 65 C = 66 Female and mean age unknown.	Spouse 75%	N = 131 I: 37% female, mean age 59 C: 32% female, mean age 60 Brain (I 17%, C 27%), gastrointestinal (I 39%, C 36%), head/neck (I 15%, C 17%), lung (I 15%, C 11%), other (I 14%, C 9%).
4.	McLean et al. (2013), Canada	RCT	27	Hospital (sessions)	N = 42 I = 22: 24% female, mean age 49 (13) C = 20: 21% female, mean age 51 (9)	Spouse	N = 42 I: 12% female, mean age 52 (9) C: 11% female, mean age 49 (12) I: N = 22: 10% blood, 10% gynec, 10% head and neck, 23% other. C: N = 20: 19% breast, 10% CNS, 7% blood, 12% other.
5.	Meyers et al. (2011), USA	Prospective, multi-institution, randomized trial	31	Unknown (sessions)	N = 449 Mean age 61	Spouse 70% Child 16% Parent 3% Unrelated 4% Other 5%	N = 449 Mean age 62 28% gastrointestinal, 27% genito-urinary, 21% thoracic, 10% breast and 15% other
6.	Mosher et al. (2018), USA	RCT	30	Home (sessions, telephone)	N = 50 Coping = 25: 68% female, mean age 52 (15) Coping + peer = 25: female 64%, mean age 55 (12)	Spouse 76% (Coping 68%, coping + peer 84%)	Advanced gastrointestinal cancer, stage IV. 38% colorectal and 26% pancreatic cancer.

TABLE 1 (Continued)

No	Author(s), year of publication, country	Design	Quality total score	Setting of the intervention	Sample characteristics of caregivers (N, gender, and mean age, standard deviation)	Relation to patient	Sample characteristics of patient (N, gender, mean age, advanced cancer type)
7.	Northouse et al. (2005), USA	RCT	28	Home (home visits and phone calls)	N = 182 Gender not described, mean age 52 (14)	Spouse 62% Child 16% Other 22%	N = 134 Mean age 54 (11) 100% breast cancer
8.	Northouse et al. (2013), USA	RCT (three-armed)	27	Home (home visits and phone calls)	N = 417 56% female, mean age 57 (13)	Spouse 74%	Advanced breast, colorectal, lung or prostate cancer (i.e., Stage III or IV)
9.	Ringdal et al. (2004), Norway and Sweden	Norway: cluster-RCT Sweden: non-RCT	29	Home (consultations)	Norway N = 285 I = 183: 70% female, mean age 58 C = 130: 68% female, mean age 58 Sweden N = 204 I = 102: 71% female, mean age 63 C = 102: 58% female, mean age 65	Norway Spouse (I 67%, C 61%) Parent (I 2%, C 0%) Child (I 27%, C 34%) Other (I 5%, C 6%) Sweden Spouse (I 76%, C 79%) Parent (I 3%, C 3%) Child (I 15%, C 11%) Other (I 7%, C 7%)	Norway Gastrointestinal (I 46%, C 38%), lung (I 14%, C 13%), breast/female genital tails (I 11%, C 19%), prostate (I 8%, C 11%) urological (I 8%, C 5%), other (I 14%, C 15%) Sweden Gastrointestinal (I 36%, C 52%), lung (I 12%, C 20%), breast/female genital tails (I 13%, C 13%), prostate (I 12%, C 4), urological (I 10%, C 3%) and other cancers (I 18%, C 9%)
10.	Sun et al. (2015; 2016), USA	Prospective, quasi-experimental study	26	Unknown (sessions)	N = 354 I = 191: 63% female, mean age 57 (14) C = 153	No information	N = 475 61% female, mean age 65 (11) 100% lung cancer

(Continues)

TABLE 1 (Continued)

No	Author(s), year of publication, country	Design	Quality total score	Setting of the intervention	Sample characteristics of caregivers (N, gender, and mean age, standard deviation)	Relation to patient	Sample characteristics of patient (N, gender, mean age, advanced cancer type)
11.	von Heymann-Horan et al. (2018; 2019), Denmark	RCT	31	Home care (sessions)	N = 249 I = 134: 63% female, mean age 61 (12) C = 115: 65% female, mean age 62 (13)	Spouse (I 77%, C 80%) Child (I 18%, C 9%) Other (I 5%, C 11%)	N = 249 Gastrointestinal (I 21%, C 22%), female genitalia (I 13%, C 11%), CNS (I 12%, C 18%), prostate (I 18%, C 4%), lung (I 21%, C 22%) and other (I 21%, C 22%)
Family							
1.	Kissane et al., 2016, Australia	RCT (three-armed, multicenter)	22	Unknown (sessions)	N = 170 families/620 individuals 60% female N = 490: 112 partners, 378 other. N = 112: mean 58 (Standard Care), 55 (6 Sessions), 60 (10 Sessions) N = 378: 34 (Standard Care), 38 (6 Sessions), 41 (10 Sessions).	Partner or other relatives	N = 130: mean 55 (Standard Care), 53 (6 Sessions), 58 (10 Sessions). 65% gastrointestinal/pancreatic, 10% melanoma, 8% lung, 4% breast and 13% other cancer
2.	Petursdottir & Svavarsdottir (2019), Iceland	Pre-experimental one-group pre- and post-test design	33	Home (home visits)	N = 48 60% female (N = 29), age 77% > 60, 13% 51–60, 6% 41%–50% and 4% 31–40	Spouse 81% Child 12% Parent 4% Other 4%	N = 48 25% lung, 17% gastrointestinal, 10% pancreatic and other cancers
Group							
1.	Holm et al. (2016), Sweden	RCT	32	Palliative home care	N = 194 I = 98: 69% female, mean 63 (13). C = 96: 64% female, mean 60 (14).	Spouse (I 55%, C 42%) Child (I 33%, C 37%), Other (I 12%, C 22%)	N = 175 (15 patients represented by >1 caregiver) 53% female, mean age 73 Advanced cancer (90%)

2.	Hudson et al. (2008), Australia	Single-group prospective study	26	Palliative home care	N = 74; 76% female, mean age 58 (23–84).	Spouse 59% Child 23% Parent 1% Other (15%)	N = 74. 45% female, mean age 69 (19–93). Advanced cancer (no further details)
3.	Hudson et al. (2012), Australia	Pre-post design	32	In-patient setting/ palliative care units	N = 126 67% female, mean age 57 (15) (n = 122).	Spouse 40% Parent 38% Child 2% Other 19% Missing 2%	N = 126 49% female, mean age 72 (41–95) Advanced cancer (no further details)
4.	Li et al. (2015), China	Pre- and post-intervention study design	26	Hospital	N = 117 67% female, mean age 57 (11)	Spouse 100% (married couples)	N = 117 33% female, mean age 58 (11) 56% digestive system, 30% lung, 11% urogenital system, 3% other cancer Stage III 39% and stage IV 62%

Abbreviations: C, Control group; CHES, Comprehensive Health Enhancement Support System; CNS, central nervous system; CR, Clinician Report; GP, General Practitioner; Gyne, gynecological; I, Intervention group; N, amount of people; RCT, Randomized Controlled Trial.

the family caregiver and the patient were supported together. Only two interventions were developed for families (*family interventions*): these interventions were targeted at the patient, the caregiver and other relatives of the patient. Four interventions were developed for peer groups of family caregivers or dyads (*group interventions*).

3.3.2 | Content of interventions

Table 3 presents the content of the interventions; more details can be found in Supporting Information S2. Twenty-two interventions included a patient caregiving component, for example, learning how to support the patient in their activities of daily living. Thirty-one interventions included a caregiver self-care component, such as learning how to deal with the family caregiver's own symptoms of burden. Half of the interventions (n = 16) included a family component, such as communicating within the family about the disease.

A total of five interventions^{24,28,30,44,48} were single component interventions and the other interventions were multicomponent interventions. Eleven multicomponent interventions included all three components (patient caregiving, self-care, family-care).

Most individual interventions focused on self-care of family caregivers, sometimes in combination with the component patient caregiving. Dyadic interventions were most often focused on all three components. Family and group interventions included both family care and caregiver self-care, sometimes combined with patient caregiving.

Five interventions included an individual needs assessment of the family caregiver. Nineteen other interventions addressed the personal situation of the family caregiver in other ways, for example, by identifying the caregivers' problems.

3.3.3 | Theories of interventions

Eleven interventions were developed based on Lazarus & Folkman's theory of stress and coping.^{22,24,25,27,32–34,36,39,46,47,57} The other interventions were based on a diversity of theories, for example, the cope theory.^{26,43} The theories used are reported in Table 3.

3.3.4 | Provider, mode, duration, dose, place

The interventions were delivered by healthcare professionals (e.g., nurses) or trained professionals. In five studies it was not indicated by whom the intervention was delivered.^{24,29,37,38,50}

Most interventions (n = 24) were delivered face-to-face, sometimes in combination with telephone contacts. All family and group interventions were provided face-to-face. Three interventions consisted of telephone contacts only^{45,51} and for another intervention it was unclear how it was delivered.^{52,53} There were also two user-

TABLE 2 Quality assessment (on Hawker Quality Assessment Tool).

Study	Abstract/ title	Introduction/ aims	Data collection	Sampling	Analysis	Ethics/bias	Results	Generability	Implications	Total ^a
Chih et al. (2013)	4	4	4	4	4	3	4	3	3	33
McMillan et al. (2006)	4	4	3	4	4	4	4	3	3	33
Petursdottir and Svavarsdottir (2019)	4	4	4	4	3	3	4	4	3	33
Holm et al. (2016)	4	4	4	4	3	3	4	3	3	32
Hudson et al. (2012)	4	4	4	3	4	3	4	3	3	32
Mitchell et al. (2013)	4	3	4	4	4	3	4	3	3	32
Sherwood et al. (2012)	4	4	4	4	4	2	4	3	3	32
Aoun et al. (2015)	4	4	4	4	4	2	3	3	3	31
von Heymann-Horan et al. (2018), (2019)	4	4	4	3	3	4	3	3	3	31
Hudson et al. (2013), (2015)	3	3	4	3	3	4	4	3	4	31
Meyers et al. (2011)	4	3	4	4	4	3	3	3	3	31
Ammari et al. (2018)	4	4	4	3	3	2	4	3	3	30
Dionne-Odom et al. (2015)	4	4	4	3	3	2	4	3	3	30
Hudson et al. (2005)	3	3	4	3	3	3	4	3	4	30
Mosher et al. (2018)	3	4	4	4	3	3	3	3	3	30
Ringdal et al. (2004)	3	4	3	3	3	4	3	3	3	29
DuBenske et al. (2014)	4	3	3	3	4	2	3	3	3	28
El-Jawahri et al. (2017)	4	4	3	3	3	2	3	3	3	28
Northouse et al. (2005)	4	4	4	3	3	1	4	3	2	28
Northouse et al. (2013)	4	2	4	3	3	2	3	3	3	27
Otani et al. (2014)	4	3	3	3	3	2	4	2	3	27
Duggleby et al. (2013)	3	3	3	4	3	2	4	2	3	27
McLean et al. (2013)	3	3	3	4	3	2	3	3	3	27
Hudson et al. (2008)	3	4	3	2	3	2	4	2	3	26
Li, et al. (2015)	3	3	3	4	3	2	3	2	3	26
Sun et al. (2015), (2016)	4	3	3	2	3	2	3	3	3	26
Cameron et al. (2004)	4	3	2	3	3	2	3	3	2	25
Lapid et al. (2016)	3	4	2	3	3	2	3	2	3	25
Lee et al. (2016)	3	3	3	3	2	2	2	2	3	23
Walsh et al. (2007)	3	3	2	3	2	2	2	3	3	23
Ferrell et al. (2019)	3	3	3	2	3	1	4	1	2	22
Kissane et al. (2016)	3	2	2	3	3	2	3	2	2	22

^aItemscores between 1 and 4, total score with a minimum of 9 and a maximum of 36.

Source: Hawker S, Payne S, Kerr C, Hardey M, Powell J (2002) Appraising the Evidence: Reviewing Disparate Data Systematically Qualitative Health Research 12: 1284–1299.

driven eHealth interventions^{25,27} and a self-administered intervention that consisted of watching a film and participating in an activity related to the topic hope.²⁸

In half of the cases interventions were supplemented with written material (e.g., guidebook, toolkit, leaflet, or

handouts)^{24,30,32,33,36,40,43–46,48,51–53} and/or audio-visual material (CD and film).^{28,32,45}

The dose of the face-to-face and telephone interventions varied between a single one-hour session and 10 sessions, spread over the period of 5 months. User-driven interventions lasted one or 2 years.

TABLE 3 Intervention content and effects.

Author, year	N (number of relatives studied)	Intervention	Theoretical framework	Interventist	Modality	Period	Dosage (number of contact moments with caregiver/relatives)	Patient-caring (content/co mponents)	Self-care (content/co mponents)	Family-care (content/co mponents)	Improved outcomes of intervention (significant) (*Subgroup/subo main)	Deteriorated outcomes of intervention (significant)	No significant effect (no outcomes of intervention)	Physical (improved physical dimension)	Psycho-emotional (improved outcomes in psychological dimension)	Social (improved outcomes in social dimension)	Spiritual (improved outcomes in spiritual dimension)	Other (daily functioning) (improved outcomes in the other dimension)	QoL (improved outcomes in QoL dimension)	Needs-assessment (needs included in intervention)	Other activities (other activities included in intervention to cope with caregivers' personal needs, problems or preferences)	Control group (CG) (intervention outcomes in controlgroup)
INDIVIDUAL																						
Aoun et al. (2015)	322	Needs-assessment (CSNA1)	Based on research family caregivers' needs	Nurse	1, 3	2-3 weeks	At least 2	✓	✓	✓	Strain	Distress, mental and physical wellbeing, workload		Strain						CSNA1, needs-assessment tool		
Camero et al. (2004)	34	Problem-solving intervention (for Release's stress, Creative, Optimistic, Plan, and obtain Expert information)	Lazarus and Folkman's stress and coping theory	Unknown	1	1 hour/ single	1	✓	✓	✓	Emotional tension	Confidence, Problem-solving ability, total mood, Assistance ADL		Emotional tension						COPE, problem-solving; define problem and plan		
Chih et al. (2013)	217	Comprehensive Health Enhancement/Support System (CHES) (SM)	Model of stress and coping	User driven	5	12 months	User driven	✓	✓	✓	Negative mood			Negative mood								
Donne et al. (2015)	122	Early telehealth palliative care delivery (for Early Caregivers' educational intervention).	COPE framework	Nurse (coach)	2	3 weeks, plus follow-up	3	✓	✓	✓	Depression, stress burden by caregivers of decedents			Depression, stress burden							COPE, problem-solving	
Dufrenske et al. (2014)	246	Comprehensive Health Enhancement/Support System (CHES) (SM)	Model of stress and coping	User driven	5	24 months	User driven	✓	✓	✓	Burden, Negative mood			Burden, Negative mood								
Duggelby et al. (2013)	36	Living with hope program	Social Cognitive Theory and the Translational Model "Hanging on the Hope"	Self-administered	4	2 weeks	User-driven	✓	✓	✓	Hope, Self-efficacy, Mental health	Physical health	Grief	Mental health			Hope	Self-efficacy				
Ferrari et al. (2019)	240	Four-part educational program for FC with financial strain	Model of Family Caregiver Quality of Life (City of Hope Cancer Center)	Nurse	1 or 2, 3	4 weeks	4	✓	✓	✓										Assessment of current self-care strategies and caregiver burden		
Hudson et al. (2005)	106	Psycho-educational intervention	Transactional model of stress and coping (Lazarus and Folkman)	Nurse	1,2,3,4	12-14 days/ 2 weeks	3	✓	✓	✓	Rewards			Rewards						Psycho-education, care plan		
Hudson et al. (2013; 2015)	298	Psycho-educational intervention	Transactional model of stress and coping (Lazarus and Folkman)	Nurse	1,2,3	4 weeks	4	✓	✓	✓	Distress (one-visit group), Preparedness, Competence (two-visits group)			Distress				Preparedness Competence	Psycho-education: needs-assessment, careplan and evaluation needs			
Lee et al. (2016)	81	Integrated caregiver support program (I-CARE) (SM) (Education)	Theory of self-efficacy and resilience, patient's model of stress and coping (Lazarus and Folkman)	Researcher with experience in cancer nursing	1,2	every 2 weeks death (3 months)	At least 3	✓	✓	✓	Distress (one-visit group), Preparedness, Competence (two-visits group), Self-efficacy			Burden				Self-efficacy	CARE, coping strategy to deal with stressors			
McMillan et al. (2006)	329	Coping skills training (COPE) (SM)	Conceptual and research literature on problem solving	Nurse and home health aid	1	<30 days	3	✓	✓	✓	QoL, Burden of patients' symptoms, Burden of caregiving tasks			Burden of patients symptoms, burden of caregiving tasks					QoL	COPE Symptom Management (SM), problem-solving		
Mitchell et al. (2013)	392	GP based intervention using Needs Assessment Tool-Carers (NAT-C)	Unknown	GP	1	3 months	2	✓	✓	✓	Mental component **, Anxiety**, Physical score**			Physical score**	Mental component **, Anxiety**				Needs-assessment GP			
Orari et al. (2014)	355	Leaflet based intervention about Delirium (SM)	Unknown	Clinician	3	unknown	1	✓	✓	✓	Knowledge (causes delirium)			Family perceived distress, the need for				Knowledge				
Sherwood et al. (2012)	225	Problem-solving intervention (SM)	Unknown	Nurse	2	8 weeks	3	✓	✓	✓	Amount of assistance**			Improvements in Symptom assistance					Amount of assistance**	Problem-solving SM		
Walsh et al. (2007)	271	Carer advisor intervention	Unknown	Carer advisor	1 (or 2)	6 weeks	6	✓	✓	✓				Psychological distress, Strain, Quality of life, Bereavement, Satisfaction					Needs-assessment domains			

(Continues)

TABLE 3 (Continued)

PKD	Author et al.	Year	Intervention	Theoretical basis	Staff	1	15 weeks	6	✓	✓	✓	QOL, anxiety and depression	Total distress (overall + caregiver subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL (overall) (anxiety subscale)	QOL 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The majority of the interventions were delivered in a home-based setting, whereas the other interventions were delivered in an outpatient hospital setting,^{24,30,41} in-patient hospital setting, palliative care unit, or hospice,^{36,39,40,42} or at the office of the general practitioner.⁴⁴ The place of delivery of some interventions was not described.^{29,37,38,43,52,53}

The effects of the interventions are shown in Table 3. Most interventions significantly improved outcomes for the family caregiver ($n = 29$). Three did not yield any significant improvements^{22,30,56} and four interventions deteriorated some outcomes of family caregivers, such as increased burden or distress.^{28,30,33,54,55}

Over two thirds ($n = 24$) of the interventions were reported to yield a significant improvement in the psycho-emotional dimension. Over one-third of the interventions ($n = 13$) showed a significant improvement on the daily functioning dimension.^{28,31,33-36,38-40,45-48,54,55} Few interventions had a beneficial effect in the social dimension ($n = 6$),^{41,43,47,49,50,52,53} the physical dimension ($n = 3$),^{38,40,44} the spiritual dimension ($n = 3$),^{28,38,43} and on quality of life ($n = 2$).^{42,43}

Beneficial outcomes appeared to be associated with a specific intervention characteristic, namely the target population. Almost all individual interventions ($n = 13$) improved outcomes in the psycho-emotional dimension, such as family caregiver burden and anxiety. Most dyadic interventions ($n = 10$) significantly improved caregiver outcomes in the psycho-emotional dimension ($n = 9$) and the social dimension ($n = 5$) for example, social wellbeing.^{52,53} Both family interventions significantly improved caregiver outcomes in the psycho-emotional dimension and in the social dimension. All four group interventions resulted in significantly improved outcomes in the dimension daily functioning.^{31,33,36}

Content of interventions, theories of interventions, provider, mode, duration, dose, and place do not seem to be associated with effect of the interventions. For example, brief interventions yielded positive effects on family caregivers' outcomes to the same extent as longer term interventions.

4 | DISCUSSION

We systematically analyzed characteristics and evidence on the effectiveness of 32 supportive interventions for family caregivers of patients with advanced cancer. The interventions concerned a wide range of settings, target population, modalities, periods, and dosages. Most interventions were primarily aimed at supporting family caregivers' self-care, sometimes in combination with patient care and family care. In addition, most interventions were provided by nurses, in one or more face-to-face meetings or by phone. Our review shows that most supportive interventions had a beneficial effect on the

well-being of family caregivers. Beneficial effects were most often found in the psycho-emotional dimension.

The effects of interventions depend on the target population of the intervention. The target populations can be categorized into four groups: individuals, dyads, families, and groups. Individual interventions had mainly positive effects on the psycho-emotional dimension. Dyad and family interventions had positive effects on both the psycho-emotional and the social dimension. Group interventions were most effective on family caregivers' daily functioning. There seems to be a growing emphasis on supporting family caregivers as dyads, together with the patient, or with their family, since eight studies on dyadic or family interventions were published after 2015.⁵⁸ This is in line with the increasing recognition that informal care takes place in the context of a family unit that includes multiple relationships, within a wider social network and community.⁵⁹ A review of Regan et al.⁶⁰ on couple based interventions already showed that dyadic interventions were effective in improving relationship functioning, including dyads' coping with the illness and marital functioning.

Whether interventions are targeted at individual family caregivers, patient-caregiver dyads or groups of family caregivers seems to be associated with the dimension where an effect is found, but we found no indication that other characteristics of the interventions are associated with outcomes, such as whether the intervention takes place face-to-face or online. However, according to Luo et al.⁶¹ and Vanstone and Fergus⁶² the power of face-to-face interventions should not be underestimated due to the wider possibility of non-verbal and affective communication and offering support in feeling comfortable. Concerns have been raised about the use of telehealth. The review of Budd et al.⁶³ shows that there may be difficulties in establishing empathy. A major challenge with telehealth is the loss of the ability to read and display non-verbal cues. However, the need for social distance and patient safety during the COVID-19 pandemic caused a shift from face-to-face interventions to telehealth, such as telephone, video, and other electronic communication in cancer care practice.⁶⁴ Studies show positive effects of supportive care delivered through telehealth, such as improved access to care, improved continuity of care for patients and their family caregivers and a reduced risk of contamination.^{65,66} In our study, two online interventions and three telephone interventions also had positive effects on family caregivers' wellbeing. The online interventions improved caregivers' burden and negative mood. The telephone interventions showed improvements in family caregivers' burden, depression, meaning in life, and the amount of assistance. Thus, despite concerns, there are communication strategies available to help health care professionals maintain quality of care using telehealth.⁶⁷

A strength of our review is that in general, the studies were rated as being of good quality. The average score on the Hawker Quality Assessment Tool was 28.4. Ethical aspects were reported less frequently than other aspects. This has previously also been reported on studies published in nursing journals.⁶⁸ Another strength is that using a broad search strategy, we were able to provide a

comprehensive overview of different types of interventions in different care settings.

4.1 | Study limitations

A limitation of our study is that most studies were conducted in Western-oriented countries. This may limit the generalizability of the study findings to non-Western-oriented countries. Another limitation is that due to the variety in outcome measurements the comparison of the effectiveness among different interventions was complex.

4.2 | Clinical implications

This review shows that almost all supportive interventions have some benefit for family caregivers involved in care for patients with advanced cancer. However, family caregivers are diverse (i.e. gender, age, health, relationship with the patient, social factors and caregiving context) and all have their unique needs and preferences.⁵⁹ Therefore, health care organizations should select an intervention that best addresses the problems and needs of the family caregivers in their context. Furthermore, organizational and financial consequences should be taken into account when choosing an intervention, for example, the number of sessions and duration of the interventions, provider-driven or self-administered, and where the intervention is delivered. As time is often an issue in clinical health-care practice, it may be helpful that there are also brief interventions which have shown positive results. In clinical practice, it should be taken into account that different types of interventions (varying in target population) demonstrate positive results in different dimensions. For example, if a family caregiver suffers mostly in the dimension of daily functioning, a group intervention may be most suitable. Of course, such decisions must be made with the unique needs and preferences of family caregivers taken into consideration.

Despite many interventions improving outcomes for family caregivers, further research is warranted to better understand which components of an intervention, in addition to the target group, resulted in better outcomes.

5 | CONCLUSIONS

We found 32 interventions to support family caregivers in palliative and end-of-life cancer care. Almost all intervention studies reported beneficial effects for family caregivers, mainly in the psycho-emotional and social dimensions. The interventions varied in target population, content, underlying theory, provider, mode, duration, dose and place of delivery. Most interventions consisted of multiple components, focusing on individual family caregivers or in connection with other relatives or peers. The effects of interventions were

studied using different outcome measures. Although most intervention studies reported beneficial effects, there appeared to be an indication that whether interventions are targeted at individual family caregivers, patient-caregiver dyads or groups of family caregivers is associated with the dimension where an effect is found. Healthcare organizations should choose an intervention that addresses the problems and needs of family caregivers in their context, while considering the organizational and financial consequences for the organization.

AUTHOR CONTRIBUTIONS

Yvonne N. Becqué and Maaïke van der Wel drafted the manuscript. Muzeyyen Aktan-Arslan and Erica Witkamp were responsible for the search strategy. Yvonne N. Becqué, Maaïke van der Wel, Muzeyyen Aktan-Arslan and Anne Geert van Driel were involved in data extraction and quality assessment. The data were analyzed and interpreted by Yvonne N. Becqué and Maaïke van der Wel, where Erica Witkamp, Agnes van der Heide, and Judith A. C. Rietjens critically reviewed them and made suggestions for revisions. All authors revised and approved the final version.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflict of interest to declare.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analyzed during the current study.

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SUPPORTING INFORMATION

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

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