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Nursing interventions to support family caregivers in end-of-life care at home: A systematic narrative review

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ABSTRACT

Background: Family caregivers are crucial in end-of-life care. However, family caregiving may involve a significant burden with various negative health consequences. Although nurses are in a unique position to support family caregivers at home, little is known about which nursing interventions are effective in this context. Therefore, this study aims to provide insight into nursing interventions currently available to support family caregivers in end-of-life care at home and to describe their effects.

Methods: A systematic search was conducted in Embase, Medline Ovid, Web of Science, Cochrane Central, CINAHL and Google Scholar. This review included quantitative studies published from January 2003 until December 2018 reporting on nursing interventions to support adult family caregivers in end-of-life care at home. Data were extracted on intervention modalities, intervention components, and family caregivers' outcomes. Methodological quality of the studies was assessed with the Cochrane Risk of Bias Tool.

Results: Out of 1531 titles, nine publications were included that reported on eight studies/eight interventions. Of the eight studies, three were randomised controlled trials, one a pilot randomised trial, one a non-randomised trial, and three were single-group prospective studies. Four intervention components were identified: psychoeducation, needs assessment, practical support with caregiving, and peer support. Psychoeducation was the most commonly occurring component. Nursing interventions had a positive effect on the preparedness, competence, rewards, and burden of family caregivers. Multicomponent interventions were the most effective with, potentially, the components 'needs assessment' and 'psychoeducation' being the most effective.

Conclusions: Although only eight studies are available on nursing interventions to support family caregivers in end-of-life care at home, they show that interventions can have a positive effect on family caregivers' outcomes. Multicomponent interventions proved to be the most successful, implying that nurses should combine different components when supporting family caregivers.

What is already known about the topic?

- Although family caregivers play a crucial role in end-of-life care at home, many experience burden and a lack of preparedness for the situation as caregiver.
- Nurses are in a unique position in primary healthcare to support family caregivers in the aim to enhance caregivers' outcomes.
- However, there is a lack of systematic synthesis of current knowledge around the effectiveness of nursing supportive interventions on family caregivers' well-being.

What this paper adds

- Supportive interventions for family caregivers comprise four main components: psychoeducation, needs assessment, practical support with caregiving, and peer support.
- The interventions may positively affect family caregivers' preparedness, competence, burden and experiences related to their role.
- Multicomponent interventions are more effective than single component interventions; the components 'needs assessment' and 'psychoeducation' seem to be the most effective.

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1. Introduction

Although about 70% of patients in their end stage of life prefers to be cared for and die at home (Higginson et al., 2014), this wish is not often met. A cross-national population-level study in 14 countries found that only 13% (Canada) to 53% (Mexico) of patients with diseases indicative of palliative care needs die at home (Pivodic et al., 2016). Family caregivers play a crucial role in the end-of-life care (Gomes and Higginson, 2006; Grande et al., 2009; Rowland et al., 2017; Visser et al., 2004). Here, we define family caregivers as adult family members or friends who provide end-of-life care to patients with a physical and life-threatening disease. Family caregivers are often intensively involved with psychological support, personal care and activities of daily living, as well as with household tasks and the coordination of care (Lund et al., 2014; Rowland et al., 2017; Stajduhar et al., 2010). For instance, in the Netherlands, they provide end-of-life care for (on average) 26 h per week (De Boer et al., 2009). In the United Kingdom, family caregivers help a median of 69 h each week in the final 3 months of life (Rowland et al., 2017). Without this help, it would be impossible for many patients to die at home (Rowland et al., 2017; Visser et al., 2004).

The position of the family caregiver can be seen as both i) providing support, and ii) needing support (Harding and Higginson, 2003). Their role is not limited to 'practical' care, since caring for a dying family member has both psychological and social implications (Payne, 2010). Family caregivers have to cope with the impending loss of a family member, and providing care in itself can be a source of stress. Many caregivers have to deal with emotional suffering, burden, stress, fear, anxiety, guilt and sleep disturbances (Funk et al., 2010; Lund et al., 2014; Morasso et al., 2008; Stajduhar et al., 2010). About 25% of family caregivers experience emotional suffering related to the patient's death or their caregiving experience (Morasso et al., 2008). One study reported that the percentage of family caregivers experiencing a heavy to severe burden, increased from 32% (in the second/third month before death) to 66% in the last week of life (De Korte-Verhoef et al., 2014). Some family caregivers feel insufficiently prepared for the caregiving tasks (Aoun et al., 2005). They require additional support from healthcare professionals, e.g. for the practical aspects of caring, as well as general information regarding the patient's disease (Bužgová et al., 2016; Funk et al., 2010; Harding et al., 2012 a; Hudson and Aranda, 2004).

Although nurses have a unique position to provide this support (Kennedy, 2005; Sousa and Alves, 2015), there is a lack of systematic synthesis of current knowledge around the effectiveness of nursing supportive interventions on family caregivers' well-being (Grande et al., 2009; Harding and Higginson, 2003; Hudson et al., 2010). Therefore, this study aims to provide insight into supportive nursing interventions that are available for family caregivers in end-of-life care at home and their modalities and components, and describes the effects of these interventions. For this aim, supportive nursing interventions are defined as '*all home-based interventions involving family caregivers of patients in the end-of-life phase that a nurse performs to enhance family caregivers' outcomes*'. This definition is based on the nursing intervention definition in the Nursing Interventions Classification (NIC) (Butcher et al., 2018).

2. Methods

We conducted a systematic narrative review. A narrative review describes *'published materials which provide an examination of current literature' (*Grant and Booth, 2009*)*. We used a systematic search and a quality appraisal; however, this quality assessment did not determine study selection. We included all studies to fully demonstrate the current state of research in this area. A narrative synthesis was used to identify the intervention components (Dixon-Woods et al., 2005).

2.1. Registration of the review

This systematic review was registered at the PROSPERO register (registration number: CRD42018084800). The full form can be accessed online at https://www.crd.york.ac.uk/prospero/.

2.2. Inclusion and exclusion criteria

Included were quantitative studies or mixed methods studies with a quantitative design component, published from January 2003 until December 2018. All nursing interventions to support family caregivers in end-of-life care at home were included; moreover, the role of the nurse had to be clearly described. Studies involving adult family caregivers who provided care to patients with cancer, organ failure or other chronic life-threatening diseases in the end-of-life phase (excluding patients with mental diseases or cognitive impairments such as dementia) were included. Studies focusing on clearly defined outcome measures related to the well-being of family caregivers were selected. Excluded were conference abstracts, letters, editorials and research reports, as well as studies published in languages other than English.

Studies had to meet all inclusion criteria to be included for further analysis.

2.3. Information sources and search

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist was used as underlying structure of this review. In July 2017, a systematic electronic search was conducted aided by a biomedical information specialist from the Medical Library, Erasmus MC. The following databases were searched: Embase, Medline Ovid, Web of Science, Cochrane Central and Google Scholar. In March 2019 we updated the search and included database CINAHL. To identify relevant studies, a broad search strategy was used built on the following concepts: i) Care, using terms such as: "palliative nursing" OR "hospice care" OR "terminal care" OR "end-of-life" OR "advanced cancer"; ii) Population, using terms like:" relative" OR "family" OR "caregiver" OR "adult child" OR "spouse"; iii) Discipline, using terms: "nurse" OR "nursing"; and iv) Setting, using terms such as: "home care" OR "home based". The four strings were combined to achieve the final result (Appendix A. in Supplementary data). Moreover, the reference lists of the reviewed studies and systematic reviews were screened for potential additional studies.

2.4. Study selection

Retrieved records were imported into Endnote®. After removing duplicates, the first author (YB) screened the study titles and abstracts for eligibility; a second author (EW) checked 20% of these titles and abstracts. This resulted in entire agreement. Then, the first author (YB) screened the full-text versions of the remaining papers. In case it was unclear whether a paper met the inclusion criteria, another author (EW or JR) was consulted and consensus was reached. In case of incomplete reporting in the publication, the corresponding author was contacted (if possible) for further clarification.

2.5. Data extraction and synthesis

A data extraction form was used to summarise the characteristics of each study and intervention. The following information was obtained on the family caregivers and their patients: sample size, gender, age, the condition of the patient, and the relationship between the family caregiver and patient. Furthermore, from each study, the first author (YB) extracted information on: the description, elements/topics, timing, and the effects of the nursing interventions on the family caregivers. Data extraction was verified by a different author (AGD). In case of disagreement, this was discussed and resolved by consensus.

Furthermore, we used an interpretative and narrative synthesis process (Dixon-Woods et al., 2005). It started with a detailed inspection of the descriptions, aims and topics of the nursing interventions as reported in the articles, and any supplementary data (e.g. from a booklet/manual). Gradually we identified the key concepts of the interventions by systematic comparison. After this, the synthesis process involves building a general interpretation grounded in the findings of the separated studies. The most powerful themes (intervention components) were identified by constant comparison: psychoeducation, needs assessment, practical support with caregiving and peer support (Dixon-Woods et al., 2006).

2.6. Quality appraisal

Two authors (YB, AGD) independently from each other assessed the risk of bias in the studies following the Cochrane Handbook for Systematic Reviews of Interventions (Higgins and Green, 2011). Any disagreement was resolved by consensus or by consulting a third author (EW). The Cochrane Risk of Bias Assessment tool, aimed to assess the risk of bias in randomised controlled trials, was used because half of the reviewed studies were (pilot) randomised controlled trials. The tool covers selection bias, performance bias, detection bias, attrition bias and reporting bias for (randomised controlled) studies, rated ‘low risk +’, ‘high risk -’ or ‘unclear?’ (Higgins and Green, 2011).

Given the fact that the included studies were not all randomised controlled trials, we also assessed the baseline data between the intervention and control group, sample size (calculation) and the follow-up.

3. Results

3.1. Study selection

After removing duplicates, 1522 publications remained and nine additional articles were identified by checking the reference lists of the reviewed studies and review articles. This resulted in 1531 publications; after screening these on title and abstract 1500 were excluded (leaving articles). Main reasons for exclusion were: i) they were related only to the experience of caregiving, ii) they were related to the needs of family caregivers, iii) the intervention was not provided by a nurse, and iv) the study population did not meet the inclusion criteria.

Finally, after scrutinising the full text of 31 publications for eligibility, nine publications (reporting on eight studies) were included in the analysis (Aoun et al., 2015; Chan et al., 2014; Holm et al., 2016; Hudson et al., 2008, 2013; Hudson et al., 2015, 2005; Leow et al., 2015; Luker et al., 2015) (Fig. 1). The main reason for the exclusion of the remaining 22 studies was that the study design did not meet the inclusion criteria. Seven studies had a qualitative design and five were literature reviews/overviews.

3.2. Study characteristics

Table 1 presents the characteristics of the included studies; a summary of the characteristics of the interventions can be found in Appendix B in Supplementary data. The eight studies comprised three randomised controlled trials (RCTs) (Holm et al., 2016; Hudson et al., 2013, 2015; Hudson et al., 2005), one pilot randomised controlled trial (Leow et al., 2015), one stepped-wedge cluster non-randomised trial (Aoun et al., 2015) and three single-group before-after quantitative designs (Chan et al., 2014; Hudson et al., 2008; Luker et al., 2015). Two publications were published in 2005–2008 and the remainder in 2013-2016. The studies were conducted in Australia (n = 4), China (n = 1), Sweden (n = 1), Singapore (n = 1) and the United Kingdom (n = 1). Five studies involved patients with cancer, and three included patients

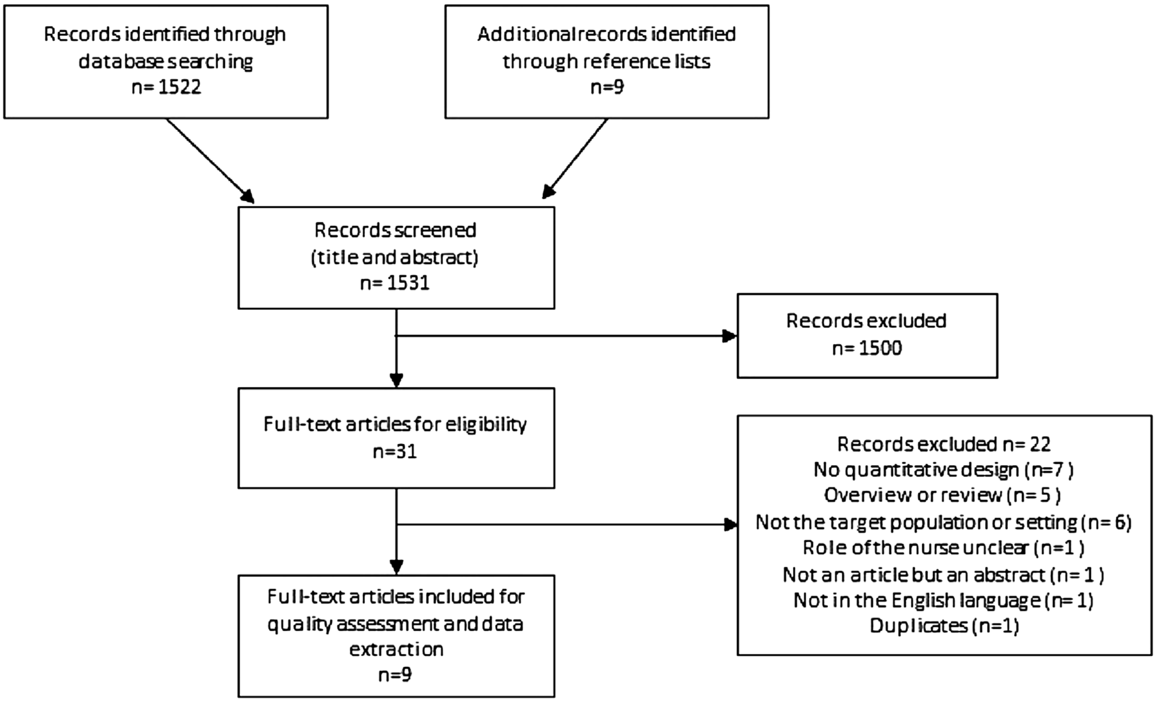


Fig. 1. Selection of the nine included articles (reporting on eight studies).

Table 1
Characteristics of the included studies.

First author; year of publication; country	Intervention	Design	Setting	Family caregivers: N	Family caregivers: gender and mean age, standard deviation (sd)	Relation to patient	Patients: N, gender mean age and condition	Outcomes and instruments	Data collection
Aoun et al. (2015), Australia	During at least two home visits nurses used the Carer Support Needs Assessment Tool (CSNAT) to identify and address support needs of family caregivers.	Stepped-wedge cluster non-RCT	Perth, Western Australia, in three sites of the Silver Chain Hospice Care Service	T1 N = 586 I = 423 C = 163 T2 N = 322 I = 233 C = 89	I = 233: 70% female, mean 62 (12). C = 89: 80% female, mean 66 (13).	Spouse, parent, adult child, sibling, other	N = 322 (I = 233, C = 89): I: 44% female, mean 70 (13). C: 39% female, mean 72 (14). Cancer and non-cancer	Caregiver strain and distress: Family Appraisal of Caregiving Questionnaire Caregiver mental and physical wellbeing: SF-12v2 Caregiver workload questionnaire developed by researchers	2 time points: T1=pre-intervention T2= post-intervention (within 3-7 days after the second visit).
Chan et al. (2014), China	An eight-week palliative care programme for dyads at home.	Pretest post-test design	Palliative home care services of participating hospitals in Hong Kong	T1 N = 24 T2 N = 6	Unknown	Spouse or adult family member, lived in the same household	N = 108: 57% female, mean = 73. With a life expectancy of more than 6 months. Cancer (52%) and non-cancer	Family satisfaction with care: Family Satisfaction Scale (FAMCARE)	3 time points: T1= pre-intervention T2= post-intervention T3= post-intervention after 3 months (no family members completed T3 assessment)
Holm et al. (2016), Sweden	A psycho-educational group intervention for family caregivers, delivered by a multidisciplinary team. The nurse acted as group leader in the three sessions.	RCT	10 specialised palliative home care settings in a regional metropolitan area in Sweden.	T1 N = 194 I = 98 C = 96 T2 N = 186 T3 N = 177	I = 98: 69% female, mean 63 (13). C = 96: 64% female, mean 60 (14).	Spouse (I 55%, C 42%), adult child (I 33%, C 37%), other (I 12%, C 22%)	N = 175 (15 patients represented by >1 caregiver), mean = 73, 53% female Cancer (90%) and non-cancer	Preparedness: Preparedness for Caregiving Scale (PCS) Competence: Caregiver Competence Scale (CCS) Reward: Rewards of Caregiving Scale (RCS) Burden: Caregiver Burden Scale (CBS) Health: Health Index Anxiety and depression: Hospital Anxiety and Depression Scale (HADS)	3 time points: T1= pre-intervention T2= post-intervention T3 = 2 months later
Hudson et al. (2005), Australia	A home-based psycho-educational intervention for family caregivers, delivered by a nurse and consisted of two visits and one follow-up phone call.	RCT	2 community (home-based) palliative care services in Melbourne	T1 N = 106 I = 54 C = 52 T2 N = 75 T3 N = 27	N = 106: 65% female, mean 61 (14).	Spouse or partner (67%), child (16%) and parent (8%)	N = 106: mean = 69 (13), 46% male and 54% female. Cancer	Preparedness: PCS Competence: CCS Rewards: RCS Anxiety and depression: HADS Self-efficacy: Self-efficacy instrument	3 time points: T1= at baseline, at home T2 = 5 weeks post baseline, by mail T3 = 8 weeks following the patient's death, at home.
Hudson et al. (2008), Australia	A psycho-educational group intervention delivered by a multi-disciplinary team, including a nurse. The semi-structured programme consisted of three sessions over a 3-week period.	Single-group prospective study	6 home-based palliative care services across metropolitan and rural/regional Victoria.	T1 N = 74 T2 N = 277 T3 N = 161	N = 74: 76% female, mean 58.	Spouse (59%), adult child (23%), parent (1%), friend (4%), sibling (7%), other (4%). 80% lived with the patient.	N = 74: 55% male and 45% female, mean = 69 Cancer	Preparedness: PCS Competence: CCS Unmet needs: Family inventory of need Reward: RCS Social support: Social Support Questionnaire Burden: Brief assessment scale for caregivers Optimism: Life orientation test	3 time points: T1= pre-intervention T2= post-intervention T3= at follow-up, 2 weeks later (via mail). Self-reported instruments

Table 1 (*Continued*)

First author; year of publication; country	Intervention	Design	Setting	Family caregivers: N	Family caregivers: gender and mean age, standard deviation (sd)	Relation to patient	Patients: N, gender mean age and condition	Outcomes and instruments	Data collection
Hudson et al. (2013) and Hudson et al. (2015), Australia	A psycho-educational intervention delivered in 4 steps: Step 1= preparing for intervention. Step 2= assessing caregiver needs and preparing a care plan. Step 3= evaluating needs and care plan. Step 4= preparing for death and bereavement. The intervention was delivered in 2 versions. Version 1= one visit and three phone calls. Version 2= two visits and two phone calls.	Three-armed RCT	4 home-based palliative care services in 3 states of Australia, rural and metropolitan areas.	T1 N = 298 I1 one visit = 57 I2 2 visits = 93 C = 148. T2 N = 277 T3 N = 161	N = 298: 71% female and 2 missing. Mean 59	Spouse/partner (54%), adult child (24%), parent (13%), friend (14%), other (16%). 79% lived with the patient.	Unknown Cancer	Psychological distress: General Health Questionnaire (GHQ) Competence: CCS Preparedness: PCS Unmet needs: Family inventory of need-part B Rewards: RCS	3 time points: T1= pre-intervention, within 2 weeks of referral to palliative care T2 = 1-week post-intervention T 3 = 8 weeks post-patient death T1 data were collected at home. T2 and T3 via mail
Leow et al. (2015), Singapore	A psychoeducational intervention, the Caring for the Caregiver Programme (CCP), consisted of a face-to-face session, a video, two follow-up phone calls and an invitation to an online social support group. The intervention group received the CCP in addition to routine home hospice care and the control group only routine care.	Pilot RCT	4 home hospice organisations and outpatient clinic in Singapore	T1 N = 80 I = 38 C = 42 T2 N = 56 T3 N = 47	I = 38: 71% female, mean 47 (12). C = 42: 64% female, mean 47 (12).	Adult child (I 61%, C 55%), spouse (I 29%, C 21%), sibling (C 7%), parent (C 5%), other (I 11%, C 12%)	N = 80 (I = 38, C = 42) Cancer	Quality of life: Caregiver Quality of Life Index-Cancer (CQOLC) Social support: Social Support Questionnaire Stress and depression: Depression Anxiety Stress Scales Relationship: general closeness scale Self-efficacy: self-efficacy in self-care scale (SESCS) Rewards: RCS Knowledge: questions developed by researcher	3 time points: T1= at baseline T2 = 4 weeks post-intervention T3 = 8 weeks post-intervention
Luker et al. (2015), United Kingdom	A single booklet with practical information for carers distributed by nurses and as an adjunct to the provision of nursing care.distributed by nurses. Regular contact was maintained with the nurses to monitor carers' circumstances.	Feasibility study	4 community districts and one hospice in the north west of England	T1 N = 31 T2 N = 24	N = 31: 74% female, mean 62	20 partners (65%), 8 adult children (26%), 1 sibling, 2 unknown.	N = 14 Cancer	Satisfaction and burden: Family Appraisal of Caregiving Questionnaire Competence: CCS Preparedness: PCS Anxiety and depression: HADS Health and well-being: SF-12v2 Symptom management: single item Likert scale developed by researchers	2 time points: T1= pre-intervention T2= post-intervention, 4-6 weeks post baseline

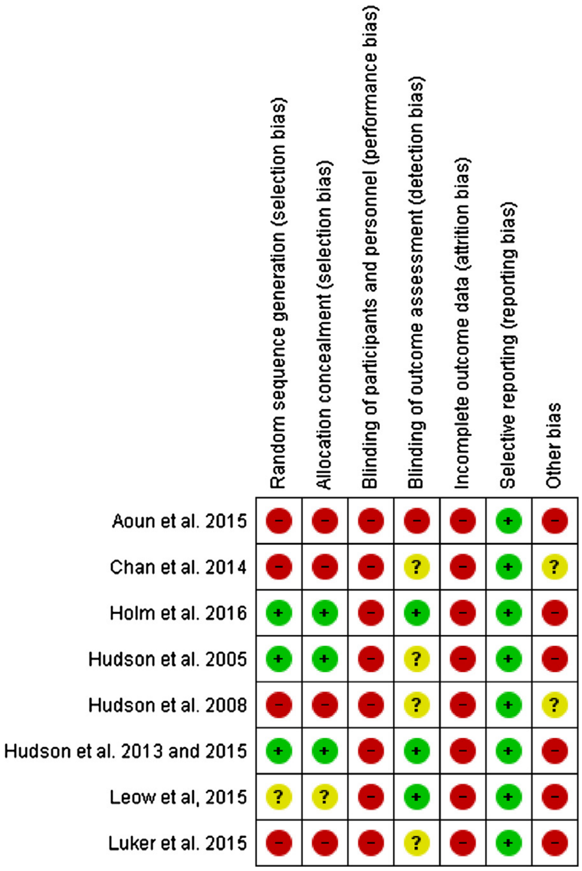
RCT = randomised controlled trial T = time point I = Intervention group C = Control group.

with cancer and non-cancer in their end-of-life phase. All patients and their family caregivers lived at home. The sample size ranged from 31 to 586 family caregivers. Mean age of the caregivers ranged from 47 to 66 years and 64–80% was female. Most family caregivers were the spouse or partner of the patient in the end-of-life phase. The eight studies used a wide range of family caregiver outcomes, of which preparedness, competence, rewards, anxiety and depression were the main outcomes of interest.

3.3. Research quality

Fig. 2 presents the results of the risk of bias assessment of the quantitative studies. All studies were assessed to have a high risk of performance and attrition bias and concerns also emerged regarding selection bias. Only the three randomised controlled trials had a low risk of selection bias. In the (pilot) randomised controlled trial no differences were observed in the baseline data, but in the non-randomised controlled trial of Aoun et al. (2015) the intervention and control group were different on a number of baseline characteristics such as age and currently engaged in paid employment.

Consideration of the other quality aspects showed that some studies provided a detailed description of the sample size calculation (Aoun et al., 2015; Holm et al., 2016; Hudson et al., 2013, 2015; Leow et al., 2015). The loss to follow-up rate in the studies ranged from 4% to 45% between Time 1 (at baseline) and Time 2 (post-intervention). The studies showed even higher attrition rates at Time 3 (Chan et al., 2014; Hudson et al., 2013, 2015; Hudson et al., 2005).



	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Aoun et al. 2015	−	−	−	−	−	+	−
Chan et al. 2014	−	−	−	?	−	+	?
Holm et al. 2016	+	+	−	+	−	+	−
Hudson et al. 2005	+	+	−	?	−	+	−
Hudson et al. 2008	−	−	−	?	−	+	?
Hudson et al. 2013 and 2015	+	+	−	+	−	+	−
Leow et al, 2015	?	?	−	+	−	+	−
Luker et al. 2015	−	−	−	?	−	+	−

Fig. 2. Review of the current authors' judgements about risk of bias items for the eight included studies.

3.4. Intervention characteristics

The studies reported on eight different nursing interventions which were delivered in the following four different formats (modalities): individual (n = 4), dyad (caregiver and patient) (n = 1), group (n = 2) and written (n = 5). One intervention (Luker et al., 2015) consisted of only a single (written) booklet distributed by a nurse, and four interventions supplemented the nurse interaction with written materials, such as a guidebook or pamphlet (Chan et al., 2014; Hudson et al., 2008, 2013; Hudson et al., 2015, 2005) (Appendix B).

Our analysis revealed four intervention components:

- Psychoeducation (n = 6)
- Needs assessment (n = 2)
- Practical support with caregiving (n = 2)
- Peer support (n = 2)

Psychoeducation uses a structured programme geared towards providing information about things such as the patients disease process and related resources while training family caregivers to respond appropriately to disease-related problems (Sorensen et al., 2002). A needs assessment intervention aims to identify and address support needs of family caregivers. Practical support comprises of providing information regarding the provision of physical and personal care. Ultimately, a peer support intervention led by a nurse is offered in a group format. Focus is placed on building rapport and creating the opportunity to discuss issues, successes, and feelings regarding caregiving (Sorensen et al., 2002).

The modalities and components of the interventions are presented in Table 2.

Most interventions (n = 6) included a psychoeducational component and were delivered in different formats: individual (n = 3), dyad (n = 1) and group format (n = 2) (Chan et al., 2014; Holm et al., 2016; Hudson et al., 2008, 2013; Hudson et al., 2015, 2005; Leow et al., 2015). Two interventions focused on assessing the individual needs of the family caregivers (Aoun et al., 2015; Hudson et al., 2013, 2015). For example, Aoun et al. (2015) used the Carer Support Needs Assessment Tool (CSNAT) to identify their needs. Family caregivers identified topics for which they needed more support; then, in a conversation between the family caregiver and nurse, an action plan was developed to address these needs.

Two interventions included practical support/information which may help family caregivers to look after a family member or friend. In the study of Luker et al. (2015) family caregivers received a booklet with practical information. The practical support in the study of Holm et al. (2016) was given during a group intervention. The information covered issues including pain, nutrition problems, mobility and personal care, and also offered practical solutions for these issues (Holm et al., 2016; Luker et al., 2015). The two group interventions also offered peer support; these interventions used the dialogue between the family caregivers to normalise the experiences, share information, and provide support (Holm et al., 2016; Hudson et al., 2008). The nurse acted as a group leader in the group sessions.

Five interventions were single-component interventions (Aoun et al., 2015; Chan et al., 2014; Hudson et al., 2005; Leow et al., 2015; Luker et al., 2015) and three were multicomponent interventions (Holm et al., 2016; Hudson et al., 2008, 2013; Hudson et al., 2015).

The frequency of the intervention delivery varied between one and eight nursing contacts over a period eight weeks maximum. For instance, in the RCT by Hudson et al. (2005), the individual intervention consisted of two home visits and a telephone call between the two visits. Chan et al. (2014) described an eight-week

Table 2
Modality, component and effect of the nursing supportive interventions.

Intervention	Modality				Component				Effect													
	Individual	Dyad	Group	Written	Needs-assessment	Psycho-education	Practical support with caregiving	Peer support	Preparedness	Competence	Rewards	Anxiety, depression, mental well being	Distress, strain, burden	Optimism	Needs met	Satisfaction	Self-efficacy	Social support	Workload	Hospital stays	Quality of life
Aoun et al. (2015)	x				x							–	↓						–		
Chan et al. (2014)		x		x		x										–				↓	
Holm et al. (2016)			x			x	x	x	↑	↑	–	–	–								
Hudson et al. (2005)	x			x		x			–	–	↑	–					–				
Hudson et al. (2008)			x	x		x		x	↑	↑	↑*		↑	–	↑			–			
Hudson et al. (2013, 2015)	x			x	x	x			↑	↑	–		↓ 1V –2V		–						
Leow et al. (2015)	x					x					↑	↓				↑					↑
Luker et al. (2015)				x			x		–	–	↑	–									

- = no significant effect.
↑ or ↓ = significant effect.
↑* = negative significant effect.
1V = one visit.
2V = two visits.

programme, including weekly sessions for both the patients and their family caregivers.

3.5. Effects

A variety of outcomes was assessed, mostly preparedness (n = 5), competence (n = 5), rewards (n = 6), anxiety and depression (n = 5) and distress or burden (n = 4). Table 2 presents a summary of the outcomes and effects of the interventions. Nursing interventions improved family caregivers' preparedness, competence, rewards and burden. With the exception of one study, no negative outcomes on family caregivers were reported. In the study of Hudson et al. (2008) caregivers' burden increased after the group education programme. The interventions hardly had any effect on caregivers' anxiety and depression. Only in the study of Leow et al. (2015) the participants in the intervention group showed a significant lower stress and depression level when compared to the control group.

Analysis of the components shows that the interventions with a psychoeducational component had a positive effect on preparedness, competence, and rewards of family caregivers. The two group interventions with a peer support component also appeared to improve family caregivers' preparedness and competence (Holm et al., 2016; Hudson et al., 2008), while the interventions including a needs assessment appeared to have a positive effect on burden (Aoun et al., 2015; Hudson et al., 2013, 2015).

In the study of Luker et al. (2015) the intervention consisted of only written material. Although it was a feasibility study, there was one significant effect and that was in relation to positive caregiving (rewards).

Compared to single-component interventions, multicomponent interventions showed significant difference on a larger number of outcomes and had a positive effect on mainly preparedness and competence.

4. Discussion

This review aimed to explore which supportive nursing interventions for family caregivers in home-based end-of-life care are available and the main effects of these interventions. The focus was on supportive interventions provided by nurses. Since only eight nursing interventions were found, this underlines the conclusion of Hudson et al. (2010) that there is a lack of research on such interventions.

The interventions in this review were based on various components (psychoeducation, needs assessment, practical support with caregiving, and peer support), of which psychoeducation was the most frequently occurring. This is expected, as psychoeducational interventions are reported to be beneficial for family caregivers (Hartmann et al., 2010; Hudson et al., 2010). For example, the systematic review of Hudson et al. (2010) included only psychoeducation and/or psychosocial interventions for family caregivers in the context of palliative care; the authors found positive effects on preparedness, competence, rewards and unmet needs of the family caregivers. These findings are consistent with reports of psychosocial interventions targeting family caregivers with chronic physical diseases. The meta-analysis of Hartmann et al. (2010) showed that psychosocial interventions for family caregivers of patients with chronic diseases resulted in significant better health of family caregivers than commonly used interventions.

Another intervention component is needs assessment; however, only studies dating from 2013 introduced this component in their intervention. Research demonstrated that family caregivers themselves report unmet needs. Because of this, during the past decade, there has been an urgent request by authors for the development of needs assessment instruments and supportive interventions focusing on the needs of the family caregivers (Grande et al., 2009; Harding et al., 2012a; Hudson and Aranda, 2004). This is consistent with the changing healthcare paradigm from more paternalistic healthcare to more participatory healthcare, emphasising a person-centred approach (Rietjens et al., 2018). Without knowing the needs of the family caregivers, it is impossible to provide personalised care and support.

The present review reveals that nursing interventions generally have a positive effect on the outcomes of family caregivers and almost no negative effects. However, the nursing interventions hardly affected the anxiety and depression of the family caregivers. This finding is in line with the meta-analysis of Northouse et al. (2010) that examined the effects of interventions with family caregivers of cancer patients in published randomised controlled trials. These interventions had many positive effects on family caregivers outcomes such as burden, coping, self-efficacy and quality of life but were not successful in reducing family caregivers depression. This might be because of the high attrition rate among depressed caregivers (Northouse et al., 2010). Another explanation is that caring for a (beloved) family member in the end-of- life phase is inevitably stressful and causes feelings of anxiety/depression despite the best possible intervention. Nurses may not be able to eliminate this underlying problem (Sorensen et al., 2002; Zarit and Leitsch, 2001).

The peer support component was delivered in a group format. The systematic review of Harding et al. (2012) included four (quasi) experimental studies reporting on group interventions for family caregivers of patients with cancer or receiving palliative care. Of these four, only two found significant benefits for the intervention group, such as improvements in quality of life and burden. The evidence for group interventions therefore is small. Moreover, the effect of the practical support component remains unknown in this review.

In the present review, the multicomponent interventions were the most successful. For example, the two randomised controlled trials (Holm et al., 2016; Hudson et al., 2013, 2015) showed that multicomponent interventions had a positive effect on the preparedness and competence of family caregivers. This is in line with others reporting that multiple component approaches were more successful than single component approaches in improving family caregiver outcomes (Hudson and Aranda, 2004; Sorensen et al., 2002). Sorensen et al. (2002) argued that multicomponent interventions are most likely to address the various needs of family caregivers (Sorensen et al., 2002).

According to Moore et al. (2015), an intervention implementation process is crucial for the impact of an intervention. However, in our review the included studies did not provide detailed information about the implementation process of the nurse-led interventions, such as nursing training and resources.

4.1. Strenghts and limitations

In this systematic narrative review, we used a systematic searching strategy. This gives a clear account of how we searched for relevant evidence. However, our interpretative synthesis involved a creative process which slightly decreased the transparency.

The findings in this review need to be interpreted in the light of several limitations. First, this review included only nurse-led interventions to support family caregivers in end-of-life care at home; this may be a limitation because these nurse-led criteria excluded other interventions/services that nurses can call in or refer patients to (e.g. respite care, or care from other healthcare professionals) (Harding and Higginson, 2003; Harding et al., 2012a, b). The second limitation is the restriction to articles published in

English only, creating the risk of publication bias. Another limitation includes the quality appraisal. We also included lower quality studies to demonstrate the current state of research in this area. For instance, almost all studies included small sample sizes. This may result in undiscovered effects of the intervention, either in negative or positive direction. Thereby, in almost all studies, there was a high risk of attrition bias which is a common problem in palliative care research because of the unpredictable illness trajectory and the vulnerability of family caregivers (Hui et al., 2013). Lastly, half of the reviewed studies stem from one research group and has been performed in Australia (Aoun et al., 2015; Hudson et al., 2008, 2013; Hudson et al., 2015, 2005). Additionally, most studies mainly concern patients with cancer. This could limit the generalisability of the study findings.

4.2. Implications for practice and research

This review shows that nurses should provide multicomponent interventions to support family caregivers in end-of-life care and target these to family caregivers' needs. To identify which modality and components or combination are the most effective, including needs assessment tools, further and robust research is warranted.

5. Conclusion

Although few studies are available on nurse-led interventions to support family caregivers in palliative home care, this review shows that nursing interventions can have a positive effect on the outcomes of family caregivers. This suggests that nurses can play an important role in supporting family caregivers in end-of-life care at home. Multicomponent interventions have the most potential to address a variety of needs of family caregivers. Potentially, the most effective components were 'needs assessment' and 'psychoeducation'. Future studies need to establish the most effective intervention modality and their related components.

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Appendix A. Search strategy

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('palliative nursing'/exp OR 'palliative therapy'/exp OR 'hospice'/de OR 'hospice care'/de OR 'hospice nursing'/de OR 'terminally ill patient'/exp OR 'critical illness'/de OR 'terminal disease'/de OR 'terminal care'/de OR 'advance care planning'/exp OR 'end stage renal disease'/de OR 'advanced cancer'/de OR (palliati* OR hospice* OR ((terminal* OR serious* OR critical*) NEAR/3 (disease* OR ill* OR phase*)) OR end-of-life OR end-stage OR (advanced NEAR/3 (cancer* OR disease*))):ab,ti) AND ('blood relative'/de OR 'first-degree relative'/de OR 'second-degree relative'/exp OR 'third-degree relative'/exp OR daughter/de OR sibling/de OR son/de OR 'family'/de OR 'family centered care'/de OR 'family coping'/de OR 'family counseling'/de OR 'family decision making'/de OR 'family interaction'/de OR 'family life'/de OR 'family relation'/de OR 'adult child'/de OR 'nuclear family'/de OR spouse/exp OR 'caregiver burden'/de OR caregiver/de OR (relative OR relatives OR (informal* NEAR/3 (care)) OR caregiv* OR carer* OR famil* OR spouse* OR husband* OR wife OR wives OR partner* OR child*-of OR adult-child* OR sibling* OR daugther* OR son OR sons):ab,ti) AND ('nurse'/exp OR 'nursing'/exp OR (nurse OR nurses OR (nursing NOT 'nursing home')):ab,ti) AND ('home care'/de OR ('home care' OR 'home nursing' OR 'home based' OR ((death* OR dying OR die OR going) NEAR/3 (home)) OR at-home):ab,ti) NOT (child/exp NOT adult/exp) NOT ([Conference Abstract]/lim OR [Letter]/lim OR [Note]/lim OR [Editorial]/lim) AND [english]/lim.

Appendix B.

Table B1
Characteristics of the interventions.

Author(s); year of publication; country	Format (modality)	Description of intervention	Elements/topics/content	Timing	Effects nursing intervention
Aoun et al. (2015), Australia	Individual	Nurses incorporated the Carer Support Needs Assessment Tool (CSNAT) into a practitioner facilitated but caregiver-led approach. Family caregivers identified domains where they needed more support. Then priorities were discussed with the nurse and they prepared a shared action plan.	Needs assessment Action plan	At least two visits, 2-3 weeks apart	The intervention group reported a significant reduction in caregiver strain (p = 0.018) and caregiver distress (not significant) from baseline to follow-up. Both groups showed a worsening on the SF12v2 Physical Component score and an increased caregiver workload (not significant) following the intervention. However, the intervention was associated with an improvement in the SF12v2 Mental component Score; not significant.
Chan et al. (2014), China	Dyad	An 8-week palliative care programme for dyads. Dyads were given a set of pamphlets and a video CD.	Symptom management. Intensive communication on advance care planning. Psychosocial intervention (supporting communication between patient and caregiver, social support, problem solving and behavioural intervention).	Sessions weekly, during 8 weeks	Family members reported improved family satisfaction scores after completion of the programme (not significant). Days of hospital stays were significantly reduced from 8.5-1.4 days per month and hospital readmission rate improved from 53%-23% in T2 (p = 0.015).

Table B1 (*Continued*)

Author(s); year of publication; country	Format (modality)	Description of intervention	Elements/topics/content	Timing	Effects nursing intervention
Holm et al. (2016), Sweden	Group	A psycho-educational group intervention for family caregivers, delivered by physician, nurse and social worker/priest. The nurse acted as group leader in the three sessions. Both the control and intervention group received standard support from their palliative settings.	Palliative diagnosis and symptom relief (educational). Daily care and nutrition problems (practical). Support and existential issues (emotional).	3 sessions, 2 h once a week over 3 weeks.	Intervention group significantly increased their preparedness for caregiving after completion ($p = 0.041$) and 2 months following the intervention ($p = 0.012$). The intervention had a positive effect on caregivers' competence for caregiving after the intervention ($p = 0.001$) but not for long. No significant and negative effects were found on rewards for caregiving, caregiver burden, health, anxiety, or depression.
Hudson et al. (2005), Australia	Individual	A psycho-educational intervention for family caregivers, delivered by a nurse. A caregiver guidebook and audiotape were used to complement the nurse interactions. Both the control and intervention group received usual care from their palliative settings.	Information about caregiver role and care provision. Caregivers' needs and plan goals and strategies. Self-care strategies. Positive emotions and spiritual support.	2 home visits and a follow-up phone call between the two visits	No significant intervention effects were found concerning preparedness to care, self-efficacy, competence and anxiety. However, the intervention group reported a significantly increased reward score compared with the control group at both 5 weeks after intervention ($p = 0.005$) and 8 weeks following death of the patient ($p = 0.036$). There were no negative outcomes in the intervention group.
Hudson et al. (2008), Australia	Group	A psycho-educational group intervention delivered by a multi-disciplinary team (palliative care physician, counsellor, social worker, palliative care nurse) to prepare them for the role of supporting a dying relative. The sessions were semi-structured in format. The caregivers also received a caregiver guidebook.	Education on the typical role of a caregiver in palliative care and services available. Strategies relating responding to a patient's physical and psychological issues. Strategies to maintain well-being. Information on what to expect when death is approaching.	3 sessions, 1.5 h, once a week over 3 weeks	The intervention had a significant positive effect on preparedness ($p < 0.001$), competence ($p < 0.01$), rewards ($p < 0.05$) and having needs met ($p < 0.05$) between baseline and completion the intervention, which was maintained at follow-up. Distress increased significantly ($p < 0.001$) after the intervention and the follow-up two weeks later. Social support and optimism remained stable over time.
Hudson et al. (2013) and Hudson et al. (2015), Australia	Individual	A psycho-educational intervention plus standard care, delivered in 4 steps: Step 1= preparing caregivers for the intervention. Step 2= assessing caregiver needs and preparing a care plan. Step 3= re-assessing needs and evaluating the care plan. Step 4= assisting to prepare for death and bereavement. The intervention was delivered in 2 versions and a control group received the usual care.	Assessing caregivers' needs and developing a care plan. Preparing caregivers for their role. Evaluating the care plan. Promoting psychological well-being. Preparing for their relative's death and bereavement.	Intervention 1= one visit and 3 phone calls. Intervention 2 = 2 visits and 2 phone calls, over 4 weeks	Non-significant changes were found in distress between baseline and one week after the intervention. There was significantly less worsening in distress between baseline and follow-up (8 week after patients' death) in the one-visit intervention group compared with the control group. However, there was no significant difference between the two-visit intervention group and the control group. Preparedness and competence increased in both intervention groups after completion of the intervention (significant for the two-visit intervention group, $p < 0.05$). No significant reduction in unmet needs or improvements in positive aspects of caregiving were found in the intervention group.
Leow et al. (2015), Singapore	Individual	A psychoeducational intervention, the Caring for the Caregiver Programme (CCP), delivered by one nurse to all participants. The intervention group received the CCP in addition to routine home hospice care and the control group only routine care.	Helping to cope with stress, frustration, depression and anticipatory grief. Improving communication between the patients and caregivers. Increasing social support for caregivers. Providing information on advanced care planning and community resources.	One-hour face-to-face session, a video clip, 2 follow-up phone calls and an invitation to online social support group	The intervention group reported significant higher quality of life ($p = 0.005$), social support satisfaction ($p = 0.03$), rewards of caregiving ($p = 0.001$), knowledge ($p = 0.00$) and a lower stress and depression ($p = 0.02$), compared with the control group. Only two of the 38 family caregivers joined the caregiver forum.

Table B1 (*Continued*)

Author(s); year of publication; country	Format (modality)	Description of intervention	Elements/topics/content	Timing	Effects nursing intervention
Luker et al. (2015), United Kingdom	Written	A single booklet with practical information for carers. District nurses distributed the booklet and regular contact was maintained with the district nurses to monitor carers' circumstances.	Pain, common bladder problems, bowel problems, loss of appetite, nausea and vomiting, breathlessness, pressure sores, mobility equipment, personal care, emotional aspects, support for carers, nearing death and bereavement.	A booklet that could be accessed at any time.	Carers reported feeling more positive about caregiving after the intervention (p = 0.015). No significant effects were found on the other variables (burden, competency, preparedness, anxiety and depression).

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