


REVIEW

Supportive interventions for family members of very seriously ill patients in inpatient care: A systematic review

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Abstract

Aims and objectives: To systematically review existing literature exploring supportive interventions for family members of very seriously ill patients in inpatient care.

Background: Being around a patient with a very serious illness in inpatient care setting is stressful and burdensome for family members. There is little information available on interventions that support family members of very seriously ill patients in inpatient care.

Design: A systematic review.

Methods: The literature review was conducted in May 2020 using four databases: PubMed (Medline), CINAHL, PsycINFO and Cochrane. A quality assessment was performed using the Quality Assessment Tool for Before-After (Pre-Post) Studies With No Control Group by the National Heart, Lung, and Blood Institute. The PRISMA checklist was used to support specific reporting and the TIDieR checklist to form detailed descriptions of the interventions.

Results: Of the 7165 identified studies, 11 studies were included in the review based on predetermined criteria. Interventions were based on meetings with family members, education or therapy. Mindfulness- and therapy-based interventions and multiple-session tailored interventions showed beneficial outcomes for psychological symptoms and educational interventions on preparedness and self-efficacy. Several different measuring instruments to evaluate similar outcomes, such as psychological symptoms and coping, were used.

Conclusions: Only a few supportive interventions for family members of very seriously ill patients in inpatient care were found, which made comparing the differences in the varying study methods and outcomes difficult. More studies on supportive interventions and their feasibility and effectiveness are essential. Further evaluation of instruments is necessary to identify the most valid and reliable ways of measuring symptoms and coping.

Relevance to Clinical Practice: The results of this study can be used in clinical practice when selecting effective interventions or assessing family members' need for

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support. Additionally, the results can be used for guidance when developing new, effective interventions.

KEYWORDS

critical illness, family, inpatients, palliative care, psychological support system, systematic review, terminal care

1 | INTRODUCTION

A serious illness describes a condition that poses a high risk of mortality for the patient (Kelley & Kelley, 2014). This study involved family members of very seriously ill patients, that is, patients with either a terminal or critical illness with a very high risk of mortality, and with an even more severe situation than patients with serious illness. Family members of such patients often experience high emotional stress and decreased psychological well-being and quality of life (Fujinami et al., 2015).

Family members of very seriously ill patients can be defined in many ways, and the spectrum of concepts is wide. Family members, relatives, friends or partners of patients are often referred to as *caregivers*, *informal caregivers* or *family caregivers*, especially when they are taking care of their loved ones and participating in care (Candy et al., 2011; Hudson et al., 2011). In this review, for patients receiving care in a hospital, the term *family member* is used to refer to the people who have personal relationships with the patient during inpatient care and can include very close friends, romantic partners, children or spouses.

Family members can experience psychological symptoms to a great degree, indicating an elevated need for psychological support, especially in inpatient care settings (Oechsle et al., 2019). Family members of very seriously ill patients have a high risk of somatisation and complicated anticipatory grief (Areia et al., 2019) and can experience great burden as well as severe fatigue (Peters et al., 2015), and anxiety and depressive symptoms (Shaffer et al., 2017; Williams & McCorkle, 2011). In particular, parents and spouses of these patients suffer higher distress and have more symptoms of psychiatric disorders than other family members (Roulston et al., 2017; Rumpold et al., 2016). Family members of very seriously ill patients are often concerned about losing their loved one as well as adapting to their new role in the situation (Li & Loke, 2013). High anxiety levels and burden are associated with psychiatric morbidity in family members of very seriously ill patients (Rumpold et al., 2016); the level of psychological morbidity has been evaluated to be much higher than was recognised earlier (Grande et al., 2018). Therefore, it would be beneficial to move from a patient-centred approach to a family-centred approach (Areia et al., 2019).

The symptoms and needs of family members of very seriously ill patients are complex during inpatient treatment; further, they often remain unmet (Wang et al., 2018). It is even possible that family members have more unmet psychosocial needs than patients themselves (Hudson et al., 2011). However, healthcare professionals do

What does this paper contribute to the wider global clinical community?

- There are only a few supportive interventions for family members of very seriously ill patients in inpatient care that are clinically heterogeneous, differing in design, intervention implementation techniques, follow-up times and measuring instruments; therefore, it was difficult to analyse the differences in their study methods in relationship to their results.
- More studies about supporting family members of very seriously ill patients in inpatient care settings are essential to identify feasible and effective interventions in this setting so that the healthcare personnel have tools to support the families and increase coping.

not always have enough knowledge to provide adequate support (Candy et al., 2011). In developed countries, most of these patients die in inpatient care, and hospitals provide a considerable extent of palliative care (Broad, 2013; Robinson et al., 2014). Being around a very seriously ill patient in a hospital inpatient care setting has been identified as a factor that has a negative effect on family members' bereavement (Roulston et al., 2017). Healthcare staff should know how to prepare family members for a patient's death in order to decrease depressive symptoms (Kuo et al., 2017). Family members of very seriously ill patients can benefit from having support from interventions used in health care (Becqué et al., 2019; Harding et al., 2012; Hudson et al., 2010; Northouse et al., 2010), as interventions can help alleviate the burden and prevent the spectrum of hidden morbidities for family members (Li & Loke, 2013; Tang et al., 2013).

In this study, *supportive interventions* are any interventions that aim to provide support to family members and are delivered by healthcare experts. Psychoeducational, psychosocial (Hudson et al., 2010) and behavioural (Chi et al., 2016) interventions have especially been found to have a positive impact on family members, particularly on their burden, coping and self-efficacy. Interventions combining different elements (Jadalla et al., 2020) and mindfulness-based interventions also reduce depression and burden in caregivers and improve their quality of life (Jaffray et al., 2016). In some studies, attempts to relieve anxiety and depression (Ahn et al., 2020; Becqué et al., 2019; Northouse et al., 2010) or improve quality of life (Alam et al., 2020) have nevertheless

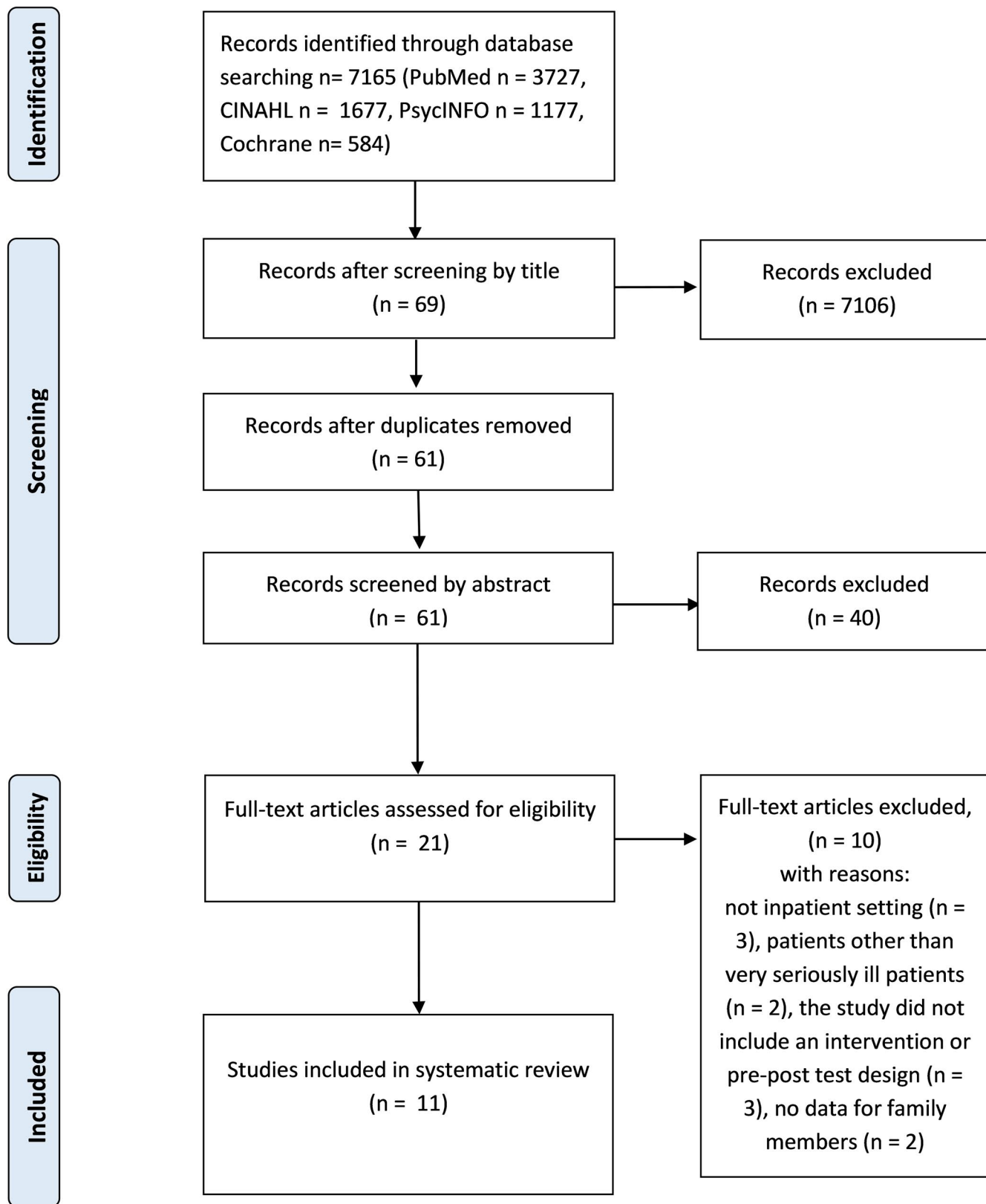


FIGURE 1 Retrieval of the studies (PRISMA). From: Moher et al. (2009)

remained deficient. Palliative care family meetings have also been used as an intervention for patients with life-limiting conditions; however, the evidence that they address the needs of the patients

and their families is low (Cahill et al., 2017). The findings of reported studies are mixed (Alam et al., 2020), and the effectiveness, impact and outcomes of the supportive interventions remain

TABLE 1 Quality appraisal of the studies (n = 11)

| | Carson et al. (2016) | Randall Curtis et al. (2016) | Davis et al. (2020) | Fegg et al. (2013) | Forbat et al. (2018) | Hannon et al. (2012) | Hudson, Trauer, et al. (2012) | Hudson, Lobb, et al. (2012) | Kühnel et al. (2020) | Lee et al., (2016) | White et al., (2018) |
|--|----------------------|------------------------------|---------------------|--------------------|----------------------|----------------------|-------------------------------|-----------------------------|----------------------|--------------------|----------------------|
| 1. Was the study question or objective clearly stated? | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| 2. Were eligibility/selection criteria for the study population prespecified and clearly described? | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | Y |
| 3. Were the participants in the study representative of those who would be eligible for the test/service/intervention in the general or clinical population of interest? | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| 4. Were all eligible participants that met the prespecified entry criteria enrolled? | Y | Y | Y | Y | Y | NR | Y | Y | Y | Y | Y |
| 5. Was the sample size sufficiently large to provide confidence in the findings? | Y | N | Y | Y | Y | Y | Y | N | Y | Y | Y |
| 6. Was the test/service/intervention clearly described and delivered consistently across the study population? | Y | Y | N | Y | N | Y | Y | Y | Y | Y | Y |
| 7. Were the outcome measures prespecified, clearly defined, valid, reliable, and assessed consistently across all study participants? | Y | Y | Y | Y | N | Y | Y | Y | Y | Y | Y |
| 8. Were the people assessing the outcomes blinded to the participants' exposures/interventions? | Y | N | N | NR | N | N | N | N | N | Y | Y |
| 9. Was the loss to follow-up after baseline 20% or less? Were those lost to follow-up accounted for in the analysis? | Y | N | N | Y | Y | Y | Y | Y | N | N | N |

(Continues)

TABLE 1 (Continued)

| | Carson et al. (2016) | Randall Curtis et al. (2016) | Davis et al. (2020) | Fegg et al. (2013) | Forbat et al. (2018) | Hannon et al. (2012) | Hudson, Lobb, et al. (2012) | Hudson, Trauer, et al. (2012) | Kühnel et al. (2020) | Lee et al., (2016) | White et al., (2018) |
|--|----------------------|------------------------------|---------------------|--------------------|----------------------|----------------------|-----------------------------|-------------------------------|----------------------|--------------------|----------------------|
| 10. Did the statistical methods examine changes in outcome measures from before to after the intervention? Were statistical tests done that provided <i>p</i> values for the pre-to-post changes? | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| 11. Were outcome measures of interest taken multiple times before the intervention and multiple times after the intervention (i.e. did they use an interrupted time-series design)? | N | N | N | N | N | N | N | N | N | N | N |
| 12. If the intervention was conducted at a group level (e.g. a whole hospital, a community, etc.) did the statistical analysis take into account the use of individual-level data to determine effects at the group level? | NA | NA | NA | NA | NA | NA | NA | NA | NA | NA | NA |
| Total quality | Good | Fair | Fair | Good | Fair | Fair | Good | Good | Good | Good | Good |

Note: Methodological quality of before-after studies using the NHLBI Quality Assessment Tool for Before-After (Pre-Post) Studies With No Control Group. Abbreviations: CD, cannot determine; N, no; NA, not applicable; NR, not reported; Y, yes.

TABLE 2 Studies included in the review (n = 11)

| Author, year, country | Intervention | Setting | Aim | Design | Participants | Follow-up |
|--|--|--|---|------------------------------------|--|---|
| Carson et al. (2016), USA | Palliative Care-Led Meetings | ICU | To determine whether family informational and emotional support meetings improve family anxiety and depression | Randomised clinical trial | Patients with chronic critical illness (n = 256) and family members as surrogate decision-makers (n = 365) | 90 days after randomisation |
| Randall Curtis et al. (2016), Australia | Communication facilitator intervention | ICU | To determine whether an intensive care unit communication facilitator reduces family distress and intensity of end-of-life care | Randomised trial | n = 168 family members of ICU patients predicted mortality greater than or equal to 30% | 3 and 6 months after the patient's death or ICU discharge |
| Davis et al. (2020), Australia | Self-help acceptance and commitment therapy intervention | Palliative care unit and unit for management of cardiac/respiratory rehabilitation and palliative care | Test the feasibility of recruitment, attrition and data collection procedures; (2) determine engagement with the intervention; and (3) evaluate acceptability of the intervention, evaluate preliminary effectiveness of the intervention | Randomised controlled trial | n = 106 carers of patients with a life-limiting illness and recognised by their treating clinician as being within the last 6 months of life | 1 month post-randomisation and 6 months post-loss |
| Fegg et al. (2013), Germany | Existential behavioural therapy | Palliative care ward | To investigate the applicability of EBT to informal caregivers of palliative care patients and its effectiveness with regard to psychological distress and QOL | Randomised controlled trial | n = 133 relatives of palliative care patients | 3 and 12 months |
| Forbat et al. (2018), country not reported | Family meeting | Specialist palliative care | To examine whether relatives report more empathy after family meeting | A pre-post-mixed method study | n = 123 family members of palliative care patients | Immediately after intervention |
| Hannon et al. (2012), Ireland | Family meeting | Specialist palliative care | To assess the effectiveness of family meetings from the perspective of the family members | A prospective study | n = 31 family members of palliative care patients | Immediately after intervention and 48 h |
| Hudson, Lobb, et al. (2012), Australia | Psychoeducational group intervention | Specialist palliative care | To develop and pilot test a psychoeducational group education programme | A pilot study with pre-post-design | n = 15 family members of palliative care patients | 3 days |
| Hudson, Trauer, et al. (2012), Australia | Psychoeducational group intervention | Specialist palliative care | Preliminary testing of psychoeducational group education | A pre-post-design | n = 126 family members of palliative care patients with advanced cancer | 3 days |
| Kühnel et al. (2020), Germany | Short-term existential behavioural therapy (sEBT) | Palliative care unit | To evaluate the effectiveness of the sEBT intervention in comparison with a usual, nondirective psychological intervention | Randomised controlled trial | n = 203 caregivers of palliative care patients | After the second intervention session, 4 weeks and 6 months after the second intervention session |

(Continues)

TABLE 2 (Continued)

| Author, year, country | Intervention | Setting | Aim | Design | Participants | Follow-up |
|---------------------------|---|------------------------|--|---|--|---|
| Lee et al. (2016), Taiwan | Caregiver support intervention. | Specialist cancer care | To assess the benefits of caregiver support intervention for caregivers of the advanced cancer patients. | A quasi-experimental clinical trial with two group comparative design with repeated measures. | n = 118 family caregivers | 3 months |
| White et al. (2018), USA | Multicomponent family support intervention. | ICU | To compare a multicomponent family-support intervention delivered by the interprofessional ICU team with usual care. | A stepped-wedge, cluster-randomised trial. | n = 1420 patients and 1106 surrogate decision-makers | 6 months after the patient's hospital discharge |

somewhat uncertain due to small sample sizes and concise study reporting (Cahill et al., 2017; Candy et al., 2011; Chi et al., 2016). Furthermore, the use of measuring instruments varies, resulting in difficulty in comparing the effects of the interventions (Ahn et al., 2020; Chi et al., 2016).

Literature reviews indicate that there is a lack of studies focusing on family members of very seriously ill patients (Aoun et al., 2013; Chi et al., 2016; Henoeh et al., 2016). The severity of the disease and fear of loss increases the burden that family members are carrying even more than with other patient groups (Papastavrou et al., 2012). Furthermore, most palliative care studies generally focus on the viewpoint of healthcare staff instead of the demands of the patients and their families (Hasson et al., 2020). The role of family members in inpatient care is significant in various ways, and the participation of family members in patient care, communication and companionship is important for the patient (Miller et al., 2016). However, hospital environments are stressful and usually unfamiliar for family members, and inpatient care settings can cause even more burden for the family members of very seriously ill patients (Belayachi et al., 2014). Although there are several reviews on supportive interventions for family members of very seriously ill patients in different settings, these reviews mainly focus on interventions in home and community care (Becqué et al., 2019; Candy et al., 2011; Chi et al., 2016; Hudson et al., 2010; Northouse et al., 2010; Sutanto et al., 2017). The burden endured by the family members in hospital care has not been thoroughly studied, and only limited information is available on supporting family members in inpatient care. To our knowledge, no review has focused on support for family members of very seriously ill patients in inpatient care so far.

2 | AIMS

The aim of this study was to systematically review the literature exploring supportive interventions for family members of very seriously ill patients in inpatient care settings and to assess the contents and outcomes of these interventions.

The research questions were as follows:

1. What interventions have been used to support family members of very seriously ill patients in inpatient care settings?
2. What are the outcomes of the supportive interventions?
3. What instruments have been used to measure the impact of supportive interventions?

3 | METHODS

3.1 | Design

A systematic review was conducted to obtain an evidential summary of previous research (Holly et al., 2017) through a systematic literature search, appraisal of the studies and synthesis of research

TABLE 3 Supporting interventions and outcomes of the interventions

| Intervention implementation based on | Intervention | Aim of the intervention | Type of provided support |
|--------------------------------------|---|---|---|
| Meeting with the family | Communication facilitators to reduce family distress and intensity of end-of-life care. | To reduce family distress and intensity of end-of-life care by supporting communication. | Meetings with the family members and the clinical team during the patient's stay at ICU and 24 h after discharge. |
| Meeting with the family | Family meetings to convey empathy. | To increase perceived staff empathy by family meeting. | One family meeting usually conducted within a week after admission. |
| Meeting with the family | Family meetings as an intervention. | To assess how family meetings affect to the concerns and needs of the family members. | Family meeting during the patient's clinical stay. |
| Meeting with the family | Pairing Re-engineered ICU Teams with Nurse-Driven Emotional Support and Relationship-Building (PARTNER) Intervention. | Provision of emotional and communicational support to lessen surrogate burden, improve the quality of decision-making and clinician-family communication, and shorten the duration of intensive treatment among patients who ultimately do not survive. | Face-to-face meetings with of interprofessional ICU team and family. |
| Meeting with the family Education | Palliative care-led meetings for families of patients with chronic critical illness. | To improve family anxiety and depression by informational and emotional support. | Minimum of two meetings with the support and information team and surrogate decision-maker. |
| Education | Psychoeducational group intervention. | To improve family members sense of preparedness and competence in caregiver role and reduce unmet needs by educating sessions. | Single-session didactic group intervention to the caregivers. |

| Intervention provider | Material | Family member outcome measurement instrument | Outcomes of the intervention ^a | Author and year of publication |
|--|--|---|--|--------------------------------|
| A nurse and social worker. | NR | PHQ-9 GAD-7 PCLC-C | Communication facilitator may be associated with a reduction in symptoms of depression 6 months after critical illness, but no significant difference at 3 months and no significant difference in symptoms of anxiety or PTSD (+/0). Reduced length of stay with decreased or similar symptoms of depression (+/0). Reduction in costs of care (+). | Randall Curtis et al. (2016) |
| One doctor and one nurse in every meeting. Inpatient social worker in all but one meeting. Pastor, occupational therapist, student and other in some of the meetings. | NR | CARE FIN | Family members reported more empathy (+). Importance of needs and needs met no change (0). | Forbat et al. (2018) |
| Primarily organised and chaired by medical social worker and attended at least one member of the medical team, a nurse and representative from physiotherapy, occupational therapy and chaplaincy when relevant. | NR | FIN SRI | Family members concerns decreased (+). Improvement with meeting care needs of family members (+). | Hannon et al. (2012) |
| The intervention was delivered by members of the interprofessional ICU team and was overseen by four to six nurses in each ICU (called the PARTNER nurses). | NR | HADS IES QOC PPPC | Intervention did not significantly affect the surrogates' burden or psychological symptoms (0). Quality of communication and the patient- and family-centredness of care were better (+). Length of stay in the ICU was shorter (+). | White et al. (2018) |
| A palliative care physician and nurse practitioner and could include social workers, chaplains or other disciplines as needed. | A printed information brochure about chronic critical illness. | HADS IES QOC After-Death Bereavement Family Interview Family Satisfaction in the Intensive Care Unit survey | Protocol-based informational and emotional support meetings did not improve anxiety or depression symptoms among family surrogate decision-makers (0). No significant effect on the patient and resource outcomes of duration of mechanical ventilation and hospital length of stay and there was no effect on survival (0). The intervention may have increased PTSD symptoms (-) There was no difference between groups regarding the discussion of patient preferences (0) | Carson et al. (2016) |
| Experienced palliative care nurses (as education facilitators) and research assistants. | Guidebook focusing on preparing family caregivers to their role, handouts. | FIN GHQ PCS CCS | Competence improved but not statistically significantly (+/0). Psychological distress not lessened nor increased (0). Improvement with needs met and preparedness for caregiving (+). All with relatively small changes | Hudson, Trauer, et al. (2012) |

(Continues)

TABLE 3 (Continued)

| Intervention implementation based on | Intervention | Aim of the intervention | Type of provided support |
|--------------------------------------|---|--|---|
| Education | Psychoeducational group intervention. | To improve family members sense of preparedness and competence in caregiver role and reduce unmet needs by educating sessions. | Single-session didactic group intervention to the caregivers |
| Education | Integrated caregiver support intervention. | Providing information and developing self-management skills help caregivers cope more effectively, resulting in the reduction in distress and caregiving burden. | Two-part support programme with 15- to 20-min face-to-face sessions and individually tailored intervention in 30- to 40-min sessions including caregiver difficulty-assessment and integrated CARE-intervention (Coping strategies, Assistance, Resources, Education) at least 3 times in 2-week intervals until patients' death. |
| Therapy | Existential behavioural therapy (EBT) to support informal caregivers of palliative patients. | To reduce psychological distress stress and improve quality of life by existential behavioural therapy. | Six group sessions with existential behavioural therapy and mindfulness |
| Therapy | Short-term existential behavioural therapy (sEBT) to support informal caregivers of palliative patients. | To evaluate informal caregivers' level of depression, anxiety, subjective distress and minor mental disorders, positive and negative affect, satisfaction with life, quality of life and direct healthcare costs | Two individual sessions with existential behavioural therapy and mindfulness |
| Therapy | Self-help acceptance and commitment therapy intervention for grief and psychological distress in carers of palliative care patients | To increase acceptance and valued living, while reducing grief and psychological distress | Acceptance and commitment therapy with skills-based booklet and telephone support |

Abbreviations: AAQ-II, The Acceptance and Action Questionnaire-II; BSI, Brief Symptom Inventory; CARE, The Consultation and Relational Empathy; CCS, Caregiver Competence Scale; CRA, Caregiver Reaction Assessment Tool; CSS, Caregiver Self-efficacy Scale; ESDS, Enforced Social Dependency Scale; FIN, Family Inventory of need; GAD-7, Generalized Anxiety Disorder-7; GHQ, General Health Questionnaire; HADS, Hospital Anxiety and Depression Scale; IES, Impact of Event Scale - Revised; NCCN, National Comprehensive Cancer Network's Distress Thermometer; PANAS, Positive and Negative Affect Schedule; PCLC-C, PTSD CheckList-Civilian Version; PCS, Preparedness for Caregiving Scale; PG-13, Prolonged Grief PG-13; PHQ-9, Patient Health Questionnaire; PPPC, Patient Perception of Patient Centeredness Scale; QOC, Quality of Communication Scale; QOL-NRS, NR; SDS, Symptom Distress Scale; SRI, Self-report Instrument; SWLS, Satisfaction with Life Scale; VLQ, The Valued Living Questionnaire; WHOQOL-BREF, World Health Organization Quality of Life instrument.

*Outcome reported with (+) = positive effect, (0) = no effect, (-) = negative effect.

evidence (Grant & Booth 2009). Because the study aim was to evaluate the outcomes of the interventions rather than their effectiveness, and the heterogeneity of the studies with varying interventions, designs and outcome measures, a meta-analysis as a review technique was excluded (Aromataris & Pearson, 2014; Ioannidis et al., 2008). The systematic review method of Bruce et al. (2018) was used, involving the following steps:

1. Deciding on the objectives and developing the research question
2. Defining criteria for the inclusion and exclusion of studies for the review

3. Finding studies broadly addressing the topic being studied
4. Selecting studies according to the eligibility (inclusion and exclusion) criteria
5. Assessing the methodological quality of the studies
6. Extracting data, that is the main findings of each study
7. Describing and compiling the results of the review (synthesising the evidence)
8. Reporting the results of the review

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Appendix S1) were followed to

| Intervention provider | Material | Family member outcome measurement instrument | Outcomes of the intervention ^a | Author and year of publication |
|---|--|---|---|--------------------------------|
| Experienced palliative care nurses (as education facilitators) and research assistants. | NR | FIN GHQ PCS CCS | No significant effect on competence, importance of information, unmet needs or psychological distress (0). Improvement on the level of preparedness to caregiver role (+). | Hudson, Lobb, et al. (2012) |
| A researcher with 12 year's experience in cancer nursing. | A CD to practice mindfulness | CRA SDS ESDS CCS Heart Rate Variability | Caregiver self-efficacy was increased (+). Caregiver burden decreased (+). | Lee et al. (2016) |
| Behavioural therapists. | A CD to practice mindfulness | BSI SWLS WHOQOL-BREF QOL-NRS PANAS | Beneficial effects on distress and QOL of informal caregivers of palliative patients (+). | Fegg et al. (2013) |
| Psychologists with several years of experience in behavioural psychotherapy | A booklet with 64 A5 pages in length and a CD with mindfulness exercises | PHQ-9 GAD-7 NCCN GHQ PANAS SWLS WHOQOL-BREF | The level of depression did not differ significantly between sEBT and control group (-) All post-treatment secondary outcomes (anxiety, subjective distress, positive/negative affect, minor mental disorders, satisfaction with life, quality of life, physical impairment) did not significantly differ between sEBT and control group (-) | Kühnel et al. (2020) |
| Clinical psychology PhD student | | AAQ-II VLQ PG-13 HADS | Tentative trends for acceptance, valued living, grief and psychological distress in helpful directions (+/0) but not statistically significantly | Davis et al. (2020) |

support specific reporting (Moher et al., 2009), and the Template for Intervention Description and Replication (TIDieR) checklist (Hoffmann et al., 2014) was followed (Appendix S2) to generate a detailed description of the interventions.

3.2 | Literature search

The literature review was conducted in May 2020 using four databases: PubMed (Medline), CINAHL, PsycINFO and Cochrane.

Limitations related to timeframe or language were not set during the search. We considered studies to include *very seriously ill patients* if the patients were in palliative care or other critical care in an inpatient unit so that the risk of mortality was high, and the family needed to prepare for the possibility of the patient's death. The search was conducted with the following keywords, their synonyms and MeSH-terms, using Boolean operators: (palliative care OR palliative nursing OR terminally ill OR very seriously ill) AND (spouse OR caregiver OR family member OR relative OR partner OR family OR wife OR husband OR loved one OR next of kin) AND (support)

TABLE 4 Instruments used in intervention outcome assessment (n = 28)

| Instrument | Category | Aim of the instrument reported in the studies | Items/scoring | Content | Validity and reliability | Source |
|------------|---------------------------|--|--|--|---|--|
| HADS | Psychological symptoms | To assess surrogates' symptoms of anxiety and depression. | 0 (best) to 42 (worst). | Scores range with higher scores indicating worse symptoms. | NR | Carson et al. (2016), White et al. (2018), Davis et al. (2020) |
| IES | Psychological symptoms | To assess surrogates' symptoms of post-traumatic stress disorder. | Scores range from 0–88. | Higher scores indicate worse symptoms. | NR | Carson et al. (2016), White et al. (2018) |
| PHQ-9 | Psychological symptoms | To measure family symptoms of depression. | 9-item questionnaire. | Higher scores predict decreased functional status, increased disability days, and increased healthcare use. | Excellent psychometric characteristics, has been validated against diagnostic interviews conducted by mental health professionals, and has good responsiveness in behavioural interventions | Randall Curtis et al. (2016), Kühnel et al. (2020) |
| GAD-7 | Psychological symptoms | To measure generalised anxiety disorder. | NR | Higher scores predict higher levels of functional impairment, more disability days, and more physician visits. | Excellent psychometric characteristics and responsiveness to behavioural interventions. | Randall Curtis et al. (2016), Kühnel et al. (2020) |
| PCLC-C | Psychological symptoms | To assess intrusive, avoidant, and arousal DSM-IV PTSD symptom clusters. | 17 self-report items. | NR | Well-established reliability and validity across trauma-exposed populations. | Randall Curtis et al. (2016) |
| BSI | Psychological symptoms | To record the severity of symptoms. | NR | Subscales of somatisation, depression and anxiety. | NR | Fegg et al. (2013) |
| SWLS | General living and coping | To record QOL. | Scores are sums of item values ranging from 0–36 | Higher scores indicating higher degree of satisfaction | NR | Fegg et al. (2013), Kühnel et al. (2020) |

(Continues)

TABLE 4 (Continued)

| Instrument | Category | Aim of the instrument reported in the studies | Items/scoring | Content | Validity and reliability | Source |
|-------------|---------------------------|--|---|---|---|--|
| WHOQOL-BREF | General living and coping | To comprise quality of life domains. | Scores range from 0–100 | Higher scores denoting higher quality of life | NR | Fegg et al. (2013), Kühnel et al. (2020) |
| QOL-NRS | General living and coping | To assess overall QOL experience. | Range 0–10, | 'How do you rate your quality of life at the moment?' | NR | Fegg et al. (2013) |
| CARE | General living and coping | To record perceptions of relational empathy. | 10-item tool. | NR | NR | Forbat et al. (2018) |
| FIN | Caregiver needs | To assess care needs of family members and unmet caregiver needs. | 14-item (Forbat et al., 2018), 20-item (Hannon et al., 2012) tool. Scale 0–10 from unimportant to very important. | Two subscales: Importance of Family Care Needs and Fulfilment of Care Needs. | Reliable and valid in assessing fulfilment of care needs of family members of advanced cancer patients. | Forbat et al. (2018), Hannon et al. (2012), Hudson, Trauer, et al. (2012), Hudson, Lobb, et al. (2012) |
| SRI | General living and coping | To identify key concerns of family members. | Scale 0–10. | Free text and numerical rating about how concerned family members were and how much the problem interfered their life and how confident they felt dealing with the concern. | NR | Hannon et al. (2012) |
| GHQ | Psychological symptoms | To evaluate whether the intervention caused any detrimental psychological effects. | 12 items. Scores are sums of item values ranging from 0–36 | Higher scores indicating higher level of mental disorder | NR | Hudson, Trauer, et al. (2012), Hudson, Lobb, et al. (2012), Kühnel et al. (2020) |
| PCS | Competence | To assess preparedness to caregiver role. | NR | NR | NR | Hudson, Trauer, et al. (2012), Hudson, Lobb, et al. (2012) |
| CCS | Competence | To assess competence to caregiver role. | NR | NR | NR | Hudson, Trauer, et al. (2012), Hudson, Lobb, et al. (2012) |
| CRA | Psychological symptoms | To measure subjective burden. | 24 items. 5-point Likert scale. | Higher scores indicate heavier caregiver burden. Five subscales: impact on schedule, caregiver esteem, lack of family support, impact on health and impact on finances. | Reliability and validity have been established. Cronbach's alpha in this study 0.89. | Lee et al. (2016) |

(Continues)

TABLE 4 (Continued)

| Instrument | Category | Aim of the instrument reported in the studies | Items/scoring | Content | Validity and reliability | Source |
|------------|---------------------------|--|---|---|--------------------------------------|----------------------|
| SDS | Psychological symptoms | To evaluate objective burden measuring symptom distress. | 13 common symptoms of cancer patients. | Higher scores indicating greater distress. | Cronbach's alpha 0.85 in this study. | Lee et al. (2016) |
| ESDS | General living and coping | To assess activities of daily living function of the patients. | 10-item rating scale with 6 items scored 1–6 and 4 items scored 1–4. | Higher scores indicate lower activities of daily living function. | NR | Lee et al. (2016) |
| CSS | General living and coping | To assess coping strategies. | 29 items, rated on 0- to 100-point Likert scale. | Higher scores indicate greater self-efficacy. Three subscales: obtaining respite, controlling upsetting thoughts and responding to disruptive patient behaviour. | Cronbach's alpha 0.81 in this study. | Lee et al. (2016) |
| QOC | Communication | To assess the quality of clinician-family communication. | Scores 0–100. | Higher scores indicating better communication. | NR | White et al. (2018) |
| PPPC | Provided care | To rate of the patient- and family-centredness of care. | Scores 1–4. | Lower scores indicating more patient- and family-centred care. | NR | White et al. (2018) |
| NCCN | Psychological symptoms | Indicates a clinically relevant level of subjective distress | Scale range 0–10 from 'No distress' to 'Extreme distress' | | NR | Kühnel et al. (2020) |
| PANAS | Intervention affect | To evaluate positive and negative affect | Scores ranging from 1–5 are means of positive and negative items | Higher scores indicating higher levels of affect | NR | Kühnel et al. (2020) |
| AAQ-II | Psychological symptoms | To measure experiential avoidance, assessing how participants relate to their thoughts, feelings and memories | 7 items Scores ranging from 7–49 | Higher total scores indicate higher levels of experiential avoidance | NR | Davis et al. (2020) |
| VLQ | General living and coping | Two-part questionnaire where participants rate the importance of domains of living and how consistently they have lived in accordance with their values within each domain over the past week. | 13 domains of living (e.g. marriage, work, leisure) Scale 1 = not at all to 10 = extremely | Higher scores indicate higher levels of valued living | NR | Davis et al. (2020) |

(Continues)

TABLE 4 (Continued)

| Instrument | Category | Aim of the instrument reported in the studies | Items/scoring | Content | Validity and reliability | Source |
|---|------------------------|---|--|---|--------------------------|----------------------|
| PG-13 | Psychological symptoms | To measure post-loss grief | 13 items, with the first 11 assessing the severity of a particular set of symptomatic thoughts, feelings and behaviours (1 = not at all to 5 = several times a day/overwhelmingly) and the final 2 items assessing the duration of symptoms (greater than 6 months for PGD) and whether they are associated with significant functional impairment. Scores ranging from 11–55 | Higher scores indicate higher levels of grief | NR | Davis et al. (2020) |
| After-Death Bereavement Family Interview | Communication | To assess patient-focused communication about the goals of care | Score range, 0 (worst) to 10 (best) | A higher problem score is an indication of more opportunities to improve care or more concerns with the quality of care | NR | Carson et al. (2016) |
| Family Satisfaction in the Intensive Care Unit survey | Provided care | To assess satisfaction to care | Score range, 0 (worst) to 100 (best) | NR | NR | Carson et al. (2016) |

Abbreviations: AAQ-II, The Acceptance and Action Questionnaire-II; BSI, Brief Symptom Inventory; CARE, The Consultation and Relational Empathy; CCS, Caregiver Competence Scale; CRA, Caregiver Reaction Assessment Tool; CSS, Caregiver Self-efficacy Scale; ESDS, Enforced Social Dependency Scale; FIN, Family Inventory of Need; GAD-7, Generalized Anxiety Disorder-7; GHQ, General Health Questionnaire; HADS, Hospital Anxiety and Depression Scale; IES, Impact of Event Scale—Revised; NCCN, National Comprehensive Cancer Network’s Distress Thermometer; PANAS, Positive and Negative Affect Schedule; PCLC-C, PTSD Checklist—Civilian Version; PCS, Preparedness for Caregiving Scale; PG-13, Prolonged Grief PG-13; PHQ-9, Patient Health Questionnaire; PPPC, Patient Perception of Patient Centeredness Scale; QOC, Quality of Communication Scale; QOL-NRS, NR; SDS, Symptom Distress Scale; SRI, Self-report Instrument; SWLS, Satisfaction with Life Scale; VLQ, The Valued Living Questionnaire; WHOQOL-BREF, World Health Organization Quality of Life-instrument.

AND (intervention OR program OR pre-post OR quasi-experimental OR RCT OR randomized controlled trial OR randomised controlled trial). A health science reference librarian was consulted to determine and improve the validity of the search. A manual search was also performed using a library database to ensure that all adequate studies were included.

The inclusion criteria for the studies were as follows:

1. The study included an intervention providing support for a family members.
2. The intervention was targeted at a family members of a very seriously ill patients.
3. The patients and family members were adults (aged over 18 years).
4. The study was conducted in an inpatient care setting.
5. The study included an outcome measurement for the intervention (pre-post, quasi-experimental or randomised control trial).
6. The study included outcome measurement results pertaining to the family members.
7. The empirical study was published in a peer-reviewed scientific journal.

The exclusion criteria were as follows:

1. The study included patients with dementia or cognitive decline.
2. The study was conducted in outpatient, clinical, community or home care settings.
3. Dissertations, editorials, statements or theoretical papers.

3.3 | Retrieval of the studies

A total of 7165 studies were identified in the following databases: PubMed, $n = 3727$; CINAHL, $n = 1677$; PsycINFO, $n = 1177$ and Cochrane, $n = 584$. After identifying the studies, duplicates were removed, and records were screened based on their titles. In total, 61 studies that met the inclusion criteria were screened based on their abstracts. This screening was independently performed by two authors, and 21 studies were selected for full-text evaluations. A language criterion was set at the abstract screening stage: studies written in languages other than English or Swedish were excluded ($n = 5$). Full-text evaluations were performed by two authors, and in cases of uncertainty, a third author was consulted. During the full-text evaluations, 10 studies were excluded because of the following reasons: the study was not conducted in an inpatient care setting ($n = 3$), the study included patients other than very seriously ill ones ($n = 2$), the study did not include an intervention or pre-post-test design ($n = 3$) or there were no data related to family members ($n = 2$). Finally, based on the retrieval process, 11 studies were included in the quality appraisal process (Figure 1).

3.4 | Quality appraisal

The Quality Assessment Tool for Before-After (Pre-Post) Studies With No Control Group by the National Heart, Lung and Blood Institute was used to evaluate the methodological quality of the included studies (NHLBI, 2020). However, the quality of the studies was not set as a criterion for including them in the review.

The tool has 12 items that can be answered with yes, no or other (cannot determine, not applicable or not reported). The overall quality of the studies based on the items could be reported as good, fair or poor. The quality of the studies was independently evaluated by two authors, and a consensus about the overall quality was reached through discussion. The appraisal revealed the total quality of the included studies to be mostly good (Carson et al., 2016; Fegg et al., 2013; Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012; Kühnel et al., 2020; Lee et al., 2016; White et al., 2018). Four of the studies were evaluated as fair (Davis et al., 2020; Forbat et al., 2018; Hannon et al., 2012; Randall Curtis et al., 2016), and none of the studies was evaluated as poor (Table 1). The quality was assessed with the quality assessment tool, focusing on the key concepts for evaluating the internal validity of a study (NHLBI, 2020) and the specific risk of bias in each study. The study rating tool was used to assess the risk of bias in each study, such that a good study had the least risk of bias and its results were considered valid, a fair study was susceptible to some bias deemed insufficient to invalidate its results, and a poor study had a significant risk of bias.

3.5 | Data analysis

Because of the limited number of the studies and the heterogeneity of the designs and outcome measurements (Fletcher, 2007), the data analysis was performed by summarising and tabulating the data and presenting it according to the research questions (Aromataris & Pearson, 2014). The data synthesis was conducted with descriptive synthesis (Popay et al., 2006). Data analysis started with extracting and tabulating the information obtained from the studies. General information about the studies is presented in Table 2 and includes information about the authors, year of publication, country where the study was conducted, name of the used intervention, study setting, study aim and design, participants and follow-up times. Data about the interventions were also extracted following the TIDieR checklist (Appendix S2). The bases and aims of the interventions, types of provided support and intervention, providers, instruments used for outcome measurement and reported intervention outcomes are presented in Table 3. Moreover, information about the measuring instruments, including the aim of each instrument, the number of items and style of scoring, content and validity and reliability reported in the studies, is presented in Table 4.

4 | RESULTS

4.1 | General description of the studies

In total, 11 studies were included in this review (Table 2). These studies were published between 2012–2020. The study settings included a specialist palliative care ($n = 4$) or a palliative care ward or unit ($n = 2$), a palliative care unit and a unit for management of cardiac/respiratory rehabilitation and palliative care ($n = 1$), an intensive care unit ($n = 3$) and a specialist cancer care unit ($n = 1$). The studies were conducted in Australia ($n = 4$), USA ($n = 2$), Germany ($n = 2$), Ireland ($n = 1$) and Taiwan ($n = 1$); the country was not reported in one study.

In the studies carried out in palliative care settings, the most common diagnosis was cancer, with only a few patients being diagnosed with other diseases. The eligibility criterion for family members in several studies was that the patient had palliative-stage cancer (Hannon et al., 2012; Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012; Lee et al., 2016) or had received palliative care otherwise (Davis et al., 2020; Fegg et al., 2013; Forbat et al., 2018; Kühnel et al., 2020). The studies conducted in ICU settings included family members of patients who required mechanical ventilation at least at the time of enrolment (Randall Curtis et al., 2016). In other ICU studies, more criteria were set for inclusion, and patients had to have had mechanical ventilation for at least four consecutive days (White et al., 2018) or at least seven days (Carson et al., 2016). In two of the studies, patients were estimated to have relatively high hospital mortality rates of $\geq 30\%$ (Randall Curtis et al., 2016) or at least 40%, or an estimated chance of severe long-term functional impairment of at least 40% (White et al., 2018).

Most of the studies had a controlled intervention study design, including randomised intervention and control groups (Carson et al., 2016; Davis et al., 2020; Fegg et al., 2013; Kühnel et al., 2020; Lee et al., 2016; Randall Curtis et al., 2016; White et al., 2018). The remaining four studies had a pre-post-test design with no control group (Forbat et al., 2018; Hannon et al., 2012; Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012). The study designs (Table 2) were reported to be a randomised controlled trial ($n = 3$), randomised trial ($n = 3$), quasi-experimental clinical trial ($n = 1$), pre-post-test design ($n = 3$) and prospective design ($n = 1$). The sample size varied from 15–1106 family members (Table 2). The smallest sample size was in the pilot study (Hudson, Lobb, et al., 2012). Additionally, one of the studies had the feasibility of the intervention as the primary outcome (Davis et al., 2020), reporting only preliminary effectiveness outcomes of the intervention.

The follow-up times between measurements varied, from right after the intervention to 12 months. The studies with a pre-post-test design had short follow-up periods, with the maximum being three days (Table 2). All the controlled studies had longer follow-up periods; the follow-up period was 1 month in one study (Davis et al., 2020), up to 3 months in two studies (Carson et al., 2016; Lee et al., 2016), 6 months in three studies (Kühnel et al., 2020; Randall Curtis et al., 2016; White et al., 2018) and 12 months in one study (Fegg et al., 2013).

4.2 | Supportive interventions for family members of very seriously ill patients

Supportive interventions for family members of very seriously ill patients in inpatient care units were implemented based on meetings with family members, education and therapy (Table 3). The type of support for the family members differed. Most commonly, interventions provided educational support (Carson et al., 2016; Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012; Lee et al., 2016). Interventions that were based on education implemented information sharing through a psychoeducational group intervention (Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012) and an integrated caregiver support intervention (Lee et al., 2016). Family meeting-based interventions included a meeting with family members and the multidisciplinary team of the healthcare staff. Interventions were implemented with the presence of a communication facilitator (Randall Curtis et al., 2016), arranging family meetings (Forbat et al., 2018; Hannon et al., 2012) and with Pairing Re-engineered ICU Teams with Nurse-Driven Emotional Support and Relationship-Building (PARTNER) (White et al., 2018). Interventions included emotional support (Carson et al., 2016; White et al., 2018) and communicational support (Randall Curtis et al., 2016; White et al., 2018). In two of the studies (Forbat et al., 2018; Hannon et al., 2012), the supportive intervention was the family meeting itself, and support was provided as the meeting was conducted. Therapy-based interventions were conducted with acceptance and commitment therapy (Davis et al., 2020), and behavioural therapy and mindfulness (Fegg et al., 2013; Kühnel et al., 2020). Two interventions had multiple components, including supporting elements for different areas, such as emotional and educational (Carson et al., 2016) or emotional and communicational (White et al., 2018) support.

The intervention aims varied (Table 3) between studies, and most of the studies intended to support family members psychologically. Interventions with a family meeting, therapy or even education were expected to decrease anxiety and depressive symptoms (Carson et al., 2016; Kühnel et al., 2020; Randall Curtis et al., 2016; White et al., 2018), distress, psychological stress and burden (Davis et al., 2020; Fegg et al., 2013; Lee et al., 2016; Randall Curtis et al., 2016; White et al., 2018). The studies that had an intervention focusing on educational support intended to improve the family members' competence, their preparedness for the caregiver role (Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012) and their self-efficacy (Lee et al., 2016). Additionally, some therapy-based interventions aimed to improve the family members' quality of life (Fegg et al., 2013; Kühnel et al., 2020), and one of the family meeting interventions focused on the level of empathy family members felt they received (Forbat et al., 2018). Family members' unmet needs were the target of some family meeting-based and educational interventions (Forbat et al., 2018; Hannon et al., 2012; Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012), and reducing concerns was the focus of one of the family meeting intervention (Hannon et al., 2012).

Most commonly, nurses were included in the team implementing the intervention; seven of the studies with family meeting- or

education-based interventions included nurses (Carson et al., 2016; Forbat et al., 2018; Hannon et al., 2012; Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012; Randall Curtis et al., 2016; White et al., 2018), and a researcher with a great deal of nursing experience was the implementer in one study (Lee et al., 2016). A physician was also part of the intervention implementation team in four of the studies based on family meetings (Carson et al., 2016; Forbat et al., 2018; Hannon et al., 2012; White et al., 2018), while a social worker was present in three family meeting-based interventions (Forbat et al., 2018; Hannon et al., 2012; Randall Curtis et al., 2016). Several interventions were carried out by multidisciplinary teams of varying composition. In addition to nurses, social workers and physicians, teams could involve chaplains (Carson et al., 2016; Forbat et al., 2018; Hannon et al., 2012), occupational therapists (Forbat et al., 2018; Hannon et al., 2012), physiotherapists (Hannon et al., 2012) and research assistants (Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012). Unlike the family meeting- and education-based interventions, the therapy-based interventions were implemented only by experts in psychology and therapy (Davis et al., 2020; Fegg et al., 2013; Kühnel et al., 2020).

4.3 | Implementation of the interventions

The implementation of the interventions was conducted in one or more sessions (Table 3). In two of the family meeting-based interventions in ICUs and in the long-form therapy intervention, the interventions were implemented within two to six sessions (Carson et al., 2016; Fegg et al., 2013; Randall Curtis et al., 2016). The educational support programme from Lee et al., (2016) had the longest implementation period: the sessions were held at least 3 times in 2-week intervals until the patient's death (Lee et al., 2016). The study with the short-term therapy intervention (sEBT) included two sessions (Kühnel et al., 2020), and in the self-help therapy intervention, the family members used the material on their own (Davis et al., 2020). Single-session interventions were also used including interventions with family meetings and psychoeducational intervention (Forbat et al., 2018; Hannon et al., 2012; Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012). However, most single-session interventions included a preliminary visit and an interview or discussion with the family members before the intervention was implemented.

Interventions were primarily implemented individually for family members, especially when an intervention was provided as a family meeting (Carson et al., 2016; Forbat et al., 2018; Hannon et al., 2012; Randall Curtis et al., 2016; White et al., 2018) or when an intervention was tailored specifically to the family members' needs (Lee et al., 2016). Short-term existential behavioural therapy was also arranged with individual sessions (Kühnel et al., 2020). The psychoeducational intervention (Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012) and behavioural therapy and mindfulness intervention (Fegg et al., 2013) were delivered in group sessions. Some interventions included written material, such as an intervention brochure (Carson et al., 2016), a guidebook (Davis et al., 2020; Hudson, Lobb,

et al., 2012; Hudson, Trauer, et al., 2012) or a practice compact disc (Davis et al., 2020; Fegg et al., 2013; Kühnel et al., 2020).

4.4 | Instruments used for intervention outcome assessment

In total, 28 instruments were used for outcome assessment (Table 4). Most instruments ($n = 12$) assessed aspects of psychological symptoms, such as anxiety, depression (Carson et al., 2016; Randall Curtis et al., 2016; White et al., 2018), burden, distress (Kühnel et al., 2020; Lee et al., 2016), post-traumatic stress (Carson et al., 2016; Randall Curtis et al., 2016) and detrimental psychological effects (Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012), in addition to the severity of symptoms (Fegg et al., 2013). Many instruments also assessed aspects of general living and coping ($n = 8$), such as the quality of life (Fegg et al., 2013), activities of daily living of the patients and coping strategies (Lee et al., 2016), perceived staff empathy (Forbat et al., 2018), values in life (Davis et al., 2020) and concerns (Hannon et al., 2012). Moreover, individual instruments assessed competence, preparedness for the caregiver role (Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012) quality of communication, patient- and family-centredness (White et al., 2018) and unmet caregiver needs (Forbat et al., 2018; Hannon et al., 2012; Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012).

The most commonly used instrument was FIN, which was the only instrument assessing caregiver needs; it was used in four studies (Forbat et al., 2018; Hannon et al., 2012; Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012). Nearly all instruments were used in only one or two studies, and there was a great diversity of instruments measuring the same outcomes from different perspectives. Seven instruments were reported to be reliable and valid, but the reliability and validity were not separately described for most instruments. Statistical data obtained using the CRA tool, SDS and CSS were reported as Cronbach's alpha (Lee et al., 2016). All instruments had been previously developed. The seven instruments that were reported to be valid and reliable are described in Table 4 based on earlier studies.

The number of items was reported for 10 of the instruments: PHQ-9, PTSD Checklist–Civilian Version (PCLC-C), The Consultation and Relational Empathy (CARE), FIN, GHQ, the CRA tool, the Enforced Social Dependency Scale (ESDS), CSS, Prolonged Grief PG-13 (PG-13) and the Acceptance and Action Questionnaire-II (AAQ-II). The number of items varied between 9–29 among the different instruments (Table 4).

4.5 | Outcomes of the interventions

The outcomes of the various interventions, as well as outcomes among the interventions with similar bases, varied (Table 3). Family meeting-based interventions did not result in a statistically significant improvement in family members' psychological symptoms. Moreover, the studies that were conducted in ICU settings did not

report any statistically significant improvement in anxiety or depressive symptoms. There was no statistically significant improvement in anxiety, as measured using the Hospital Anxiety and Depression Scale (HADS) (Carson et al., 2016; White et al., 2018) or the GAD-7 instrument (Randall Curtis et al., 2016). Inconsistent results were noted concerning depressive symptoms measured using the Patient Health Questionnaire (PHQ-9), with slightly reduced symptoms being noted after 6 months ($p = .017$), but no statistically significant difference was observed after 3 months. Two family meeting-based interventions measured depressive symptoms using the Impact of Event Scale (IES) and reported either no improvement (White et al., 2018) or an increase in symptoms in the intervention group ($p = .049$), indicating negative effects on family members by increasing post-traumatic stress reaction symptoms (Carson et al., 2016). In a family meeting-based intervention in a specialist palliative care unit, Hannon et al. (2012) noted a clear improvement in family members' needs being met ($p < .001$ in 14 of 20 items and $p < .05$ in two of the items). In contrast, in another family meeting-based intervention in specialist palliative care, there was no change in meeting family members' needs in family meetings (Forbat et al., 2018). Still, Hannon et al. (2012) further reported a positive impact in meeting family members' concerns ($p < .001$) (Hannon et al., 2012). Other studies also reported improvements in the quality of communication ($p = .001$), patient- and family-centredness ($p = .006$) of care (White et al., 2018) and perceived staff empathy ($p = .001$) (Forbat et al., 2018).

Educational interventions resulted in an improvement in family members' psychological symptoms in one study (Lee et al., 2016), but not in the other two educational intervention studies (Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012). The multiple-session, individually tailored, caregiver support intervention decreased family members' burden, as measured using the Caregiver Reaction Assessment (CRA) tool ($p < .01$) and the Symptom Distress Scale (SDS) ($p < .001$) (Lee et al., 2016). The psychoeducational group intervention did not have any significant effect on family members' distress, as measured using the General Health Questionnaire (GHQ) (Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012). All studies based on educational interventions reported an improvement in the preparedness for caregiving or self-efficacy. The level of preparedness for the caregiver role was improved, as measured using the Preparedness for Caregiving Scale (PCS) [($p < .05$) (Hudson, Lobb, et al., 2012), ($p < .001$) (Hudson, Trauer, et al., 2012)], and caregiver self-efficacy was enhanced, as measured using the Caregiver Self-Efficacy Scale (CSS) ($p < .01$) (Lee et al., 2016). Some, although not statistically significant, improvement was noted in family members' competence using the Caregiver Competence Scale (CCS) in one study (Hudson, Trauer, et al., 2012), but no improvement was noted in the pilot study using the same intervention (Hudson, Lobb, et al., 2012). Family members' unmet needs were found to be improved in a psychoeducational group intervention study using the Family Inventory of Need (FIN) instrument ($p = .028$) (Hudson, Trauer, et al., 2012), but in the pilot phase of the psychoeducational intervention, no significant effects were noted (Hudson, Lobb, et al., 2012).

Therapy-based interventions had differing outcomes. The multiple-session existential behavioural therapy and mindfulness intervention had statistically significant effects on anxiety after the intervention ($p < .006$), but not in the 3-month or 12-month comparison, as measured using the Brief Symptom Inventory (BSI) instrument (Fegg et al., 2013). It also improved depressive symptoms, but only 12 months after the intervention ($p = .04$). However, it did not affect somatisation (Fegg et al., 2013). Another behavioural therapy and mindfulness intervention with short-term implementation did not have an impact on family members' symptoms of anxiety, as measured using PHQ-9 or the Generalized Anxiety Disorder-7 (GAD-7) instrument, or on their distress, as measured using the National Comprehensive Cancer Network's (NCCN's) distress thermometer (Kühnel et al., 2020). Self-help acceptance and commitment therapy intervention also caused some improvement in distress, as measured using HADS; however, because the study primarily concentrated on the feasibility of the intervention and effectiveness was only a secondary outcome, the effectiveness was minimally reported (Davis et al., 2020).

In a therapy-based intervention study (Fegg et al., 2013), an improvement was noted in the quality of life in the post-intervention measurement using various measuring instruments: Satisfaction with Life Scale (SWLS, $p = .009$), World Health Organization Quality of Life instrument (WHOQOL-BREF, $p = .007$) and Quality of Life Numeric Rating Scale (QOL-NRS, $p < .001$). Further, in the 3-month (SWLS, $p = .04$; WHOQOL-BREF, $p = .10$ and QOL-NRS, $p = .23$) and 12-month (SWLS, $p = .10$; WHOQOL-BREF, $p = .06$ and QOL-NRS, $p = .002$) comparisons, some improvement was still noted in the quality of life, albeit with less impact (Fegg et al., 2013). No improvement was noted in the quality of life following short-term existential behavioural therapy (Kühnel et al., 2020).

5 | DISCUSSION

This review examines supportive interventions for family members of very seriously ill patients in inpatient care settings, and the contents and outcomes of these interventions. Supportive interventions for family members of very seriously ill patients were found to be rare, and they were implemented using different approaches, such as meetings with family members and a multidisciplinary team, provisions of education and information, or provisions of therapy. Although no date limitation was set for the review, the included studies had been carried out quite recently. This is probably due to the facts that studies have commonly concentrated on viewpoints other than families (Aoun et al., 2013; Chi et al., 2016; Hasson et al., 2020; Hensch et al., 2016), that intervention studies have been mainly conducted in home and community care (Becqué et al., 2019; Candy et al., 2011; Chi et al., 2016; Hudson et al., 2010; Northouse et al., 2010; Sutanto et al., 2017), and that the involvement of families in research has increased over the last decade.

The interventions varied in terms of their content and goals. Many existing interventions for inpatient care have focused on meetings with family members and the healthcare staff, with different supporting goals. Meetings with family members have been a commonly used procedure in inpatient care where very seriously ill patients are treated; however, the effectiveness of these meetings has been poorly researched (Cahill et al., 2017). Several interventions offer educational support to enhance competence and preparedness for the caregiver role, as it has been noticed that caregivers have unmet informational needs during inpatient care (Preisler et al., 2019), and they struggle when adjusting to their role as a caregiver (Fujinami et al., 2015; Li & Loke, 2013).

Concerning the outcomes, an improvement in psychological symptoms was difficult to achieve through supportive interventions. Positive results were mainly noted in studies that included therapy-based interventions (Davis et al., 2020; Fegg et al., 2013), multiple-session interventions (Fegg et al., 2013; Lee et al., 2016) and interventions individually tailored for family members' needs (Lee et al., 2016). It may be particularly difficult to relieve anxiety and depressive symptoms through interventions, and numerous and repeated sessions and efforts are required to target an intervention to specifically meet psychological needs (Northouse et al., 2010). For instance, the short-term version of existential behavioural therapy did not have a positive impact on family members' psychological symptoms or quality of life (Kühnel et al., 2020), while the long version of the same therapy showed some improvement in both areas (Fegg et al., 2013). It should also be noted that none of the family meeting-based interventions improved family members' psychological symptoms. One study reported that the intervention may have even increased the post-traumatic stress reaction symptoms (Carson et al., 2016).

The educational interventions had consistent positive effects on preparedness for the caregiver role and self-efficacy but not on psychological symptoms. Improvements have been noted even though educational support interventions were very different in terms of the content and the manner of implementation. Psychoeducational interventions have been found to have beneficial impacts on family members (Hudson et al., 2010); this was also seen in this review. However, as the interventions were very different from each other, it is possible that self-efficacy and preparedness for the caregiver role may be areas that could be more easily influenced by interventions than other areas for which support was provided.

Findings regarding the outcomes and effects on family members' well-being were partly mixed in this review, as has been reported previously (Alam et al., 2020). Intervention designing for vulnerable groups is not simple. Shorter interventions may be easier to implement, but in terms of effectiveness, multiple and longer sessions may have higher impacts, especially on psychological symptoms. However, intensive interventions can be burdensome for family members. Therapy-based and tailored interventions have the most positive effects on psychological symptoms, but they require resources and time and can be implemented only by therapists. More studies on interventions that can be valid and feasible in inpatient

care settings are needed. Additionally, studies need to be conducted to identify useful and effective ways of supporting family members of very seriously ill patients. Studies on interventions that have an impact on family members' health, psychological symptoms and quality of life also need to be conducted to guarantee quality care in inpatient care.

In addition to the interventions being very different from each other, the instruments used for outcome assessment were numerous and varied. Many instruments can be used to assess mental health and psychological outcomes; however, only a single instrument has been used to assess unmet needs of family members in several studies (Forbat et al., 2018; Hannon et al., 2012; Hudson, Lobb, et al., 2012; Hudson, Trauer, et al., 2012). The validity and reliability of the instruments have been minimally reported. It should be noted that since almost every study used different measuring instruments for assessing the outcomes, it is very difficult to estimate the actual differences between the effectiveness of the interventions involving distinct outcomes. For example, mental health and psychological symptom outcomes were evaluated using the same instrument in only a few interventions, while most studies used different instruments for assessing different outcomes. The disparity in the use of measuring instruments in studies involving interventions for family members of very seriously ill patients has also been previously noted (Ahn et al., 2020; Chi et al., 2016). Thus, the comparison of different instruments, as well as the outcomes of the interventions, is very difficult.

There have been limited studies on supportive interventions for family members of palliative care and critically ill patients (Aoun et al., 2013; Chi et al., 2016; Henoeh et al., 2016), and most existing interventions are designed to be used in home and community care (Candy et al., 2011; Harding et al., 2012; Hudson et al., 2010; Jaffray et al., 2016; Sutanto et al., 2017). According to this review concerning interventions in inpatient care settings, there are still only a few interventions targeting family members of very seriously ill patients in inpatient care.

The number of patients in inpatient care units is high, particularly in developed countries (Broad, 2013; Robinson et al., 2014). Hospital settings have a negative impact on bereavement (Roulston et al., 2017) and psychological symptoms (Oechsle et al., 2019) of family members of very seriously ill patients. Family members have received more attention in studies as care provided at homes has become increasingly common. However, family members should not be forgotten in inpatient care, even if the role of the caregiver is different from that in home care. There is an urgent need for interventions that could be used in inpatient care to meet the complex needs of family members of very seriously ill patients (Candy et al., 2011). Interventions targeting inpatient care are essential in providing healthcare professionals with tools for supporting family members of patients near death to decrease their depressive symptoms (Kuo et al., 2017) and high psychological morbidity levels (Areia et al., 2019; Grande et al., 2018; Rumpold et al., 2016). As family members are the ones who survive after the patient's death and the ones who must continue to live, stay

healthy and survive the death of the patient, there should be more focus on supporting family members and reducing their burden and morbidity.

5.1 | Strengths and limitations

Systematic reviews have some limitations. Setting a limitation on language and focusing only on peer-reviewed publications can exclude some studies. However, only peer-reviewed studies were selected in this review to ensure that the review was based on studies of a sufficiently high scientific standard. The quality of the studies included in this review was evaluated as fair to good, and none of the studies were of poor quality. The systematic review was conducted following the review method of Bruce et al. (2018). Several databases were used, and two authors independently conducted the review and performed the quality appraisal. Tools, such as the Quality Assessment Tool for Before-After (Pre-Post) Studies With No Control Group by the National Heart, Lung and Blood Institute, PRISMA guidelines and the TIDieR checklist, were also followed to minimise the bias and affirm the quality assessment and reporting. In some studies, the identification of the study setting (home care, community care, outpatient or inpatient care) was challenging and may have limited the inclusion of the studies. The study setting was precisely defined at the beginning, and the definition was strictly followed throughout the process. The number of studies included in this review was limited because there are only a few studies on supportive interventions for family members of very seriously ill patients in inpatient care. It was possible to extend the inclusion criteria; however, that would have hampered the scope of the review.

6 | CONCLUSIONS

There are not many supportive interventions that are directly specialised for family members of very seriously ill patients in hospital inpatient care. The interventions had great clinical heterogeneity with differing designs and follow-up times and used very different measuring instruments. Moreover, the outcomes of the reviewed interventions varied. Therefore, it was difficult to compare the differences between the study methods and their results. More studies on supportive interventions for family members of very seriously ill patients are essential so that their needs can be met. The feasibility and effectiveness of the interventions used in inpatient care settings also need to be studied further. The instruments need to be evaluated to identify the most valid and reliable instruments for measuring the psychological symptoms and coping of family members of very seriously ill patients. This review considered the content and outcomes of the interventions, though their effectiveness and feasibility require further study. The unmet needs, burden and morbidity of the family members of very seriously ill patients require more attention from healthcare

professionals, who would be able to better support family members with more knowledge and tools.

7 | RELEVANCE TO CLINICAL PRACTICE

This review presents a general description of supporting interventions for family members of the very seriously ill patients in inpatient care. Knowledge about the interventions and their outcomes may be exploited to improve the quality of care by giving information about different interventions that can be used when working with very seriously ill patients and their families in inpatient care. The results can be used with the selection of effective interventions for use in practice and evaluating the suitability of different supporting interventions in different situations and inpatient settings. Effective and feasible interventions are needed so that healthcare personnel have tools to support the families and increase coping. The interventions outlined in this review could be used when finding ways to support family members in inpatient care in situations where the patient is in critical or otherwise serious condition. The measurement instruments can be used in clinical practice when assessing the very seriously ill patient's family members need for support, as well as the burden caused by the situation. Additionally, the results of this review can be used as guidance when developing new, effective interventions.

CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

AUTHOR CONTRIBUTIONS

Anu Soikkeli-Jalonen Conceptualised the study, contributed to methodology, investigated the study, curated the data, wrote—original draft, wrote—review and editing and visualised the study. Kaisa Mishina contributed to methodology, investigated the study, wrote—review and editing and supervised the study. Heli Virtanen and Andreas Charalambous wrote—review and editing. Elina Haavisto conceptualised the study, contributed to methodology, wrote—review and editing, involved in funding acquisition, supervised the study and involved in project administration.

DATA AVAILABILITY STATEMENT

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

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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