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Review Article

How Nurses Can Support Families Where a Person with Serious Illness Is Living at Home: A Scoping Review

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More tasks and responsibilities have been transferred to the caregivers of a seriously ill person living at home. The caregivers risk getting overburdened and sick themselves and therefore cannot help with sufficient support. Limited knowledge exists about what applies in a private home, and there is a general lack of knowledge about how healthcare professionals can support the caregivers. In this review, we investigated how nurses can support caregivers where a seriously ill person is living at home. The design was a scoping review. Literature published from 2007 to 2022 was searched in four databases: PubMed, CINAHL, Embase, and PsycINFO. Quality assessment was made by Hawkers model, and $n = 18$ studies from Northern Europe, the USA, and Canada were included. The methods used were 11 qualitative, 5 quantitative, and 2 mixed-method studies, including 971 caregivers, 217 patients, and 10 healthcare professionals. Multidisease, cancer, apoplexy, and recipients of palliative care were the main focus, but other diseases were also represented. The nurse's task is to ensure the presence of a number of prerequisites for the care process to be successful and to be aware that caregivers may find themselves in a number of dilemmas and to try to remedy these dilemmas. If possible, the nurse should facilitate that the care burden is shared between several members of the family. Care must be performed according to the principles of family nursing, meaning that all relevant members of the family, appointed by the patient, are included, and collaboration is established. Future research and practice should focus on the nurses, the framework home care nurses work under, and how they can practice family nursing, so that family nursing becomes a natural part of primary care.

1. Introduction

When a person gets a seriously illness, it is not only the person but also their close caregivers who suffer [1]. This strain can be so severe for the caregivers, they risk becoming sick themselves, and then they cannot offer sufficient support to the care receiver. By creating a culture where the caregivers are involved, you may avoid one patient becoming two [2].

In a national survey about caregiver support initiatives among hospitals and municipalities, the Danish Knowledge Center for Rehabilitation and Palliative Care (REHPA) highlights that especially the primary care setting needs to be improved [3]. In 25% of the

municipalities, vulnerable caregivers were systematically identified, in 27% of the municipalities, primary care asked caregivers systematically how much they wanted to be involved, and in 30% of the municipalities, they uncovered how much support the caregivers needed. Thus, systematic caregiver involvement seems to be a disregarded area in the primary care setting.

Family-focused nursing identifies the resources and the challenges of the family, and in a hospital setting with multiple patients, it has been shown that nurse-led family meetings can support the family to improve communication, manage everyday life, and be able to live together with the new circumstances of the disease [4]. However, there is

a need for further research in primary care settings with families with a serious disease living at home. Over the years, more tasks and more responsibilities have been transferred from society to the caregivers. The policy strategy within the healthcare system has for years been to shorten admissions and discharge patients quickly [5]. Therefore, it is often the caregivers who, with varying support from the municipality, must support the seriously ill person in their private home. Research shows that caregivers can support a sick family member, and that the sick person has a better quality of life, better rehabilitation, and fewer readmissions and relapses when the caregivers are involved in the care process [6–8]. However, the research is sparse on how specifically to support the caregivers in the primary care setting. One review from Australia by Whitehead et al. investigated how caregivers can contribute to promoting and supporting the self-care of the chronically ill person in their own home. Whitehead et al. found that the caregivers play an important role in supporting the patient, and that families as units are able to adapt, so the challenges of the disease are met, and the patient can live as normal a life as possible. But Whitehead et al. also found that there is a lack of knowledge about how health professionals can best support the caregivers, so they in turn can support the patients in gaining control over and learning to cope with their illness [9]. However, the review by Whitehead et al. did not include seriously ill patients, with conditions that carry a high risk of mortality and may negatively impact quality of life and daily function. In general, the research available about seriously ill patients has been carried out in a hospital setting. A study from the College of Nursing in Utah, USA, aimed to identify the social support needs of nurses and family caregivers. This study questioned focus groups, where family caregivers and nurses related their experiences of home hospice care. They found discrepancies about which support was seen as the most important by nurses and caregivers. The findings showed the need for nurses to make skilled individual family assessment and tailor care to meet each family's needs. However, there were several limitations with the study. It was small with only 14 caregivers and 13 nurses, and its limited focus group design coupled with the risk of selection bias may have affected their findings [10]. Thus, there is a lack of knowledge about what applies in a private home, when a person is seriously ill, and the caregivers provide support and care to the patient, possibly with aid from the professional healthcare system. The aim of this review is to investigate how nurses can support the caregivers who in turn support the patient in gaining greater control and coping with his/her seriously illness in the private home. In addition, to examine the needs of the caregivers as hidden patients and evidence-based interventions to prevent or reduce caregivers potential illness.

2. Materials and Methods

The design is a scoping review [11] to create an overview of existing evidence available and themes and factors related to how nurses can support caregivers in their care of the seriously ill patient in their own home as well as to find what

evidence is available of both quantitative and qualitative nature and where there may be a lack of evidence.

We performed literature searches for peer-reviewed publications from January 2007 to January 2022 in the databases PubMed, Embase, CINAHL, and PsycINFO, based on the PEO model (Table 1) [12].

Searching the four databases resulted in 1359 hits. All hits were transferred to Endnote, where duplicates were removed. Subsequently, the articles were collected in the Rayyan program [13]. All articles were screened by the author CF and co-author EJ. The first 50 items were sorted together after which the remaining ones were sorted independently. Some articles were directly excluded or included, while others were discussed and decided jointly.

> Inclusion criteria: studies in Danish, English, or Norwegian, studies that dealt with next of kin but were carried out where the patient primarily stayed in their own home, studies where the person participated in training or care in a health center, in a rehabilitation department, an outpatient clinic, or a similar facility a few times a week, studies that dealt with persons with seriously illness, regardless of the nature of the illness, and where the person was over the age of 18 years, and studies with >25 points according to the quality assessment [14].

> Exclusion criteria: reviews or systematic reviews, studies with less than five participants, studies that did not deal with seriously ill persons and their caregivers, or studies that dealt with children and young people under 18 years of age.

2.1. Quality Assessment. The articles were evaluated based on the model of Hawker et al. (Table 2). This model was developed to assess the quality of evidence obtained from the health sector and takes into account the challenges that may be involved in assessing and evaluating, in particular, qualitative research in a review [14].

2.2. Theoretical Framework. The review is based on a hermeneutic framework, as the review seeks an understanding of how nursing can support the caregivers of seriously ill persons in their own homes. Essential in hermeneutics is the pre-understanding, which is inevitably present, and consists of the culture, the experiences, prejudices, and attitudes which we bring into the review [15]. The pre-understanding consists of our professional work as nurses. There have been many experiences and stories shared by caregivers, and a certain knowledge of caregivers has therefore been built up. Our position is that caregivers should be seen as an asset in the care of the seriously ill patient. We are aware that in some families, there may be challenges where it can be difficult to see the caregivers as a resource. We are aware that pre-understanding plays into the interpretation and understanding of the articles selected. But the pre-understanding also contributes to an increased

Table 1: Search words (PubMed search strategy).

Block 1 Caregivers		Block 2 Seriously ill		Block 3 Own home
Families		Serious disease		MH "home care services"
Partner		Life-threatening		MH "home nursing"
Carers		Critically ill		MH "home health nursing"
Next of kin	AND	MH "critical illness"	AND	MH "nurses, community health"
Relative		MH "multiple chronic conditions"		MH "primary health care"
MH "caregivers"				MH "primary nursing"
MH "spouses"				MH "primary care nursing"
MH "family"				

understanding related to practice and a deeper interpretation in relation to the problem and the results produced in this review [15].

2.3. Theory. In the 1980s, Family Systems Nursing, a phrase coined by Wright and Leahey, explained how nursing interventions must involve the entire family. The concept focuses on the needs of the family as a whole, where reciprocity and interaction between the family and the nurse are essential [16]. In Denmark, family-focused nursing, a phrase coined by Østergaard and Wagner, is developed and characterized by its systemic approach, which is based on the premise that when a person is affected by an illness, it also affects the whole family and not just the individual [2]. Within systems theory, health and illness are therefore seen as a social phenomenon. The family is seen as a socially open system, where each member's perspective is included in the conversation, so there are many perspectives on the same topic. By applying a family perspective in the care of families affected by illness, stability can be achieved, as resources and strengths in the family are in focus [17]. The family nurse helps to identify the strengths of the family to achieve specific goals, and the nurse's assignment is to facilitate communication in the family, so the tasks can be solved together.

2.4. Analysis. The text materials were analyzed based on Malterud's analysis model [18]. The model is suitable for analyzing and creating meaning in qualitative data such as various types of interviews but can also be used to analyze quantitative data, so the empirical phenomena that are desired can be understood. The analysis model consists of four steps: (1) total impression, where the text is read, the content is understood, and ideas for codes arise; (2) identifying and sorting meaning units, where the text is separated and codes are written on the text about the issues we plan to investigate; (3) condensation, where the content is collected to codes that are close to the text and contain a complete and exhaustive description of what is being talked about, so that no meaning is lost; and (4) synthesizing, where the text summaries are gathered into themes. Here similarities, differences, patterns, and hierarchies are established in a reflexive process. [18].

3. Results

The literature search resulted in 1231 hits (Figure 1). The final number of articles included in the review was 18 studies. Twelve studies were conducted in Northern Europe [20–31], five in the USA [32–36], and one in Canada [37]. Approximately 971 caregivers participated in the studies, as well as 217 patients and 10 healthcare professionals. All studies deal with the care of seriously ill patients in their own home. Multidisease, cancer, apoplexy, and recipients of palliative care were the main focus, but COPD, cardiovascular disease, Parkinson's disease, spinal cord injury, general chronic disease, dementia, life-threatening disease, kidney disease, heart failure, and neurological disease were also represented. The review included 11 qualitative, 5 quantitative, and 2 mixed-method studies (Table 3).

In the analysis of the results, 5 themes emerged: *inevitable conditions, prerequisites for a good care process, informal caregiving—a commitment of balance, identifying the caregivers' need for extra support,* and *family interventions and tailored support.*

3.1. Inevitable Conditions. In most of the studies, inevitable conditions are present for the caregivers when one of their loved ones suffers from a seriously illness and needs to be cared for in their own home. The caregivers often have more household chores, they have difficulty leaving the patient [21], and the risk of depression and anxiety is increased [22]. The caregivers experience cases of deterioration in the condition of the patient, and feelings of fear and helplessness arise, which can lead to poor health in the caregivers [25]. The caregivers, who cared for loved ones with Parkinson's disease, experienced psychosocial challenges, such as lack of communication with the patient, not being able to save their loved ones, having to bear an increased responsibility [34], and worries about the future:

One challenge I think about all the time is what's in the future? I know we're not supposed to dwell on the future, but I think you have to be realistic. I've seen her digress so much in the last few months that I'm thinking if she continues at this rate, in 6 months...will I be able, to be ready to care for her? [35].

TABLE 2: Quality assessment by Hawkers model [14].

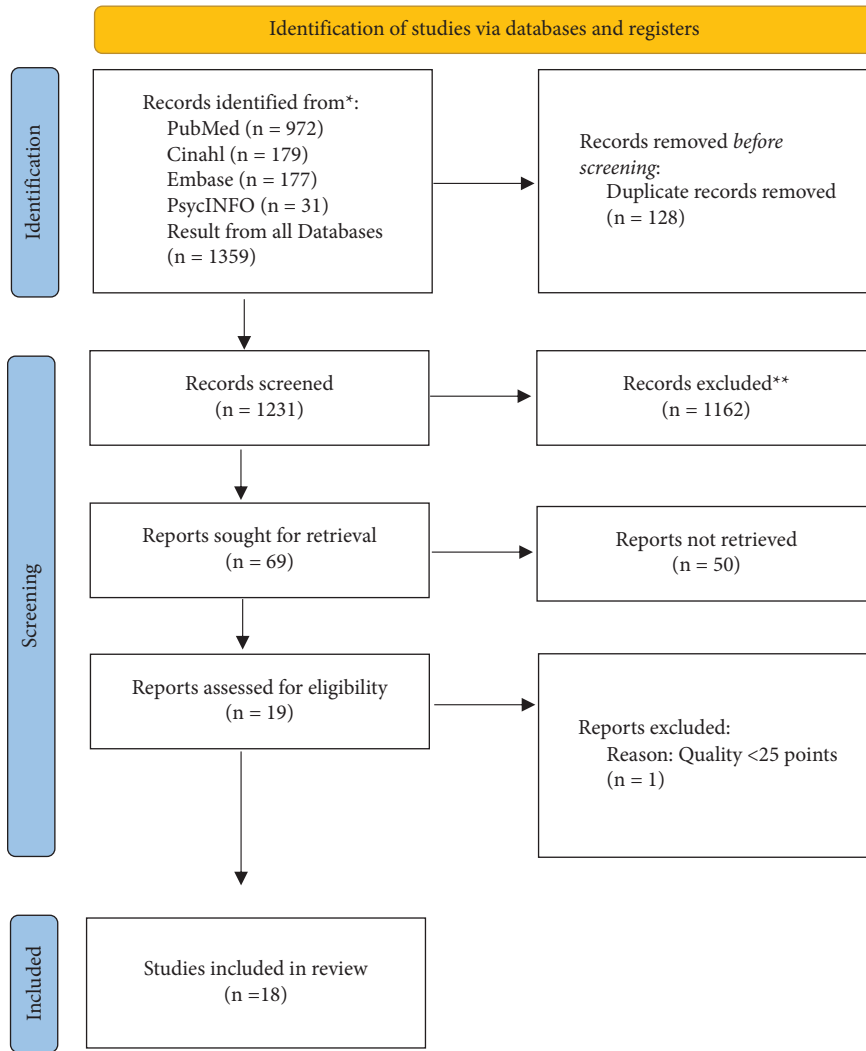| Number and author of article	(1) Abstract and title	(2) Introduction and aim	(3) Method and data	(4) Sampling	(5) Data analysis	(6) Ethics and bias	(7) Results	(8) Transferability or generalizability	(9) Implications and usefulness	Result max. 36 & minimum 9 points
(1) Aasbø et al.	3	3	3	2	4	3	4	2	4	28
(2) Aschbrenner et al.	4	3	3	4	4	2	4	3	4	31
(3) Baumann et al.	3	4	4	4	3	3	2	4	3	30
(4) Behm et al.	4	3	3	3	4	4	4	3	4	32
(5) Bijnsdorp et al.	4	4	4	3	3	2	4	3	3	30
(6) Borson et al.	4	2	3	3	3	2	4	3	4	28
(7) Carlander et al.	4	4	4	3	4	4	4	3	4	34
(8) Galatsch et al.	4	4	4	4	3	3	4	3	4	33
(9) Groh et al.	4	2	4	4	2	2	4	3	4	29
(10) Gysels et al.	4	4	4	3	3	1	4	3	4	30
(11) Jeyathevan et al.	4	3	4	4	4	2	4	4	4	33
(12) Martin	3	4	4	2	3	3	4	2	4	29
(13) McLennon et al.	3	4	4	3	3	2	3	3	4	29
(14) Norinder et al.	4	4	4	4	4	4	3	4	3	34
(15) Robinson	3	4	4	3	4	2	3	3	3	29
(16) Seidlein et al.	4	4	4	3	3	2	3	3	4	30
(17) Weibull et al.	4	4	4	4	4	2	4	4	4	34
(18) Wennman et al.	4	4	4	3	3	4	4	3	4	33

Figure 1: PRISMA flowchart: model downloaded from the Internet [19].

The feeling of burden for the patient, the caregivers, and the professionals creates a dependency between them, which influences decision making in relation to medical treatment and care, which can lead to unmet care needs [29]. The caregivers experience a lack of self-confidence and the feeling of being left alone [30].

3.2. Recognition and Acknowledge Caregivers in Partnership of Care. A number of prerequisites must be present for the caregivers to experience the care process as a success. The caregivers need professional support for the challenges they face in everyday life [20] and to be included in the possibilities for support [27]. They lack recognition for the responsibility they take and for the expertise they have built up through prolonged care. The caregivers need to be involved in care decisions, as this creates feelings of security and control. Increasing the feeling of security is essential for the caregivers [26], so that the caregivers can contact a team around the clock, receive support in everyday life, help to prevent unnecessary hospitalizations, and lower the caregiver's level of anxiety and depression. The caregivers must

be met with understanding and flexibility [23] and receive enough help in caring for the patient at home [33]. Several studies demonstrated the importance of including the caregivers in care decisions [27]. As in Jeyathevan et al. [37], it was found that positive coping, social support, skills training, access to municipal services, continuity in care, and the integration of the caregivers in rehabilitation and discharge processes were necessary prerequisites to increase the durability of the caregivers.

Other prerequisites for increasing the quality of life for the caregivers included maintaining or pursuing a hobby, making use of relevant local offerings, not neglecting one's own physical and mental needs [34], having time for oneself during the day, receiving practical help at home and support coping with feelings and worries, the opportunity to express individual challenges, and understanding the complexity of the situation as explained by the professionals [28]. The family-focused approach was a prerequisite for success because it included all relevant members, also friends [36], and it involved caregivers in the organization of care [29]. The caregivers who reflected positively on their care

TABLE 3: Presentation of included studies.

Author	Year	Country	Magazine	Aim	Participants	Setting	Method	Results
Aasbø et al. [20]	2017	Norway	Health and Social Care in the Community	To explore how spouses perceive their role in relation to the patient with COPD and in relation to the health professionals in connection with acute exacerbations of the disease	10 spouses 4 men 6 women	Own home: primary sector	Qualitative: 10 individual semi-structured interviews	The caregivers need professional support, recognition for the responsibility they take, recognition for the expertise they have built up, and to be involved in decisions, as this leads to the feeling of security and control for the family. The caregivers experience that they have to balance their involvement with the health professionals. The caregivers may risk being excluded if they interfere and at the same time they feel the need to interfere for the sake of their own and their loved one's safety.
Aschbrenner et al. [32]	2014	USA	The International Journal of Psychiatry in Medicine	Exploring caregivers' involvement in medication administration and health-related support for older adults with severe mental illness and increased risk of cardiovascular disease	28 people with severe mental illness and increased risk of cardiovascular disease, 13 men, 15 women, and 13 caregivers	Own home: primary sector	Mixed-method, 28 participants completed questionnaires, 10 semi-structured interviews were conducted with the participation of the patient and his/her caregiver	The caregivers play an active role in supporting medication administration in the mentally ill. Through conversation with the providers, the caregivers showed interest in how they could help their loved ones change unhealthy habits. Lifestyle changes present a potentially promising opportunity to engage caregivers of elderly mentally ill citizens so that, in collaboration with health professionals, they can reduce the risk of cardiovascular disease.

TABLE 3: Continued.

Author	Year	Country	Magazine	Aim	Participants	Setting	Method	Results
Baumann et al. [21]	2013	Luxemburg	Healthcare Policy	To determine the emotional and social repercussions of an apoplexy for caregivers with low life satisfaction (LS), their characteristics, and any neurological repercussions of the survivors living in their own home two years after the apoplexy	62 dyads or couples, a total of 124 people	Own home: primary sector	Quantitative: questionnaires dealing with apoplexy-related consequences. The relatives also filled in forms about their self-perceived LS.	The care-related daily activities add meaning to the lives of the caregivers, and they appreciate providing care for their loved ones. But half of the caregivers have an LS score below 7 (where 10 is highest and the average LS for citizens in Luxembourg is 7.9). Characteristic of this group is that it is often one caregiver who is responsible for the care of the sick.
Behm et al. [22]	2018	Sweden	Scandinavian Journal of Caring Sciences	To describe the mental health in relation to anxiety and depression, and reactions to care provision, in caregivers of elderly people with multiple illness after hospitalization	345 caregivers of elderly people over the age of 65 who have multiple diseases	Own home: primary sector	Quantitative: questionnaire survey in a cross-sectional study, where anxiety and depression (HADS) and positive and negative reactions to care (CRA) were assessed	The health professionals must increase life satisfaction for the caregivers, by providing care for their loved one. The results show that the risk of depression and anxiety increases significantly with increased negative reactions in the caregiver; therefore, a possible solution could be to screen caregivers for this. By assessing the individual situation for each individual caregiver, nurses and other health professionals can offer tailored support to the caregivers.

TABLE 3: Continued.

Author	Year	Country	Magazine	Aim	Participants	Setting	Method	Results
								If too many factors are out of balance, such as lack of flexibility from work, too great demands on the caregivers, and lack of help with home care, then the caregivers experience stress and this affects their well-being and health. For the combination to be successful, there must be understanding and flexibility from work, there must be support from health professionals, and it is important that the care tasks can be shared with others. The caregivers could be better supported in this balance by the health professionals
Bijnsdorp et al. [23]	2021	Netherlands	BMC Palliative Care	To gain insight into experiences of combining paid work and being a caregiver and providing family care to patients at the end of life. To investigate what factors facilitate and hinder this combination and what support needs there are.	18 caregivers of people with a life-threatening illness	Own home: primary sector	Qualitative semi-structured interviews	
Borson et al. [33]	2018	USA	PLOS One	To describe and investigate whether the tool Managing Your Loved One's Health (MYLOH) can be used to identify deficiencies in the caregivers' knowledge, skills, and access to clinical and personal support	190 caregivers of citizens with chronic life-limiting illness such as dementia, cancer or heart disease, COPD, and kidney disease	Own home: primary sector	Quantitative: with questionnaire of how much they agree with each statement. 29 statements divided into 7 topics.	MYLOH is relevant for identifying caregivers' needs for coaching and support for all types of chronic illness. MYLOH can be used as a guide for conversations between health professionals and caregivers and to organize interventions that can support the role as a caregiver. 4 themes were problematic for the caregivers: to find enough help with care, to cope with day-to-day tasks, to understand and cope with medication, and to recognize and respond to changes in the patient's health.

TABLE 3: Continued.

Author	Year	Country	Magazine	Aim	Participants	Setting	Method	Results
Carlander et al. [24]	2011	Sweden	Qualitative Health Research	To describe how everyday life close to death is experienced and managed in families where a person suffers from life-threatening illness	5 families participated, one of whom suffers from life-threatening illness such as cancer or heart problems	Own home: primary sector	Qualitative: 28 interviews of 1-2 h duration were conducted	The main theme is to find the best possible way to cope with life when one in the family suffers from life-threatening illness. Nurses can support this process by involving the family in the care plan and inviting the family along with the patient to discuss and listen to each other's feelings and thoughts about everyday life and the future. They can encourage family members to find space for themselves. They can inquire into the family plan and provide support based on this. By supporting the family as a group, the family's identity can be strengthened.
Galatsch et al. [25]	2019	Germany	BMC Palliative Care	To use the "Stressful Caregiving Adult Reactions to Experiences of Dying" (SCARED) scale to assess caregivers of patients dying with critical illness and relate the caregivers' own psychological distress and general health to the frequency of deterioration in the dying person's condition	49 primary caregivers of dying patients	Own home: primary sector	Quantitative: questionnaire of the SCARE scale to assess the frequency of aggravation, fear, and helplessness. And the scale SF-36 to assess the caregivers' general health.	The caregivers experience several cases of aggravation in the dying condition and these cases produce fear and feeling of helplessness and this results in poor health. The SCARE scale can be used as a tool, in a palliative care context in the citizen's own home, to identify needy caregivers who potentially need extra support.

TABLE 3: Continued.

Author	Year	Country	Magazine	Aim	Participants	Setting	Method	Results
Groh et al. [26]	2013	Germany	Journal of Palliative Medicine	To evaluate the impact of one of the first specialized outpatient palliative care teams (SOPC) in Germany	60 patients receiving palliative care and 53 caregivers	Own home: primary sector	Quantitative: with two questionnaires. The first is completed within the first week, and the next 8 weeks after the SOPC team enters the home.	Involving a SOPC team significantly increases satisfaction and quality of care. The team significantly improved both the patient's and the caregiver's quality of life. By allowing the team to be contacted around the clock, this increases the feeling of security and prevents unnecessary hospital visits. The team eased the caregivers' care burden, and their level of anxiety and depression was lowered after the team joined the care.
Gysels et al. [27]	2009	England	Palliative & Supportive Care	To examine care experiences of caregivers of persons with an advanced progressive disease, suffering from shortness of breath, and diseases such as COPD, heart failure, cancer, or neurological disease	15 caregivers	Own home: primary sector	Qualitative: with semi-structured interviews	They found themes that may threaten or affect the nurturing role in a negative direction, as well as what coping strategies the caregivers could use to reduce or eliminate these threats. Caregivers need to be included in the options available for support. Involvement from nurses can ease the heavy responsibility of caring. Nurses can contribute with problem-solving skills and build on the coping strategies the caregivers draw on. Shortness of breath is challenging, and the caregivers lack strategies to relieve the symptoms and they are too ill-prepared for acute exacerbations.

TABLE 3: Continued.

Author	Year	Country	Magazine	Aim	Participants	Setting	Method	Results
Jeyathevan et al. [37]	2020	Canada	Disability and Rehabilitation	To explore people with spinal cord injuries and their caregivers' perceptions about what promotes and hinders the care role in their own home and to suggest strategies for improvement	34 participants, 19 were patients with spinal cord injuries and 15 caregivers	Own home: primary sector	Qualitative: with semi-structured interviews	Positive coping, social support, skills training, access to municipal services, and continuity in care contribute significantly to the durability of the caregiver. Need to integrate the caregivers in rehabilitation and discharge processes, as well as routine assessments of the caregivers. The factors promoting the sustainability of the caregiver can be used to develop interventions in the health system that help maintain the caregivers' role in long-term care.
Martin [34]	2015	USA	Journal of Neuroscience Nursing	To contribute knowledge to the unexplored field around the psychosocial perception of being a partner of a person with Parkinson's disease and what challenges are experienced, both related and unrelated to care	23 caregivers who are spouses or cohabiting with a person with Parkinson's disease	Participants choose the place, most chose their own home, but also restaurants, churches. and university buildings were used	Qualitative: semi-structured interviews with 21 couples and 2 interviews where only the partner participated	A family-centered approach is needed to take care of patients with Parkinson's disease. Health professionals can benefit from training partners for the newly diagnosed in what they may face in the future. Both in relation to care, but also in relation to other things, for example, for the caregiver to maintain a possible hobby and to be introduced to relevant local offers, it is imperative not to neglect his/her own physical and mental needs as a caregiver.

TABLE 3: Continued.

Author	Year	Country	Magazine	Aim	Participants	Setting	Method	Results
McLennon et al. [35]	2010	USA	Journal of Neuroscience Nursing	To identify common themes from the caregivers who have decided that their loved ones with Alzheimer's or Parkinson's disease should move to an institution	11 participants, 9 caregivers of ones with Alzheimer's disease, and 2 caregivers of ones with Parkinson's disease	Own home: primary sector	Qualitative: with semi-structured interviews	They expressed concerns about the future and discussed the need for assistance or alternatives for their loved ones. These discussions took place 3-4 months before the patient was institutionalized, but if the health professionals were able to recognize risk situations earlier and initiate interventions quickly, then institutionalization could be delayed or prevented.
Norinder et al. [28]	2021	Sweden	BMC Palliative Care	To explore connections between the caregivers' need for support and the quality of life when the caregiver cares for their spouse or partner who receives specialized palliative home care	114 spouses or partners of a person receiving specialized palliative care. 96 of the patients had cancer and 15 had heart-lung disease, and 3 with other diseases.	Own home: primary sector	Mixed-method: questionnaire with demographic questions, the tool CSNAT which assesses the caregivers' support needs, and QOLLTI-F which assesses the quality of life, and an open question where the participant could write his thoughts about the situation	The higher the need of support to the caregiver, the poorer the caregiver's quality of life. Caregivers needed most support: "knowing what to expect in the future" (69%), "having time for themselves during the day" (66%), "coping with emotions and concerns" (63%), and "practical help at home" (51%). The CSNAT tool can be used as a communication tool that is integrated into a person-centered approach to assessment and support in practice.

TABLE 3: Continued.

Author	Year	Country	Magazine	Aim	Participants	Setting	Method	Results
Robinson [36]	2017	USA	Qualitative Health Research	To further develop theory to inform about patient- and family-centered care, so that living well with chronic illness can be facilitated and improved	43 members from 17 families	Own home: primary sector	Qualitative: semi-structured focus group interviews with the individual family, in their home. 33 interviews were conducted.	Taking a family-focused approach to the topic. Families living well and sharing the burden of illness share their emotional and spiritual experience of living with chronic illness and include more nontraditional members such as friends of the family. Families experiencing difficulties: it was the woman/wife/mother who bore the burden of the disease almost alone, she was alone with her problems and worries, and both she and the family were caught up in traditional thinking about care and about who should provide support.
Seidlein et al. [29]	2019	Germany	Bioethics	To gather insight into the experiences of burden from the three parties in the care: the one who receives the care, the caregivers, and the professionals	10 elderly persons who suffer from several chronic diseases and who need long-term home care, 8 informal caregivers, and 10 professional carers	Own home: primary sector	Qualitative: 28 semi-structured interviews with each included person. Held at home, in the workplace, and in the researchers' offices.	The feeling of being a burden is very present in long-term home nursing, not only for the patient but also for the caregivers. The feeling of burden creates a mutual dependence between the parties, which is relevant for decision making, and which often leads to unmet care needs. This highlights the need to recognize the burden and to organize care so that the burden is reduced. And on that basis, it is important to involve all parties in the organization of care.

Table 3: Continued.

Author	Year	Country	Magazine	Aim	Participants	Setting	Method	Results
Weibull et al. [30]	2008	Denmark	BMC Palliative Care	To explore the impact of surviving spouses' active involvement in medication and physical care based on their experience of the palliative care process	7 surviving spouses to terminally ill persons with cancer. 3 men and 4 women.	Own home: primary sector	Qualitative: semi-structured individual interviews	Spouses can benefit from participating in medication and physical care because it makes the last time easier and less dependent on professionals. They experienced satisfaction by getting involved in home care, they were willing to be active, and everyone would do it again. Negative impacts: a lack of self-confidence and a sense of loneliness. Prerequisites were security—professional back-up 24 hours a day, trust—from the professionals of the caregivers' abilities, and dialogue—to be asked about the degree of involvement and influence in decisions.
Wennman et al. [31]	2020	Sweden	American Journal of Hospice and Palliative Medicine	To examine patients who need palliative care and their caregivers' experience of receiving "advanced home care." This care is characterized by a team of specialists whose task is to provide care.	11 interviews, 8 with the sick and 1 or 2 caregivers, and 3 interviews with the patient alone. 8 sick men, 3 sick women.	Own home: primary sector	Qualitative: unstructured interviews, 8 group interviews and 3 individual interviews	To create a safe environment because the need for safety is big. To see the patient and the caregivers as the unique persons they are. To avoid hospitalization via the emergency department because this is associated with great uncertainty, long waiting times, and the staff not knowing the patient's history.

TABLE 4: Work tool for the nurse: prerequisites for successful care partnerships.

The nurse's approach	(i) Include all relevant members in the care of the patient, including friends or neighbours who are interested in helping (ii) Involve all relevant family members in the organization of care, in decisions, and in rehabilitation and discharge processes (iii) Trust the abilities of the caregivers (iv) Create dialogue, constantly ask about the degree of involvement: is it too much? Do they have the courage for more? (v) Meet the caregivers with understanding and flexibility, give them space to express individual challenges (vi) See the patient and the caregivers as the unique people they are
The needs of the caregivers—which the nurse must help to fulfill	(i) To be recognized for the responsibility they take (ii) To be recognized for the expertise they have built up—to feel safe and secure (iii) To share feelings and worries (iv) To receive support in everyday life, also socially (v) To have time for oneself and one's own needs in everyday life
Practical prerequisites—which the municipality must help to fulfill	(i) Opportunity to contact professionals around the clock (ii) Receive enough practical help at home (iii) Receive professional support (iv) Real prevention of unnecessary hospitalizations (v) Receive skills training, in specific areas related to the disease (vi) Municipal services available for the family, such as caregiver support groups, relief, and day center care (vii) Continuity in care (viii) A priority that caregivers have a leisure interest

experience reported a satisfaction with getting involved and a willingness to be active:

> Afterwards, I cannot blame myself for taking the easy way out and not being involved–so I am actually feeling quite pleased with myself [30].

The prerequisites for caregivers to do it again are professional back-up 24 hours a day, professionals having confidence in their abilities, an open dialogue about the caregivers' degree of involvement, care taking place in a safe environment, the need for security is met, and the professionals seeing the people involved as unique [31] (Table 4).

3.3. Informal Caregiving: A Commitment of Balance. Caregivers experience that they have to balance their involvement, as they may risk being excluded by the health professionals if they interfere, and at the same time they feel compelled to interfere for the sake of their loved ones [20]. In a study from the USA [32], the caregivers showed interest about how they could help their loved ones change unhealthy habits. The researchers concluded that lifestyle changes were a potentially promising opportunity to engage caregivers of elderly mentally ill citizens, to reduce the risk of cardiovascular disease. The caregivers appreciated caring for their loved ones, and the care-related activities added meaning to their lives [21]. However, the caregivers experienced stress [23], it was difficult for them to find time for themselves [24], and they were often trapped in traditional thought patterns around care and support. The burden risks became too heavy, so the caregivers themselves often became ill [36]. Nevertheless, it is an advantage for the caregivers to participate in care and medication administration, as it makes the end easier and more independent from professional help:

> Actually I was glad I could do it. . ..then we had the day to ourselves, without all these comings and goings [30].

3.4. Identifying the Caregivers' Need for Extra Support. Many caregivers have a self-perceived life satisfaction level below average. They are socially isolated and need special attention, as they are at an increased risk of becoming ill themselves [21]. As Baumann and Bucki found:

> For a great majority of family caregivers—in particular, spouses with low satisfaction—their experience of caregiving reflects a lifestyle that puts their health at risk [21].

There is a need for screening caregivers in relation to negative reactions to providing care [22] and to examine whether there are factors out of balance [23]. There are several tools, such as the SCARE scale, which can be used to identify caregivers who need extra support [25]. MYLOH is suggested as a guide in conversations, to identify the caregivers' needs [33]. The CSNAT tool can be used as a communication tool in a person-centered approach to

assessment and support in practice [28]. The professionals can advantageously examine which coping strategies the caregivers use, whether they lack strategies to relieve symptoms in the patient, and whether they are prepared for acute situations [27]. Three to four months before institutionalization, for example, in a care center, there should be discussions about the need for assistance or alternatives to the situation at home. The nurse should recognize these risk situations and initiate interventions to postpone institutionalization [35]. The nurse must be aware that in those families where it is difficult, it is often a woman who bears the burden of the disease alone, and she is often alone with her worries and problems [36]. The nurse must recognize the burden and plan the home care, so the burden is reduced for the caregiver [29].

3.5. Family Interventions and Tailored Support. The family consists of individuals with different needs, who support each other. The nurse can support the family as a group and strengthen the family's identity by involving all relevant members, by getting the family to discuss and listen to each other [24], sharing emotional and spiritual experiences [36], by asking about the family's plan, and organizing support based on this [24]. Several studies conclude that the involvement of nurses eases the burden of care [26, 27] because they can contribute problem-solving skills and coping strategies, in addition to what the caregivers already use [27]. As Gysels and Higginson found:

> Negotiated involvement of a care professional could buffer the heavy responsibilities related to home care. They could provide problem-solving skills and build on the resources that carers draw on in response to what they experience as most threatening to their caring role [27].

There is a need for a family-centered approach, where the caregivers are informed about what they can expect support needs to be in future [28, 34]. In practice, professionals should try to avoid hospitalizations via emergency departments, provide support measures at home, facilitate contact with other professionals, and provide easy access to services that provide security for the patient and caregivers [31]. In vulnerable families, the duties of the nurse are to increase the life satisfaction of the caregiver by providing home care [22]. This can be accomplished by providing tailored support [22, 28, 33], by distributing the care tasks among several family members [23, 36], and by ensuring that the caregivers are able to respond to changes in the patient's condition [33].

4. Discussion

4.1. Discussion of Results. The review includes 12 studies from Northern Europe, primarily from well-developed countries in Europe. Thus, there is a lack of research from Southern and Eastern Europe, where healthcare systems are built upon the fact that the families largely take care of the sick person at home, or pay for help [38]. Therefore, it

could have been interesting to incorporate knowledge from studies produced in these countries. In Australia, all residents are covered by public health insurance [39], similar to Denmark. To further illuminate this system, research from Australia could have been relevant. In the initial literature search, an Australian review was found which dealt with the chronically ill, but their exclusion criteria were critically ill, terminal and dying citizens, and quantitative studies. Therefore, that research could not be used in this review.

In qualitative studies, there is predominantly knowledge about how caregivers can be supported to become an asset for the seriously ill patient in their own home. Therefore, more quantitative research might be needed to further elucidate this area. The studies included in this review are published from January 2007 to January 2022. However, there has been an increased publication rate within the last five years, where ten of the studies have been published, which indicates that the subject is a growing area of research. Most studies used in this review indicate that family nursing is a useful and positive approach when nurses support caregivers in their care of a seriously ill person. However, it can also be complicated to involve the family as some family members may not want to get involved, and some families may not want to cooperate. To involve the family can be beneficial, but if there are conflicts in the family, which the family nurse cannot resolve, the task is instead about clarifying what the patient and the caregivers need and want [40].

4.2. Recognition and Acknowledge Caregivers in Partnership of Care.

The results showed that several prerequisites must be present for the process, in which the caregivers contribute to the homecare of their seriously ill loved ones, to be successful. The family-focused approach is a prerequisite where all relevant family members and friends must be included [36]. In family nursing, the family is defined as individuals with a desire for involvement in each other's lives and with a sense of connectedness [17]. The findings concluded that caregivers should be involved in care and decisions [20, 27], as this creates the feeling of security and control [26]. In family nursing, a real partnership is entered into between the caregivers, the patient, and the nurse, around the treatment and care of the patient, where communication, relationship, and interaction between the parties are central [17, 41]. In the partnership, the caregivers receive recognition for the care responsibility they take on and for the expertise they have built up [20]. The nurse takes on the role of supervisor [17]. Feeling protected and safe is essential for the caregivers [27] and helps to lower their level of anxiety and depression [26]. The caregivers want to be met with flexibility and the understanding of the complexity of care [28]. These needs can apparently be met by family nursing, which forms the foundation for the nurse's understanding of the caregivers and the patient. In the partnership with the family, the nurse must create an environment of trust, respect, and equality [17, 41], so the family feels able to express individual challenges [28]. Other prerequisites for success are that the caregivers have time for themselves in everyday life, time to maintain their hobbies, or make use of local offers, so they do not neglect their own physical and mental needs because of care commitments to the patient [34]. The family nurse is concerned with the well-being of the family, and her job is to ensure that the caregivers get breaks from the care in everyday life [17]. The caregivers need professional support to meet challenges in everyday life [20], and the family nurse's job is to initiate change in the family, so everyday life is adapted to the new context, in which the family finds itself [9].

4.3. Informal Caregiving: A Commitment of Balance.

One dilemma for caregivers is that they feel they must balance their involvement, as they risk exclusion from care, while simultaneously feeling compelled to intervene, for the sake of the safety of their loved ones [20]. Family nursing works on the premise that all families have their own strategies for coping with stressful and difficult situations, and the nurse's job is to ensure a trusting partnership, guided by the caregivers, with the nurse as facilitator and supervisor [17, 41]. Including the caregivers in decision making provides an opportunity to engage, activate, and support them in solving the tasks in the care situation [34]. This is in line with the family nurse recognizing the resources in the family, encouraging the caregivers to cooperate, valuing their knowledge, and supporting their role [19]. It can be beneficial for caregivers to participate in the home care, as it increases independence and makes the dying patient's last time easier [30]. Caregivers appreciate caring for their loved ones, as it adds meaning to their lives [21], and they experience satisfaction by getting involved [30]. The family nurse works to create a successful care experience through a balanced presence, where he/she offers teaching and information at an appropriate pace, is available when needed, and supports, corrects, and affirms the caregivers, so that they have space and time to learn, and their independence is ultimately increased [17]. Caregivers experience stress [23], but according to family nursing, the stress factors are often embedded in a passive role as caregiver, where lack of control and anxiety are significant factors [41]. Caregivers who experience stress are often trapped in traditional thought patterns around care and support in the family [36]. Thus, the family nurse's job is to initiate change, in relation to the family's behavior and function, as the nurse can help them reflect on their internal division of roles and whether this is appropriate in relation to the new situation the family is in [17, 41].

4.4. Family Interventions and Tailored Support.

The life satisfaction of the caregivers can be increased by the nurse offering tailored support to the family [22, 28, 33], acknowledging and highlighting the family's strengths, normalizing their concerns as understandable and natural, and helping the family resist feelings of despair and hopelessness. Thus, the nurse can increase the resilience of the family and give them confidence to overcome the problems ahead [17]. When the family is involved in the care of the patient, the care tasks are shared and thus the burden is shared [23, 36],

and the family is seen as individuals with different needs, but with the ability to support each other. Therefore, the nurse must support and encourage networking and family collaboration [41], facilitate family discussions where they listen to one another [24], and share emotional and spiritual experiences [36]. By asking about the family's care plan and organizing support based on this [24], the nurse ensures that care goals are set for the whole family [17]. When nurses are involved in the home care process, the care burden for the caregivers is eased [26] because nurses contribute additional problem-solving skills and coping strategies [27]. The nurse takes on a counselor or consultant function in family nursing, where it is a matter of building and maintaining family resilience to the challenges ahead [41]. Caregivers need to be prepared for what the future may bring [34], as well as how support needs may change [28]. This is solved by a family nursing approach, where caregivers expect that the stimuli they will encounter in the future are predictable, or that the stimuli that come as a surprise, such as worsening of the disease, can be explained and fit into a context [17, 41]. In the study by Wennman, they concluded that admissions via the emergency department should be avoided because it is associated with waiting time and great uncertainty [31]. Research has shown that using family nursing can also cause less concern in the family [17].

4.5. Strengths and Limitations. The strengths of this review include the data collection, which has been carried out over a relatively long period, namely, 15 years, and both quantitative and qualitative studies have been included, which is an advantage in relation to illuminating the topic in the best possible way. In a scoping review, there may be a large difference in the quality of the studies, as there is no requirement to assess the quality, but to offset these possible quality differences, it was decided that all studies in this review were quality assessed (Table 2). The studies included achieved between 28 and 34 points out of a possible 36 points, so the quality of these studies is reasonably high.

Weakness of this review is that no studies were found meeting the inclusion criteria from Southern and Eastern Europe, Australia, or the Far East, such as China or Japan, where the healthcare systems are different and where there may be experiences beneficial to this topic. If we had wanted to include studies from these countries, we could have included other languages in our search, which would have required extensive language skills and more time. In relation to the chosen keywords, other words could have been chosen, which allegedly would have resulted in other studies, but attempts were made to take this into account by consulting a librarian and by performing a pilot search.

5. Conclusion

In this review, answers were sought on how nursing could support caregivers as a resource for the seriously ill patient in their own home. Nursing must be performed according to the principles of family nursing, where all relevant family members and friends are included, and there is a collaboration between the patient, the caregivers, and the nurse, where communication, relationship, and interaction between all parties are central. Several prerequisites must be present for the care process to be successful, and it is the nurse's task to ensure these. The caregivers may find themselves in a number of dilemmas and the nurse should be aware of and try to remedy these dilemmas, by increasing confidence, intervening with extra support, and by being a balanced presence. The care burden must be distributed between several family members, and primary care nurses are in a key position to facilitate this. The nurse takes on a consulting and advisory function focused on building and maintaining the family's resilience to the challenges ahead.

Future research is needed as to how primary care nurses work with the caregivers in everyday life, how they include them in the care of the patient, and what obstacles exist in including the caregivers. The structure and organization of care in the municipalities should be changed so that caregivers can be more involved in the process of care. This review has identified the support needed for caregivers to be able to take care of a seriously ill person in a private home. Further research should focus on nurses' needs, the framework they work under, and how they handle family nursing, for instance, do nurses need additional training, or should their work be organized differently so that family nursing has a natural flow in primary care.

Data Availability

The data used in this review can be found in the databases PubMed, Embase, CINAHL, and PsycINFO.

Additional Points

What Is Known about This Topic. (i) When a person gets sick with seriously illness, the close relatives become caregivers. This strain can be so severe for the caregivers that they risk getting sick themselves. (ii) Caregivers play an important role in providing emotional and physical support to the patient living at home. (iii) Family research has mostly been carried out in a hospital setting; therefore, there is a lack of knowledge about what applies in a private home and how nurses can support the family as a unit. *What This Paper Adds.* (i) By using a family-focused approach, nurses can involve the family and help them share the burden of disease, share tasks, and improve communication with one other. (ii) Family-focused nurses become aware of and identify vulnerable caregivers and provide tailored support and care to increase the well-being of the caregiver. (iii) There is a need for a family-centered approach, where the caregivers are prepared for what the future may bring and how support needs may change.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Acknowledgments

References

[1] K. B. Dieperink, E. Coyne, D. K. Creedy, and B. Østergaard, "Family functioning and perceived support from nurses during cancer treatment among Danish and Australian patients and their families," *Journal of Clinical Nursing*, vol. 27, no. 1-2, pp. e154–e161, 2018.

[2] B. Østergaard and L. Wagner, "The development of family nursing in Denmark: current status and future perspectives," *Journal of Family Nursing*, vol. 20, no. 4, pp. 487–500, 2014.

[3] REHPA, "Caregiver support initiatives," 2020, https://www.rehpa.dk/wp-content/uploads/2020/01/RAPPORT-P.C3.A5r.C3.B8rendest.C3.B8tte-FINAL.pdf.

[4] B. Voltelen, H. Konradsen, and B. Østergaard, "Family nursing therapeutic conversations: family reorganization processes after diagnosis," *Family Relations*, vol. 67, no. 5, pp. 600–614, 2018.

[5] Danish Patients, "About danish patients," 2022, https://danskepatienter.dk/about-danish-patients.

[6] K. Sundin, B. Bäckström, V. Lindh, M. Lindkvist, B. Saveman, and U. Östlund, "Responses after participating in Family Health Conversations in families with a family member who has suffered a stroke: a mixed methods research study," *Clinical Nursing Studies*, vol. 4, 2016.

[7] D. Figueiredo, J. Cruz, C. Jácome, and A. Marques, "Exploring the benefits to caregivers of a family-oriented pulmonary rehabilitation program," *Respiratory Care*, vol. 61, no. 8, pp. 1081–1089, 2016.

[8] S. Suter-Riederer, R. M. Imhof, C. Gabriel, J. Kesselring, W. Schnepp, and L. Imhof, "Consenting on principles of rehabilitation nursing care: a delphi study," *Rehabilitation Nursing*, vol. 43, p. 1, 2017.

[9] L. Whitehead, E. Jacob, A. Towell, M. Abu-Qamar, and A. Cole-Heath, "The role of the family in supporting the self-management of chronic conditions: a qualitative systematic review," *Journal of Clinical Nursing*, vol. 27, no. 1-2, pp. 22–30, 2018.

[10] M. Reblin, K. Cloyes, J. Carpenter, P. Berry, M. Clayton, and L. Ellington, "Social support needs: discordance between home hospice nurses and former family caregivers," *Palliative & Supportive Care*, vol. 13, no. 3, pp. 465–472, 2015.

[11] M. Peters, C. M. Godfrey, P. Mcinerney, and C. B. Soares, *Methodology for JBI Scoping Reviews*, Joanna Briggs Institute, Adelaide, Australia, 2015.

[12] M. J. Metzler and G. A. Metz, "Analyzing the barriers and supports of knowledge translation using the PEO model," *Canadian Journal of Occupational Therapy*, vol. 77, no. 3, pp. 151–158, 2010.

[13] Rayyan Systems Inc, "Rayyan- intelligent systematic review," 2022, https://www.rayyan.ai/.

[14] S. Hawker, S. Payne, C. Kerr, M. Hardey, and J. Powell, "Appraising the evidence: reviewing disparate data systematically," *Qualitative Health Research*, vol. 12, no. 9, pp. 1284–1299, 2002.

[15] M. Dowling, "Hermeneutics: an exploration," *Nurse Researcher*, vol. 11, no. 4, pp. 30–39, 2004.

[16] J. Bell, "Family systems nursing, re-examined," *Journal of Family Nursing*, vol. 15, no. 2, pp. 123–129, 2009.

[17] L. M. Wright and J. M. Bell, "Retrospective—nurses, families, and illness: a new combination," *Journal of Family Nursing*, vol. 10, no. 1, pp. 3–11, 2004.

[18] K. Malterud, "Systematic text condensation: a strategy for qualitative analysis," *Scandinavian Journal of Public Health*, vol. 40, no. 8, pp. 795–805, 2012.

[19] Prisma, "Flow diagram," 2021, http://prisma-statement.org/prismastatement/flowdiagram.aspx.

[20] G. Aasbø, J. Rugkåsa, K. N. Solbrække, and A. Werner, "Negotiating the care-giving role: family members' experience during critical exacerbation of COPD in Norway," *Health and Social Care in the Community*, vol. 25, no. 2, pp. 612–620, 2017.

[21] M. Baumann and B. Bucki, "Lifestyle as a health risk for family caregivers with least life satisfaction, in home-based post-stroke caring," *Healthcare Policy | Politiques de Santé*, vol. 9, no. SP, pp. 98–111, 2013.

[22] L. Behm, E. Björkman, and G. Ahlström, "Mental health and reactions to caregiving among next of kin of older people (65+) with multi-morbidity discharged home after hospitalization," *Scandinavian Journal of Caring Sciences*, vol. 32, no. 4, pp. 1458–1467, 2018.

[23] F. M. Bijnsdorp, B. D. Onwuteava-Philipsen, C. R. L. Boot, A. J. van der Beek, H. T. Klop, and H. R. W. Pasman, "Combining paid work and family care for a patient at the end of life at home: insights from a qualitative study among caregivers in The Netherlands," *BMC Palliative Care*, vol. 20, no. 1, pp. 1–13, 2021.

[24] I. Carlander, B. Ternestedt, E. Sahlberg-Blom, I. Hellström, and J. Sandberg, "Being me and being us in a family living close to death at home," *Qualitative Health Research*, vol. 21, no. 5, pp. 683–695, 2011.

[25] M. Galatsch, H. G. Prigerson, W. Schnepp, F. Zu Sayn-Wittgenstein, and J. Li, "Caregiver exposure to critical events and distress in home-based palliative care in Germany a cross-sectional study using the Stressful Caregiving Adult Reactions to Experiences of Dying (SCARED) scale," *BMC Palliative Care*, vol. 18, no. 1, p. 9, 2019.

[26] G. Groh, B. Vyhnalek, B. Feddersen, M. Führer, and G. D. Borasio, "Effectiveness of a specialized outpatient palliative care service as experienced by patients and caregivers," *Journal of Palliative Medicine*, vol. 16, no. 8, pp. 848–856, 2013.

[27] M. H. Gysels and I. J. Higginson, "Caring for a person in advanced illness and suffering from breathlessness at home: threats and resources," *Palliative & Supportive Care*, vol. 7, no. 2, pp. 153–162, 2009.

[28] M. Norinder, K. Årestedt, S. Lind et al., "Higher levels of unmet support needs in spouses are associated with poorer quality of life – a descriptive cross-sectional study in the context of palliative home care," *BMC Palliative Care*, vol. 20, no. 1, pp. 132–211, 2021.

[29] A. H. Seidlein, I. Buchholz, M. Buchholz, and S. Salloch, "Relationships and burden: an empirical-ethical investigation of lived experience in home nursing arrangements," *Bioethics*, vol. 33, no. 4, pp. 448–456, 2019.

[30] A. Weibull, F. Olesen, and M. A. Neergaard, "Caregivers active role in palliative home care- to encourage or to dissuade? A qualitative descriptive study," *BMC Palliative Care*, vol. 7, no. 1, p. 15, 2008.

[31] I. Wennman, A. Ringheim, and H. Wijk, "We are here for you all the way—patients and relatives experiences of receiving advanced home care," *American Journal of Hospice and Palliative Medicine®*, vol. 37, no. 9, pp. 669–674, 2020.

[32] K. A. Aschbrenner, R. Pepin, K. T. Mueser et al., "A mixed methods exploration of family involvement in medical care for older adults with serious mental illness," *The International Journal of Psychiatry in Medicine*, vol. 48, no. 2, pp. 121–133, 2014.

[33] S. Borson, P. Mobley, K. Fernstrom, P. Bingham, T. Sadak, and H. R. Britt, "Measuring caregiver activation to identify coaching and support needs: extending MYLOH to advanced chronic illness," *PLoS One*, vol. 13, no. 10, Article ID e0205153, 2018.

[34] S. C. Martin, "Psychosocial challenges experienced by partners of people with Parkinson disease," *Journal of Neuroscience Nursing*, vol. 47, no. 4, pp. 211–222, 2015.

[35] S. M. McLennon, B. Habermann, and L. L. Davis, "Deciding to institutionalize: why do family members cease caregiving at home?" *Journal of Neuroscience Nursing*, vol. 42, no. 2, pp. 95–103, 2010.

[36] C. A. Robinson, "Families living well with chronic illness: the healing process of moving on," *Qualitative Health Research*, vol. 27, no. 4, pp. 447–461, 2017.

[37] G. Jeyathevan, B. Catharine Craven, J. I. Cameron, and S. B. Jaglal, "Facilitators and barriers to supporting individuals with spinal cord injury in the community: experiences of family caregivers and care recipients," *Disability & Rehabilitation*, vol. 42, no. 13, pp. 1844–1854, 2020.

[38] C. Montoro-Gurich and C. Garcia-Vivar, "The family in Europe: structure, intergenerational solidarity, and new challenges to family health," *Journal of Family Nursing*, vol. 25, no. 2, pp. 170–189, 2019.

[39] N. Rosdahl, "Australien- sundhedsforhold," 2015, https://denstoredanske.lex.dk/Australien_-_sundhedsforhold.

[40] C. S. Henry, A. Sheffield Morris, and A. W. Harrist, "Family resilience: moving into the third wave," *Family Relations*, vol. 64, no. 1, pp. 22–43, 2015.

[41] M. Leahey and L. M. Wright, "Application of the calgary family assessment and intervention models: reflections on the reciprocity between the personal and the professional," *Journal of Family Nursing*, vol. 22, no. 4, pp. 450–459, 2016.