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Palliative Home Care

Nurses' Experiences and Perceptions in Providing care

A literature review

Palliativ hemsjukvård

Sjuksköterskors erfarenheter och upplevelser i vården

En allmän litteraturstudie

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ABSTRACT

Background: Demands to be cared for and die at home are increasing nowadays. The holistic approach of palliative care is to emphasize on alleviating physical and psychological distresses and psychosocial support to patients and their families. The nurses have a significant role in promoting palliative care as guidelines of The National Board of Health and Welfare and The World Health Organization (WHO).

Aim: To describe nurses' experiences and perceptions in providing palliative care to adult patients at home.

Method: A general literature review of ten scientific articles were retrieved from CINAHL and MEDLINE. The collected data were analysed systematically before processing into the result.

Results: Three themes and seven subthemes are identified. Three themes describe: supporting patients and their families, improving work efficiency and organizational factors. Seven subthemes present nurses' experiences in handling psychosocial and emotional issues, strengthen empowerment, building relationships, interprofessional collaboration, self-development, workload and lack of time, and organization support.

Conclusion: The results indicate the importance of increasing knowledge and skills in providing the holistic palliative home care for patients and their families. Organizations' supports and effective interprofessional collaboration are fundamental attributions in promoting adequate palliative care.

Keywords: dying patients, literature review, nurses' experience, nurses' perception, palliative home care, the end of life.

SAMMANFATTNING

Bakgrund: Allt fler väljer att vårdas och dö hemma vilket medför ett ökande palliativt vårdbehov i hemmet. Holistiskt förhållningsätt av palliativ sjukvård fokuserar på att lindra fysiskt, psykiskt symtom och existentiellt stöd till patienter och deras familjer. Sjuksköterskor har en viktig roll i att främja palliativ omvårdnaden utifrån vägledningen av Socialstyrelsens och Världshälsoorganisationen (WHO).

Syfte: Att beskriva sjuksköterskors erfarenheter och upplevelser av palliativ vård av vuxna patienter i hemmet.

Metod: En allmän litteraturöversiktstudie genomfördes på tio vetenskapliga artiklar som hämtades från databaserna CINAHL och MEDLINE. Insamlad data analyserades systematiskt innan de bearbetades för resultaten.

Resultat: Tre huvudteman och sju underteman har identifierats. De tre huvudteman beskriver upplevelser av: stöd till patienter och deras familjer, förbättring av arbetseffektiviteten och organisationsfaktorer. De sju underteman beskriver hur sjuksköterskor hanterar psykosociala och emotionella frågor, förstärkande av empowerment, hur man bygger upp en vårdrelation, interprofessionellt samarbete, självutveckling, arbetsbelastning och tidsbrist samt organisationsstöd.

Slutsats: Resultaten pekar på angelägenheten i att förbättra vårdpersonalens kunskap och färdigheter i att sörja för holistiskt palliativ hemsjukvård av patienter och deras familjer. Organisationsstöd och goda interprofessionella samarbeten är en förutsättning för att förbättra kvaliteten i den palliativa sjukvården.

Nyckelord: döende patienter, litteraturöversikt, sjuksköterskans erfarenhet, sjuksköterskans perceptioner, palliativ hemsjukvård, patienter i livets slut skede.

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INTRODUCTION

Palliative care can be provided in a hospital, inpatient wards, residential care and at the patient's home. Caring for seriously ill and dying patients has gradually moved from hospitals to residential care homes and patients' own homes. Besides, both international and Swedish studies show that many people have a desire to die in their own homes. The World Health Organization (WHO, 2016) states that home-based care services help the patient and the family feel comfortable in privacy and confidentiality and the family members are integrated into the caring process, which can strengthen the empowerment of the patient and the family.

According to our experiences as assistance nurses in-home care service, and observations during the time of traineeships in primary health care units we have seen how nurses have worked and managed with challenges that come from patients, their relatives, other related health care staff, and their organizations in palliative care. These complexities can obviously influence the quality of palliative care for patients and their families. That is a reason why we want to explore nurses' experiences and perceptions to provide good care, relieve the pain and improve quality of life to patients in palliative care at their own home.

BACKGROUND

Definitions of palliative care

Palliative care is defined as an approach that promotes quality of life of patients and their families facing the problem associated with life-threatening illness. Palliative care's goal is to prevent and relieve suffering through early identification and treatment of pains. Thus, palliative care emphasizes the multidimensional assessment of the physical, psychological, social and spiritual needs and values of patients and families (WHO, 2016)

In Sweden, palliative care is split into general and specialized palliative care. General palliative care is provided to patients whose needs are met with a palliative team with basic competence. It is provided in hospitals and municipal nursing homes in association with primary care. Specialized palliative care is provided to patients with complex symptoms or disease, which demands special care of the multi-professional palliative team (The National Board of Health and Welfare [NBHW], 2016).

Palliative care at the end of life focuses on providing the best possibilities to maintain a good quality of life along with relief of suffering and improving symptom control. The concept "care at the end of life" contains the care offered in short times, several days or weeks or months. Palliative caregivers need to identify patients' final stage of terminal illness in order to collaborate with other professional teams and the family to prepare good plans for caring for the end of life (NBHW, 2018).

At the transition to palliative care at the end of life, the physician will have a breakpoint conversation, in which the patient is informed about his illness situation, which leads to life-sustaining treatment. The breakpoint conversation puts demands on the physician's competence and experience, as well as on respecting the patient's autonomy, integrity and palliative approach. During the conversation, the family or next of kin can take part depending on the patient's desire. The nurses' and other care providers' presences play an important role at the breakpoint conversation. According to this approach, palliative care does not terminate with the patient's passing away, but, to the contrary, it will continue by providing grief and bereavement support to the family and next of kin after the death (NBHW, 2018).

Development of palliative care

History of providing care to persons who have been suffering from severe and incurable diseases in the long term was developed from guesthouses or hospices to the professional palliative care of today. It is known that the modern form of palliative care was started by Dame Cicely Saunders, who founded St. Christopher's Hospice in England in 1967 to provide

care for patients with terminal illnesses. She thought that it was necessary to get the patients' families involved in caring work and then realized that the patients' families also had the need to be supported, which was a significant element in a healthcare process to improve the quality of life for both patients and their families. In Sweden, Professor Barbro Beck-Friis is known as a pioneer in founding palliative home care in Motala in the early 1970s. At the end of the 1970s, the advanced home care form for adults, which was known as “Motalamodellen” was presented in the country. In the 1980s two palliatives, Diaconal Bräcke in Göteborg and Ersta Diaconal, Stockholm were started (The National Council for Palliative Care, 2010).

Nowadays the palliative care has developed and been upgraded into professional organizations in Sweden and other countries with the humanitarian aim to improve the quality of life for patients in the last years of their life. As estimated by NBHW (2016), about 90.000 people die every year and 80 percent of them need some form of palliative care in Sweden. As estimated by WHO (2016), around 40 million people need palliative care in the world every year, but only 14 percent of them receive palliative care and care for the end of life.

Palliative Home Care

Home-based care service is a form of health care, in which caregivers are responsible for medical duties based on a nursing plan at the patients' own home. In Sweden, the home-based care service includes basic home care and advanced home care. The home-based care service is connected to primary care and managed by the municipality. The advanced home-based care is often connected with hospitalization care service. Palliative home care is a part of advanced home care (SOU 2011:55).

Palliative homecare provides care to patients with chronic, life-limiting health problems such as cancer, renal and respiratory diseases, HIV/AIDS at the patient's home. A palliative homecare approach is to facilitate for the patient's family to integrate into the care process, which in turn contributes to enhancing autonomy for the patient and family (WHO, 2016). In a research to measure quality of life of cancer patients who were discharged from hospital home, Melin-Johansson et al. (2010) indicated that the patients' health status was improved, with less physical distress and anxiety. Furthermore, both patients and families felt secure with support of the palliative homecare team.

Similarly, the demand for being cared for and dying at home has increased in Sweden. In a survey on the choice of place for caring and death conducted in 1999, most answers expressed a wish to be cared for and to die at home (SOU 2001:6). Furthermore, with a systematic review of 399 articles studying preference of death place in Europe, Canada, USA, Australia and Asia, Nilsson et al. (2017) found that the preference of home death averaged by 59.9% throughout all studies, but the average amount of patients who actually died at home was only 40.4%. That incongruence was caused by factors influencing patients' choice of home death,

which included insufficient care at home, stress, anxiety about deteriorating physical condition, feeling of being a burden to the family, etc. (ibid). On the other hand, obstacles to dying at home can be insufficient coordination between care settings in the healthcare system. These obstacles lead to inadequate preparations, lack of discharge planning and information reported to community nurses (O'Brien & Jack, 2010). Thus, to identify factors that impact patients' desire of dying at home is an essential approach to promote quality of life for patients and their families.

Palliative Care Approach

In order to provide a good palliative care service, it is required to focus on essential principles, which contain physical and psychological/spiritual care, planning and coordination, and communication. Palliative care does neither hasten nor postpone death, but uses ethical principles to identify essential needs to promote the quality of life for the patient at the end of life and support to the family both during the illness and after bereavement (WHO, 2016). The palliative care approach is to dignify human values of the patient and family. Thus, a palliative care provider is required to have professional competences, the skill of communication and good collaboration with multi-professional teams (ibid).

In line with the definition of WHO, the four keystones were formulated in SOU 2001:6 as a guideline for palliative nursing in Sweden. The keystones consist of alleviating suffering from symptoms and other distresses, multi-professional collaboration, improving communication with the patient and family and supporting the family during illness and after death. The four keystones' principles stress on respecting the patient's integration and autonomy, promoting equal care and strengthening relationships, cooperation between the patient and the palliative care providers.

Nurse's role and responsibilities in palliative home care

According to the International Council of Nursing (2012), nursing is defined as an integral part of the promotion of health, prevention of illness and the care of disabling and dying people. Nurses, therefore, comply with fundamental principles in The ICN Code of Ethics for Nurses (2012).

The registered nurses' role and competencies are described in the Swedish society of nursing (2017), which registered nurses having responsibilities to practice nursing care with respect for the patient's safety, integrity, and holistic needs. That means the registered nurses are responsible to lead and collaborate with multi-professional teams to promote person-centered care for the patient and the family. In Sweden, The Patient Safety Act (SFS 2010:659), The

Swedish Health and Medical Services Act (HSL) (SFS 1982:763) and other authority documents navigate nurses as well as other healthcare providers in practicing their profession.

Previous studies on palliative home-based care have emphasized much on nurses' roles to achieve effective practice, such as those capabilities of teamwork and communication are significant elements for nurses as a bridging coordinator between patients, families and interprofessional teams. In a systematic review on the role of the specialist palliative care community nurse, Mulvihill, Harrington and Robertson (2010) found that nurses need to clarify their roles and responsibilities, as well as have knowledge about other members' in the multidisciplinary teams because clarification of role is imperative and contributes into heightening interprofessional relationships to work effectively in coordinated health care.

On the issue of supporting families in palliative care at home, Lees, Mayland, West and Germaine (2014) have mentioned that nurses' compassion and dignity play a fundamental role in supporting patients and their families during difficult periods at the end of life. Also, the authors concluded that nurses' competence and skill have a strong effect on delivering quality care for patients at the end of life.

In dealing with emotional issues of patients and families, Tornøe, Danbolt, Kvigne, and Sørli (2015) found that nurses have an important role in spiritual and existential care through helping patient and families to achieve reconciliation that is reinforced by good mutual communication and the relationship between nurses, patients and their families.

PROBLEM STATEMENT

Palliative care nowadays is highlighted as a primary priority in the healthcare system. Demands of being cared for at home and dying at home are increasing in Sweden and the world. However, access to home-based palliative care is less than actual needs. In addition, there are other existential questions influencing patients' desires of where to be cared for and die. Therefore, the goal of promoting the quality of life for patients and families might not be achieved. On the other hand, in the home-based palliative care, the nurses work independently and have a central role as a link between multi-professional teams across the health system and between patients and families. Accordingly, that working environment may have a positive or negative impact on the nurses' practicing, which might influence patient-centered care and eventually the whole care chain. Obtaining a deep understanding of nurses' experiences is valuable and constructive in improving palliative homecare in both organizational and individual levels.

AIM

The aim of study was to describe nurses' experiences and perceptions in providing palliative care to adult patients at home.

METHOD

Design

To gain insight into nurses' experiences and perceptions in providing good care to palliative patients at home, a literature review was conducted on scientific research articles, which were relevant to the purpose of this study. The literature review is the most common thesis format within the healthcare and nursing science area and is a useful approach to compile relevant knowledge for practical applications in the future (Kristenssen, 2014). The flow of tasks in this study was based on Polit and Beck (2017), in order to conduct a high-quality literary review as shown in Figure 1.

Each step in the flow of tasks was explained in a sample, data collection and data analysis.

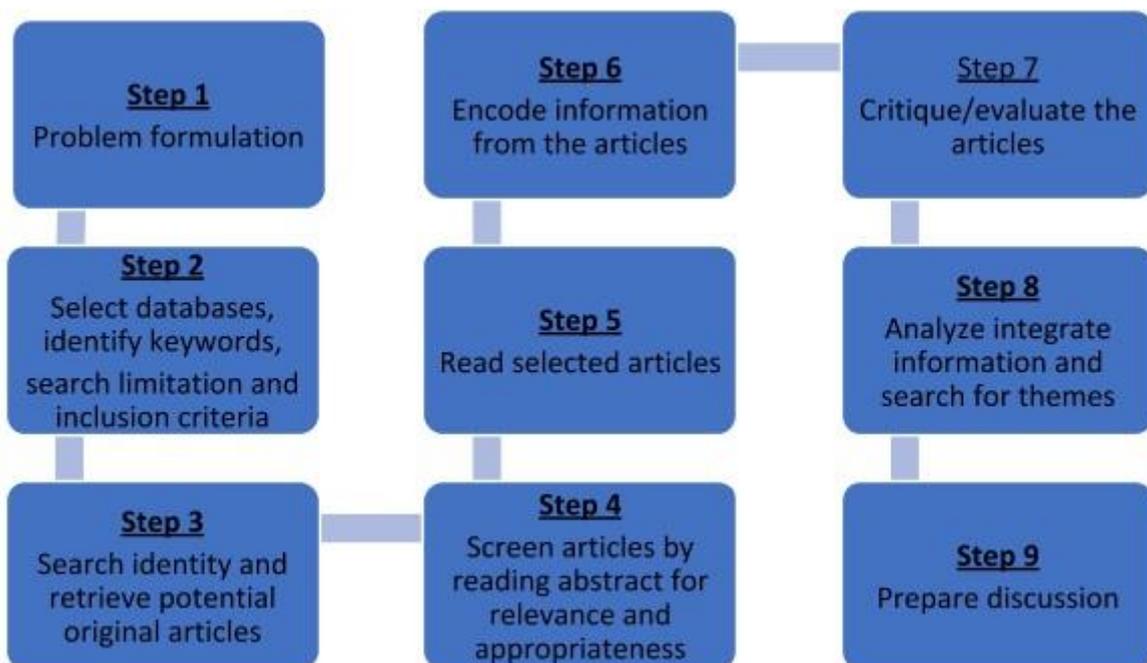


Figure 1. the flow of tasks in a literature review (Polit & Beck, 2017, p.89)

Sample

After the problem area for the study was decided, the background was outlined to match the focused problem (step one). Databases were selected and keywords, search limitations and inclusion criteria were identified (step two). Two different database search engines (CINAHL and MEDLINE), which cover a wide range of academic nursing research, were accessed, using the following keywords: challenges, death, dying, experiences, experiences*, home, home care, nurse, nurse*, palliative, palliative care, palliative home care and terminal. Polit and Beck (2017) describe that these databases have focused on nursing care.

Search limitations of articles were English language, peer reviewed, abstract, references, male and females aging from 18 years old upward, dating from 2009 to 2019. Articles were included in the literature review if the articles reported exploring nurses' experiences and perspectives that care for adult patients at their home, were original sources and academic journals, studied with qualitative methods, without a geographical limitation and had been ethically reviewed.

Data collection

The data collection began with database searches with the aim of obtaining relevant articles for the result. The potential scientific articles were retrieved from the databases CINAHL and MEDLINE by using the keywords and search limitations. Boolean operators such as "AND" and "OR" were used, and the truncation symbol was used to expand the search term. Irrelevant articles were discarded (step three).

All abstracts of the retrieved articles were read and screened for the relevance of the literature review with help of the inclusion criteria (step four). The relevant articles were read in full text (step five). Information from the relevant articles was encoded and noted for further evaluation (step six).

The relevant articles were evaluated and critiqued for their quality (step seven). The assessment checklist for qualitative research studies – patients' and clients' perspectives were used in evaluating (Swedish Agency for Health Technology Assessment and Assessment of Social Services [SBU], 2017). The quality assessment checklist is shown in Appendix 1. The quality assessment checklist was composed of close-ended questions that were answered with yes, no, unclear or not applicable. Overall assessment of study quality was divided in high, moderate and low. The relevant articles were evaluated individually and later discussed to reach consensus with criteria for the assessment of scientific quality as shown in Appendix 2 (SBU, 2017). The articles that were included in the result were considered with high to moderate quality.

In summary, the results of data collection were summarized in the table of data collection matrices as shown in Table 1. A total of 282 potential articles were retrieved in the search. Irrelevant articles were discarded. All abstracts of the retrieved articles were read. A total of 23 relevant articles were read in full text. Finally, 10 articles were included in the result of this literature review study. The relevant articles were examined by using an overall critique of a qualitative research report (Polit & Beck, 2017). Each article was conducted with ethical approval and respected ethical principles.

Table 1. Data collection matrices

Search date	Database	Keyword	Number of retrieved articles	Read abstracts	Read full text	Included in result
22 Jan 2020	CINAHL	Palliative home care AND nurses AND experiences	81	81	10	3
24 Jan 2020	MEDLINE	palliative home care OR terminal nurses AND experiences*	23	23	3	1
30 Jan 2020	CINAHL	palliative OR terminal AND home care AND nurs*	51	51	4	3
7 February 2020	CINAHL	Palliative AND dying AND home AND nurs*	47	47	1	1
18 February 2020	CINAHL	Palliative care AND death AND home AND nurses AND challenges	18	18	2	1
20 February 2020	CINAHL	palliative care AND home OR dying at home	62	62	3	1
	Total (articles)		282	282	23	10

Data analysis

Information from the articles included in the literature review results were analyzed, integrated and searched for themes for further discussion (step eight and nine). To understand the whole picture of each included article, the literature matrix table was formulated with "authors, title, purpose, method, participants and results" as shown in Appendix 3.

Each included article was read carefully and individually to gain an understanding and an overall picture. Next, the content of the articles was discussed in order to reach a consensus on what sentences were relevant to the aim of the literature study, and to sort out what was not.

All meaningful sentences were highlighted with different colors. Then they were collected and classified in respective groups, according to their similarity. The meaningful sentences, including a reference to the article, including a quote of participants from the results of each article were finally written down in a separate Word file.

The next step in the process was to code the information. Each long sentence was cut, removed and condensed into phrases or short sentences. The condensed data were analyzed and discussed together in order to code them into themes and subthemes. An example of analyzing data into themes and subthemes is shown in Table 2. According to Polit and Beck (2017), it is important to develop a coding scheme in order to carefully read data and identify concepts, and to reduce and convert them into manageable units in the data analysis.

Table 2. Analysis of data into themes and subthemes

Data	Condensed data	subthemes	themes
Some district nurses were unable to enter a patient’s inner, emotional dying world because there was insufficient time to develop a relationship. Patients were then unable to disclose their emotional world: “We had a patient who died, not that long ago, and she was absolutely terrified of dying” (Law, 2009, 2635).	Insufficient time to establish relationships and support emotional needs of patients.	Handling psychosocial and emotional issues	Supporting patients and their families

Ethical considerations

This literature study was conducted without plagiarism and distortion of results of data. No data were distorted to benefit the literature review. The results of the selected articles have been treated as objectively as possible. The articles were read individually and discussed together in order to minimize misinterpretation and prevent translation errors. Careful reference management in accordance with a given guideline was used to avoid the risk of plagiarism. Polit and Beck (2017) state that ethical conduct in research is to preserve high standards of integrity, and avoid such forms of research misconduct as plagiarism, fabrication of results or falsification of data.

In addition, this study used only scientific peer-reviewed articles. The included articles in the result of this study were shown to be reliable from an ethical perspective. Nine of ten articles were approved by the appropriate research ethics committee either from the university department or government organization. One of the ten articles stated it was not subject to regulations, and accordingly ethical approval was not needed. However, its study was conducted in line with ethical principles in which participants were self-determined, had given consent and received information about autonomy.

According to Kristensson (2014), a formal ethical permit is almost always required to carry out a planned study within medical research. Even those who are going to do a literature review need to consider ethical issues, as to determine whether the studies to be reviewed are ethically justifiable or not.

RESULTS

The results of the literature study are based on ten scientific articles and present the nurses' experiences and perceptions in providing palliative care to adult patients at home. Three themes and seven sub-themes have been identified during the result analysis and are presented in Table 3. The three themes comprise: supporting patients and their families, improving work efficiency and organizational factors. The seven subthemes are the following: handling psychosocial and emotional issues, strengthening empowerment, building relationships, interprofessional collaboration, self-development, workload and lack of time, and organization support.

Table 3. Results of the study are structured as bellows.

Themes	Subtheme
Supporting patients and their families	<ol style="list-style-type: none"> 1. Handling psychosocial and emotional issues. 2. Strengthen empowerment 3. Building relationships
Improving work efficiency	<ol style="list-style-type: none"> 1. Interprofessional collaboration 2. Self-development
Organisational factors	<ol style="list-style-type: none"> 1. Workload and lack of time 2. Organisation support

Supporting patients and their families

The first theme describes nurses' experiences in facing patients' and families' reactions in the last stage of life and nurses' different resolutions in supporting psychosocial aspects, enforcing empowerment as well as how to meet the patients' emotional needs.

Handling psychosocial and emotional issues

Most nurses in the studies mention the importance of supporting psychosocial and emotional issues of patients and families. They also express their sympathies, understandings and engagements to caring (Chong & Poon, 2011; Danielsen, Sand, Rosland & Førland, 2018; Funk, Stajduha & Purkis, 2010; Holmdahl, Sävenstedt and Imoni, 2014; Marchessault, Legault & Martinez, 2012; Tunnah, Jones & Johnstone, 2012). The nurses emphasize that they "sought to support the family through this difficult time to the best of their ability" (Marchessault et al., 2012, p.1). For instance, the nurses try to create a good environment, time flexibility, visiting plans to meet the patients' and families' wishes (Danielsen et al., 2018; Marchessault et al., 2012). On the other hand, several nurses feel unconfident to deal with the emotional reactions of the patients and the families when patients and families do not want, or have not been ready to accept that the patient's last stage is coming close (Marchessault et al., 2012). Some nurses even feel it difficult or uncomfortable to tell the truth about patients' actual illness status (Chong & Poon, 2011; Marchessault et al., 2012). The nurses have experiences of agony deciding of terminating home parenteral nutrition, which is attached to "a symbolic meaning connected to hope and life" (Holmdahl et al., 2014, p.93). Thus, terminating infusion is interpreted by the nurses as terminating hope of the patients and families. With providing care at the end of life to patients, who are discharged from hospital, nurses experience that the patients and families lack information about palliative home care

nurses' roles, as well as the palliative care system, which may result in raising unrealistic expectations, and consequently make the patients and families disappointed or worried when their expectations are not fulfilled (Jack & O'Brien, 2010). Furthermore, the nurses perceive that prolonged duration of illness and a lack of caring knowledge of the family are negative factors that impact the patients' psychology.

In palliative home care, the nurse has a bridging role by meeting the emotional needs of the patients, to maintain a balance between being ill and healthy at the last stage of life (Law, 2009). However, some nurses in the study have difficulty dealing with the patients' inner emotional dying world. Several nurses focus more on promoting physical care for the patients than emotional support. However, some other nurses emphasize the importance of helping patients to have a positive outlook and "try to help them adjust their life to living with this because they have to live until they die... And trying to be a bright spot...to lift their spirits" (Law, 2009, p. 2637). In summary, the nurses perceive that once nurses look at the emotional needs from patients' perspectives with honesty, it will create trust and facilitate psychological support to the patients

Strengthen empowerment

In some studies, the nurses perceive the importance of enhancing empowerment in a variety of ways, such as respecting decisions, control and promoting the independence of the patient and family (Funk et al., 2010; Marchessault et al., 2012; Stajduhar et al., 2010). The nurses' experiences of promoting empowerment are diverse. Some nurses in the study of Funk et al. (2010) assume that empowerment means respecting and accepting patients' and families' decisions. But in some cases, nurses experience frustration or powerlessness in relation to the families. Sometimes the nurses are forced to accept this in order to avoid a conflict and maintain the relationship. Several nurses in the studies believe that empowerment is to support the patients and families to make their own decisions and to take responsibilities. Furthermore, other nurses experience that empowerment is to support the families to take part in the care process, and to educate them to "perform caregiving tasks; indeed, many family caregivers welcome such opportunities" (Funk et al., 2010, s.72).

Building relationships

Nurses in several studies emphasize the importance of building relationships with patients and their families (Danielsen et al., 2018; Holmdahl et al., 2014; Marchessault et al., 2012; Stajduhar et al., 2010). Building these relationships creates confidence and trust, which facilitates nursing (Holmdahl et al., 2014). It also helps nurses in assessing patients' needs and families' capacity to take care of the patients. However, nurses should recognize boundaries and be professional (Stajduhar et al., 2010).

when you have made a connection with a client when it doesn't seem that other people have. And to be objective, there should be the recognition that this could be manipulation behavior by the client or, this should be a red flag, that the client is identifying that there's only one nurse that understands them. (Stajduhar et al., 2010, p.281)

Nurses consider those good relationships with patients' relatives essential in determining the success of palliative home care and they suggest establishing the relationship from the very first day (Danielsen et al., 2018).

Improving work efficiency

This theme presents nurses' experiences in collaborating with their colleagues and nurses' perceptions on their self development, which are considered as factors influencing work efficiency when providing palliative care.

Interprofessional collaboration

In palliative homecare, collaborating with physicians plays an important role in nurses' expertise. Many nurses express needs for more support from physicians in order to give good care for patients (Chong & Poon, 2011; Danielsen et al., 2018; Holmdahl et al., 2014; Mojapelo, Usher & Mills, 2016). However, several nurses mention that there always are obstacles when collaborating with physicians, for instance due to the hierarchy between the physicians and themselves, causing conflicts when making decisions on patients' situations, or physicians disregarding nurses' opinions.

Nurses state that they understand their patients' needs of pain relief, but doctors do not listen to their opinions (Chong & Poon, 2011; Mojapelo et al., 2016). Because of physicians' attitudes and those conflicts, nurses feel powerless when they have to follow physicians' orders (Chong & Poon, 2011) and feel unconfident in discussing with the physicians about patients' situations, because they feel that their opinions were not listened to, and feel powerless to advocate patients' health. A nurse gave the opinion that "since we are not palliative care nurses, we cannot argue much though we would like to advocate for our patients in pain. Because we do not want patients to suffer" (Mojapelo et al., 2016, s.1601).

Nurses also feel alone without support from physicians in making difficult decisions (Holmdahl, et al., 2014). The nurses need to establish collaboration with physicians, especially when patients' life expectancy is short. Furthermore, collaboration across the health system from the physicians in hospital and primary care and nurses is a crucial factor to enable that the health care system is driven smoothly, which is fundamental for the quality of palliative care (Danielsen et al., 2018).

Nurses express that they need to work in cooperation with their colleagues (Chong & Poon, 2011; Holmdahl, et al., 2014; Jack & O'Brien, 2010; Marchessault et al., 2012; Tunnah et al., 2012). Support from colleagues are needed, such as to reduce workload, to make conversation and interaction (Holmdahl, et al., 2014; Marchessault et al., 2012; Tunnah et al., 2012). Nurses feel that they work in a team and individually and it results in positive and negative ways

(Chong & Poon, 2011). However, isolation and difficulty in making decisions alone make nurses experience heavy load and agony (Holmdahl, et al., 2014; Marchessault et al., 2012).

Some nurses experience lack of communication and understanding between hospital nurses and home care district nurses that impacts patients' psychology when being discharged from hospital to home. For instance, several nurses give evidence that patients and families have unrealistic expectations and therefore misunderstand the district nurse's role because of inaccurate information about palliative home care provided by hospital nurses (Jack & O'brien, 2010).

Self-Development

The second theme presents the importance of knowledge and experience of nurses in palliative care. Nurses express that they have inadequate experience or limited knowledge (Chong & Poon, 2011; Danielsen et al., 2018; Law, 2009; Marchessault et al., 2012; Mojapelo et al., 2016). This is evidenced in new nurses who start out working with palliative care (Chong & Poon, 2011; Law, 2009). On the other hand, nurses with many years of experience also require growing knowledge and competence such as relevant courses in palliative care and meetings with other professions (Danielsen et al., 2018). The lack of knowledge in palliative care makes nurses feel unconfident in providing care (Mojapelo et al., 2016). They wish to have training and education about palliative care to facilitate and improve safety care to patients and their families (Danielsen et al., 2018; Marchessault et al., 2012).

The nature of nurses' emotional reflections emerges during the time of caring for the patients. (Chong & Poon, 2011; Marchessault et al., 2012). The nurses mentioned that palliative care helps them grow personally and professionally. In addition, the majority of nurses mention that palliative care encourages them to reflect upon their practice and contributes to their professional development (Marchessault et al., 2012).

Organizational factors

This theme describes factors, which impact nurses' providing quality care to the patient and family and nurses' thoughts about organizational culture and management system.

Workload and lack of time

Nurses' experience of heavy workload in providing care to patients and families is varied, but the common point is that nurses must carry out a lot of duties alone. For instance, the nurses have to implement a huge number of assignments such as taking care of patients and their families, collaborating with other professionals and doctors, educating patients' families, assessing needs of patients and families, handling with emotional issues, families' complex issues and transferring visits in long distances (Marchessault et al., 2012; Stajduhar et al., 2010; Tunnah et al., 2012). In providing care for dying patients, unpredictable needs always

arise and sometimes, that forces nurses to work overtime and to contribute unpaid extra work for patients and their families (Chong & Poon, 2011; Marchessault et al., 2012). Moreover, the workload is caused by a lack of staff, equipment, resources, equipment and time, which impacts nurses' caring plan and quality care (Marchessault et al., 2012; Mojapelo et al., 2016; Stajduhar et al., 2010).

Nurses describe their lack of time as a factor that prevents them from providing good quality care in alleviating pains. Nurses experience high workload demand and shortages of nurses which results in no time to be with patients and assess patients' pain. A nurse said that "my view is that we do not treat pain adequately because we do not have time to assess the patients" (Mojapelo et al., 2016, p.1601).

Nurses believe that lack of time is a restriction in establishing relationships with patients, which in turn reduces nurses' chance to get to understand the patients better (Law, 2009). The lack of time also affects their planning and decision making as nurses in the study express. They have to manage the time in order to balance caseloads, visit patients, drive, chart and make all the phone calls. It requires a lot of time to care for patients, especially high-need patients (Stajduhar et al., 2010).

Organizational support

Some studies show that the support of the organizations is meaningful. Although nurses have a variety of experiences about their organization's support, many nurses have positive points of view on their organization (Chong & Poon, 2011) and experience that "the organized support and professional guidance are needed" (Holmdahl et al., 2014, p.92). However, other nurses express that the organizations need to have a correct understanding of nurses' workload, to back up nurses in difficult situations (Marchessault et al., 2012; Stajduhar et al., 2010). In terms of psychological support, nurses express the need to have support from their organization, because their emotions are affected by patients' end-of-life experiences such as death (Marchessault et al., 2012).

DISCUSSION

Discussion of methods

The discussion of methods consists of evaluating the strengths, weaknesses, ethical considerations, things that could have been done differently and factors that may have affected the results are also mentioned in this discussion.

Kristensson (2014) states that literature reviews are commonly used in the thesis of nursing for gathering relevant and deep knowledge with the aim to find an answer to a specific clinical problem. In addition, Forsberg and Wengström (2016) explain that the purpose of the

literature review is to describe the state of knowledge within a certain area. This method contributes strength to the study because it brings together knowledge about palliative home care nurses' experiences and perceptions in providing care from different scientific articles.

The literature review study is conducted by following the flow of tasks in a literature review from Polit and Beck (2017). We consider our study to be strong because it has been carried out by a systematic method. According to Polit and Beck (2017), a high-quality study is conducted systematically and has no bias. Moreover, reliability refers to the accuracy and consistency of information obtained in a study.

All selected articles come exclusively from original resources and studies with a qualitative method. The studies with qualitative methods are suitable and appropriate for answering palliative home care nurses' experiences and perceptions in providing care. According to Polit and Beck (2017), the quality study examines human experiences, investigates phenomena through the collection of narrative materials but the quantitative study investigates phenomena that lend themselves to process measurement.

Keywords are used and cover all of the related subjects in searching for articles. The use of Boolean operators and truncation symbols are used so that all related articles are included in the research. CINALH and Medline are used because they are databases that contain articles with a focus in nursing care. Polit and Beck (2017) mention that CINALH and Medline are two frequently used databases where nursing research can be found. Appropriate keywords and databases give varieties in the results of the searches.

The included articles were all peer reviewed. This is to ensure the quality of articles that are selected. It also increases the validity of this literature review study. Polit and Beck (2017) describe the validity of the peer-reviewed studies because the studies are reviewed thoroughly by independent reviewers and refer to validity as the soundness of the study's evidence.

The age of the patients is limited to 18 years and upward. Children and young patients are not taken into account, because we wanted to limit the scope of the study, and nurses' experiences and perceptions of care are also likely to differ from adult patients. The time span of the selected articles is limited to 2009 – 2019, to ensure that the result of the study is based on current research in the field. Different keywords and combinations of keywords are used to increase possibility in finding articles.

Design, sample and data collection in this literature review study are described in detail step by step, so that it can be followed by other researchers. Polit and Beck (2017) express that reliability depends on the methods used to measure the result and the result's accuracy and consistency.

In the data analysis, the included articles were analyzed by a systematic methodology, which were described in detail in the method analysis. To avoid misinterpreting the results, we read

the articles several times to gain an understanding, analyzed the results individually and then discussed them. We always reminded ourselves of the aim of this literature study.

SBU's assessment checklist for qualitative research studies and its criteria for assessment are used with the included articles in the result (SBU, 2019). SBU (2019) is an independent national authority that assesses health care and social service interventions. Its assessments are thorough and rigorous. The included articles in the result are of high and medium-high quality. Therefore, the quality assessment of the articles increases the validity of this literature study. Polit and Beck (2017) explain that the validity is achieved when the study's results are unbiased and well-grounded.

The literature study was conducted by two nursing students. The included articles were first to be read individually to get a good understanding and to find answers relevant to the aim of this study. The key findings were discussed between the two authors to avoid misinterpretation and were later included in the result. This approach is believed to strengthen the validity of the literature review. Polit and Beck (2017) state that the absence of bias and hence high credibility can be achieved when systematic rules for evaluating information by triangulating the interpretations of multiple researchers in the team are followed.

Transferability is the quality that enables findings to be transferred or have applicability in other settings or groups of settings. To improve transferability, researchers provide descriptive information about the context of their studies (Polit & Beck, 2017). In this literature review study, the authors have clearly described their methods in designing, sampling, data collecting, and data analyzing. In addition, the data is collected from studies conducted in different countries, which provide rich information of nurses' experiences in palliative home care.

Considering ethical aspects, all articles followed ethical principles and had obtained ethical approval. Polit and Beck (2017) state that conducting ethical reasoning is fundamental in all modern research. The selected articles were studied without changing or distorting the text to benefit the literature review. Besides, the authors do not have any personal interest related to the results of the thesis. Ethical consideration is considered to be the strength of this study. We did not encounter any ethical difficulties during the research process.

A clear common goal and good collaboration between the authors is also seen as an advantage in a literature review. Disagreements between the authors were resolved through open dialogues and discussions between themselves. Open communication and friendly atmosphere during the work make the authors feel that they could express their views freely throughout the process. The distribution of work was perceived to be fair. The authors used an online document to make the work material accessible to both. Scheduled meetings were held.

A weakness in this study was a limitation of the number of articles found in the databases, because some retrieved articles were not available in full text because of limited access. However, we could find enough articles that answered to the aim of this study. Some articles

that were found describe other professions' perspectives, but we selected only those from the perspective of nurses.

We are aware that our preconceptions may affect the result, even though we try to be as objective as possible. These preconceptions come from our own life experiences, professional experience, nursing education and previous knowledge of the area to be studied. Polit and Beck (2017) describe one of the factors that results in bias in a study is the researcher's subjectivity. Researchers may misinterpret information in the direction of their expectation or in line with their own experiences.

Things that could have been done differently

With more time we could have made a more systematic literature review, in order to collect more data relevant to the study, which would have strengthened the results. It would have been possible to use qualitative methods such as interviewing nurses, instead of only a literature review.

Factors that may have affected the results

Factors that may have affected the results of this literature review study are databases, language scope, period and study method. If we had more databases, more relevant articles could have been found and thus the result could either have been the same or different. Limitation of time is a factor that restricted us from finding relevant articles for the study. We only used articles in the English language and a time span of eleven years. Articles in different languages such as Swedish, Thai or Vietnamese, or articles older than eleven years may have contributed to more important findings.

Discussion of results

The purpose of the study is to explore nurses' experiences and perceptions in providing palliative care to patients at home. The results found are presented in three main themes: the nurses' experiences in supporting patients and families, in improving work efficiency and organizational factors. Seven sub-themes are demonstrated to clarify the nurses' experiences and perceptions.

Challenges in emotional support and promoting relationships

In supporting patients and their families, the nurses often experience hard times when they must tell the truth about patients' illness situations since the nurses do not want to convey bad news or bear a burden of diminishing hope from patients and their families. Consequently, the nurses often feel unconfident or uncomfortable when facing strong reactions such as denial, anger, and depression from the patients and families (Chong & Poon, 2011; Marchessault et al., 2012; Holmdahl et al., 2014). It is understandable to the nurses' sense when their goal to

prolong life is not achieved as expected that leads to feeling like a failure and bearing responsibility in nurses. Regarding truth-telling, many healthcare staff argue that withholding the truth is to protect patients from negative impacts such as diminished hope. On the contrary, the protection of healthcare providers from discomfort is a reason for withholding information from patients (Pergert and Lützen, 2012). Hence, healthcare providers need to acknowledge that truth-telling is to respect patients' and families' autonomy, physical and psychological benefit, since, truth-telling is an approach to help patients and families to prepare, cope with the situation (ibid). Therefore, in this case, good communication and being honestly interested in building relationships with the patient and the family is a significant element in conveying both the 'truth' and hope (ibid). As SOU 2001:6 and WHO (2016) mention that improving communication is one of key principles in providing quality palliative care to patients and their families.

Providing emotional support to the patients at the end of life is a challenge for many nurses, especially junior nurses with limited experiences. In order to obtain deep understandings about patients' emotional needs, many nurses found it challenging when the patients are not open and do not disclose their fear (Law, 2009). To explain for the patients' feelings demonstrated, some previous reviews on psychological issues associated with end-stage cancer patients pointed out that the sufferings that the cancer patients bear inside manifested itself through powerlessness, loneliness, isolation and they very rarely expressed their sufferings to care professionals (Borg & Noble, 2010). Furthermore, many patients have negative self-images because of the dependency and feeling of burden for the families, which in turn might influence their choice of being cared for and dying at home as Nilsson et al. (2017) have explored. Therefore, it is important if nurses and other care providers understand the nature of suffering and try to identify what is meaningful in life to patients and their families and enforce patient empowerment (Borg & Noble, 2010). Lees et al. (2014) have also emphasized that nurses' compassion and dignity play a fundamental role in supporting patients. Accordingly, respecting a patient's self-identity, self-esteem, self-management of illness symptoms, involving patients in decision – making is attributing to strengthening empowerment, which is fundamental in emotional support (Wakefield et al., 2018).

Regarding supporting families, the nurses emphasized on improving empowerment to the families through respecting families' independence and decisions, as well as educating families in promoting how to provide care to the patients (Funk et al., 2010; Marchessault et al., 2012; Stajduhar et al., 2010). However, psychological support to the families was not focused much by the nurses in this present study. As WHO (2016) affirmed that the palliative care approach is to alleviate distress not only for the patients but also for family members through practical and psychological support. Indeed, the life situation of the family carer is chaotic when living with the patient with incurable illness in the transition period. Consequently, the family's psychology is influenced by the patient's mood, illness status (Janze & Henriksson, 2014). Therefore, Handsaker, Dempsey and Fabby (2012) suggested that it is necessary to identify early symptoms of distress equally to both patients and families.

In addition, the family's psychological distress can influence the patient's preference of home death because of the feeling of burden and anxiety as Nilsson et al (2017) have mentioned.

In establishing relationships with patients and families, the nurses affirm that good relationships facilitate their providing care (Danielsen et al., 2018; Holmdahl et al., 2014; Marchessault et al., 2012; Stajduhar et al., 2010). However, several nurses think that it is necessary to set up boundaries between patient and family - professional relationships (Stajduhar et al., 2010). In a qualitative study, Funk, Peters and Roger (2017) explored that many staff mentioned that it was important to be cheerful, friendly, and make light conversations with patients and families. Funk et al. (2017) implies that by reducing professional distance and promoting a sense of normalcy in the relationship between healthcare providers and the patient and family help not only break up tensions but also to encourage emotional openness in the patient and family. Hence, being honest, trustworthy with sincere respect were believed to be fundamental elements to promote security, discharge fear and worry (ibid).

Collaborations with multi - professional team

Findings in the study indicate common barriers in interprofessional collaboration between nurses and general physicians and other colleagues. These barriers are reasons for nurses' stress and influence providing care to patients and families (Chong & Poon, 2011; Danielsen et al., 2018; Holmdahl et al., 2014; Mojapelo, Usher & Mills, 2016). These findings are directly in line with previous findings of Shawa, Kearney, Glens and McKay (2016). Therefore, it is suggested that in palliative care, affirming a common goal, sharing responsibilities and experiences in the team play an important role in promoting quality of care to the patients and families (Shawa et al., 2016). Furthermore, sharing knowledge, mutual trust, and emotional support are essential conditions to build up an effective teamwork (ibid). In palliative home care, misunderstandings and different points of view can occur in collaboration between nurses and general physicians. Mertens et al. (2019) have found that factors that have negative impacts on fluid teams are hierarchy, non-open communication, time restriction and lack of expertise. Conversely, positive factors can help to establish a good relationship, such as approachable, knowing each other, open communication and absence of hierarchy. Thus, to build up an effective interprofessional team, it requires contributions from different professionals. This is in agreement with evidence that Mulvihill et al. (2010) have found that in order to maintain an effective collaboration in the palliative care team, nurses need to acknowledge their own roles and responsibilities, as well as other professions' roles in the team. Hence, strengthening the interprofessional team in palliative care is an imperative and essential factor to quality palliative care.

Findings in this study indicate that the nurses are stressed by workload with restricted times with a load of duties without support from the management system. In the similarity, a prior study found evidence that palliative care nurses always work in stressful situations (Peters et al., 2012). Stressor for palliative care nurses are, for instance, related to inadequate resources, unrealistic expectations of the organization, especially, high workloads are a major

contributor to stress. To solve stress for the nurses in palliative care, it needs to improve managing systems, organizational facilities and reinforce human resources. In addition, Törnquist, Andersson and Edberg (2012) have reported registered nurses' narratives about needing regular and systematic supervision. That means management mechanisms are crucial for nurses to maintain motivation and strength to dedicate to working.

Besides requirements on enhancing collaboration with other colleagues, nurses are required to upgrade knowledge about palliative care, which includes competencies in pain relief, psychological distress and improving communication skills to meet patients' and families' emotional needs (SOU 2001: 6 & WHO, 2016). As Tornøe, Danbolt, Kvigne, and Sørli (2015) have mentioned that nurses have a crucial role in spiritual and existential care for patients and families. Hence, in order to provide palliative care holistically, the nurse needs to have a comprehensive knowledge in a wide range and have compassion, engagement in caring. The nurses further need to be open to exchange knowledge, experiences with colleagues to improve skills and competencies. However, organizational support is a crucial element to help the nurse to upgrade their competences and skills.

Concerning nurses' emotions in caring for dying patients, Wilson and Kirshbaum (2011) have found in a reviewed study that working with grief and bereavement in palliative care can put healthcare staff in touch with their losses and enhance mutual empathy and identification. The study also shows that in grief support and education for healthcare staff, the organization's role is highly appreciated.

Conclusion

The results in the study align with the aim is to describe nurses' experiences and perceptions in providing palliative care at patients' homes. The study has reviewed ten original articles with qualitative studies. The results found are nurses' experiences in supporting patients and families in psychosocial and psychological issues in difficult stages in palliative care. The difficult situations nurses have experienced help the nurses in developing personally and professionally. The experiences nurses have gone through, such as, relationships between nurses and patients and their families, experiences in interprofessional collaborations, stressor of workload, lacking time and organizational support are general challenges for palliative home care nurses.

Through this study, we find that the nurse's role in palliative home care nursing is significant. Therefore, the nurses need to improve comprehensive knowledge about palliative home care, such as communication skills, teamwork skills and improving other knowledge to meet the psychological needs of the patient and family. However, in order to improve the quality of life for patients and their families it needs contributions from different multi-professional teams and an effective management system.

Clinical significance

With this reviewed study, we hopefully can draw the attention of healthcare organizations, new graduate nurses and nurse education to develop research to obtain deeper insights into how nurses' experiences and perceptions in providing palliative care to adult patients at home.

This study can contribute to upgrading management systems in making plans to facilitate nurses' working conditions and professional knowledge. Through developing professional skills, particularly, communication skills, breakpoint conversation, person-centered and holistic palliative home care, the nurse can become more confident in working. In addition, organizations need to facilitate working conditions that include promoting working environments, to support the nurse's psychological issues and to develop effective caring plans between interprofessional teams.

We suggest organizing reflective forums or conferences for the healthcare team to exchange experiences, strengthening collaborations and creating greater understanding among professions. These reflections can contribute to enhancing relationships with patients and their relatives.

The study can also be valuable information for inexperienced and newly graduated nurses. They can gain a greater understanding of palliative home care. We believe that inexperienced and newly graduated nurses should be given longer introductions and mentoring to adapt and meet the demands and challenges in palliative home care. Lastly, the study can also contribute to the current nurse education on what should be emphasized in palliative home care.

Suggestion for further research

Researchers need to continue conducting further research to determine the factors that help nurses improve coping strategies in dealing with psychosocial and spiritual questions, for example, why interprofessional team collaboration fails in palliative home care and what routines and working methods contribute to better collaboration. Additional research is how health care organizations face current challenges and how they can improve palliative home care. All suggested for further research are to help improve palliative home care in the future.

Authors contribution

Both nursing students contributed to all parts of this literature review study.

REFERENCES

Borg, L., & Noble, H. (2010). Psychological issues associated with end-stage cancer patients. *End of life care journal*, 4(2), 8-12.

*Chong, P.H., & Poon, W.H. (2011). The lived experience of palliative homecare nurses in Singapore. *Singapore Medical Journal*, 52(3), 151-157.

*Danielsen, B.V., Sand, A.M., Rosland, J.H., & Førland, O. (2018). Experiences and challenges of home care nurses and general practitioners in home - based palliative care: a qualitative study. *BMC Palliative Care*, 17(95), 1-13. doi:10.1186/s12904-018-0350-0

Forsberg, C., & Wengström, Y. (2016). *Att göra systematiska litteraturstudier: Värdering, analys och presentation av omvårdnadsforskning*. Stockholm: Natur & Kultur.

*Funk, L.M., Stajduhar, K.I., & Purkis, M.E. (2010). An exploration of empowerment discourse within home-care nurses' accounts of practice. *Nursing Inquiry*, 18, 66–76. doi:10.1111/j.1440-1800.2010.00502.x

Funk, L.M., Peters, S., & Roger, K.S. (2017). Caring about dying persons and their families: Interpretation, practice and emotional labour. *Health & Social Care in the Community*, 26(4), 519-526. doi:10.1111/hsc.12559

Handsaker, S., Dempsey, L., & Fabby, C. (2012). Identifying and treating depression at the end of life and among the bereaved. *International Journal of Palliative Nursing*, 18(2), 91-97.

*Holmdahl, S., Sävenstedt, S., & Imoni, R.M. (2014). Parenteral nutrition in home-based palliative care: Swedish district nurses experiences. *Scandinavian Journal of Caring Sciences*, 28, 89–96. doi:10.1111/scs.12038

International Council of Nurse (2012). *Nursing definition*. Retrieved 11 february, 2020 from <https://www.icn.ch/nursing-policy/nursing-definitions>

International Council of Nurse (2012). *The ICN Code of Ethics for Nurses*. Retrieved 11 february, 2020 from https://www.icn.ch/sites/default/files/inline-files/2012_ICN_Codeofethicsfornurses_%20eng.pdf

*Jack, B., & O'Brien, M. (2010). Dying at home: community nurses' views on the impact of informal carers on cancer patients' place of death. *European Journal of Cancer Care*, 19(5), 636-642. doi:10.1111/j.1365-2354.2009.01103.x

Janze, A., & Henriksson, A. (2014). Preparing for palliative caregiving as a transition in the awareness of death: family carer experiences. *International Journal of Palliative Nursing*, 20(10), 494-501. doi:10.12968/ijpn.2014.20.10.494

Kristensson, J. (2014). *Handbok i uppsatsskrivande och forskningsmetodik: för studenter inom hälso- och vårdvetenskap*. Stockholm: Natur & Kultur.

*Law, R. (2009). 'Bridging worlds': meeting the emotional needs of dying patients. *Journal of Advanced Nursing*, 65(12), 2630–2641. doi:10.1111/j.1365-2648.2009.05126.x

Lees, C., Mayland, C., West, A., & Germaine, A. (2014). Quality of end-of-life care for those who die at home: views and experiences of bereaved relatives and carers. *International Journal of Palliative Nursing*, 20(2), 63-67.

*Marchessault, J., Legault, A., & Martinez, A.M. (2012). Providing in-home palliative care within a generalist caseload: a chance for nurses to reflect on life and death. *International Journal of Palliative Nursing*. 18(3), 135-141.

Melin-Johansson, C., Axelsson, B., Gaston-Johansson, F., & Danielson, E. (2010). Significant improvement in quality of life of patients with incurable cancer after designation to a palliative homecare team. *European Journal of Cancer Care*, 19(2), 243-250. doi:10.1111/j.1365-2354.2008.01017.x

Mertens, F., De Gendt, A., Deveugele, M., Van Hecke, A., & Pype, P. (2019). Interprofessional collaboration within fluid teams: Community nurses' experiences with palliative home care. *Journal of Clinical Nursing* 28(19/20): 3680-3690. doi:10.1111/jocn.14969

*Mojapelo, T.D., Usher, K., & Mills, J. (2016). Effective pain management as part of palliative care for persons living with HIV/AIDS in a developing country: a qualitative study. *Journal of Clinical Nursing*, 25, 1598–1605. doi:10.1111/jocn.13145

Mulvihill, C., Harrington, A., & Robertson, A. (2010). A literature review of the role of the specialist palliative care community nurse. *International Journal of Palliative Nursing*, 16(4), 163-169.

Nilsson, J., Blomberg, C., Holgersson, G., Carlsson, T., Bergqvist, M., & Bergström, S. (2017). End-of-life care: Where do cancer patients want to die? A systematic review. *Asia-Pacific journal clinical oncology*, 13(6), 356-364. doi:10.1111/ajco.12678.

O'Brien, M., & Jack, B. (2010). Barriers to dying at home: the impact of poor co-ordination of community service provision for patients with cancer. *Health & Social Care in the Community*, 18(4), 337-345. doi:10.1111/j.1365-2524.2009.00897.x

Pergert, P., & Lützen, K. (2012). Balancing truth-telling in the preservation of hope: A relational ethics approach. *Nursing Ethics* 19(1), 21–29. doi:10.1177/0969733011418551

Peters, L., Cant, R., Sellick, K., O'Connor, M., Susan, L., & Burney, S. (2012). Is work stress in palliative care nurses a cause for concern? A literature review. *International Journal of Palliative Nursing*, 18(11), 561-567.

Polit, D.F., & Beck, C.T. (2017). *Nursing research: generating and assessing evidence for nursing practice* (10th ed.). Philadelphia: Wolters Kluwer.

SFS 1982:763. Hälso- och sjukvårdslagen. Stockholm: Socialdepartementet.

SFS 2010:659. Patientsäkerhetslag. Stockholm: Socialdepartementet.

Shawa, J., Kearney, C., Glenss, B., & McKay, S. (2016). Interprofessional team building in the palliative home care setting: Use of a conceptual framework to inform a pilot evaluation. *Journal of Interprofessional Care*, 30(2), 262-264. doi:10.3109/13561820.2015.1115395

SOU 2001:6. Döden angår oss alla- Värdig vård vid livets slut. (Slutbetänkande). Statens offentliga utredningar (SOU). Stockholm: Socialdepartementet.

SOU 2011:55. Kommunaliserad hemsjukvård. Betänkande av utredningen. En nationell samordnare för hemsjukvård. Stockholm: Socialdepartementet.

*Stajduhar, K.I., Funk, L., Roberts, D., McLeod, B., Cloutier-Fisher, D., Wilkinson, C. & Purkis, M.E. (2010). Home care nurses' decisions about the need for and amount of service at the end of life, *Journal of advanced nursing*, 67(2),276-86. doi:10.1111/j.1365-2648.2010.05491.x.

Swedish agency for health technology assessment and assessment of social services. (2017). *Kriterier för bedömning av vetenskaplig kvalitet [Criteria for assessment of scientific quality]*. Retrieved 18 february, 2020, from Swedish agency for health technology assessment and assessment of social services, https://www.sbu.se/globalassets/ebm/metodbok/sbushandbok_kapitel08.pdf?fbclid=IwAR2Sz b7vXhPlrTFoH5sxp1yN-IpB6zQ0nHBmKh3vhuPdu71Y71IUvkFBMmQ

Swedish agency for health technology assessment and assessment of social services. (2017). *Quality assessment checklist for qualitative research studies – patients' and clients' perspectives*. Retrieved 18 february, 2020, from Swedish agency for health technology assessment and assessment of social services, https://www.sbu.se/contentassets/14570b8112c5464cbb2c256c11674025/appendix-5-general_description_methods_used_qualitative_research.pdf

Swedish agency for health technology assessment and assessment of social services. (2019). *About SBU*. Retrieved 20 february, 2020, from Swedish agency for health technology assessment and assessment of social services, <https://www.sbu.se/en/about-sbu/>

The Nation Board of Health and Welfare. (2018). *Palliative care - illustration and concrete explanations of definitions*. Retrieved 7 february, 2020, from The Nation Board of Health and Welfare, <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2018-8-6.pdf>

The Swedish Council for Palliative Care. (2010). *Palliativguiden - vägvisaren till lindrande vård*. Retrieved 7 february, 2020, from The Swedish Council for Palliative Care, <https://www.nrpv.se/wp-content/uploads/2012/10/Palliativguiden-2010-sid-1-18.pdf>

The Swedish Society of Nursing. (2017). *Kompetensbeskrivning för legitimerad sjuksköterska*. Retrieved 18 February, 2020 from <https://www.swenurse.se/globalassets/01-svensk-sjukskoterskeforening/publikationer-svensk-sjukskoterskeforening/kompetensbeskrivningar-publikationer/kompetensbeskrivning-legitimerad-sjukskoterska-2017-for-webb.pdf>

The World Health Organisation. (2016). *Planning and implementing palliative care services: a guide for programme managers*. Retrieved 7 february, 2020, from The World Health Organisation, <https://apps.who.int/iris/bitstream/handle/10665/250584/9789241565417-eng.pdf?sequence=1&isAllowed=y>

Tornøe, K.A., Danbolt, L.J., Kvigne, K., & Sørli, V. (2015). The challenge of consolation: nurses' experiences with spiritual and existential care for the dying-a phenomenological hermeneutical study. *BMC Nursing*, 14(62), 1-12. doi:10.1186/s12912-015-0114-6.

*Tunnah, K., Jones, A., & Johnstone, R. (2012). Stress in hospice at home nurses: a qualitative study of their experiences of their work and wellbeing. *International Journal of Palliative Nursing*, 18 (6), 283-289. doi:10.12968/ijpn.2012.18.6.283

Törnquist, A., Andersson, M., & Edberg, A.K. (2012). In search of legitimacy – registered nurses' experience of providing palliative care in a municipal context. *Scandinavian Journal of Caring Sciences*, 27, 651–658. doi:10.1111/j.1471-6712.2012.01074.x

Wakefield, D., Bayly, J., Selman, L.E., Firth, A.M., Higginson, I.J., & Murtagh, F.E.M. (2018). Patient empowerment, what does it mean for adults in the advanced stages of a life-limiting illness: A systematic review using critical interpretive synthesis. *Palliative Medicine*, 32(8), 1288 –1304. doi:10.1177/0269216318783919

Wilson, J., & Kirshbaum, M. (2011). Effects of patient death on nursing staff: a literature review. *British Journal of Nursing*, 20(9), 559-563.

APPENDIX

Appendix I. Quality assessment checklist for qualitative research studies – patients’ and clients’ perspectives

SBU’s check-list for quality assessment is an adaptation based on previously published material [1,2].

Author: _____ Year: _____ Identification no: _____

Overall assessment of study quality:

High Moderate Low

Instructions:

- "Unclear" is used when the information is not retrievable from the paper.
- N/A (not applicable) is used when the question is not relevant.
- There are comments of clarification to some of the questions. These are found at the back of this document.

Yes No Unclear N/A

1. Aim

a) Is the study based on a well-defined statement of the problem or a well-formulated research question?

Comments on aims, discussion of problem, research questions, etc

	Yes	No	Unclear	N/A
2. Sample selection				
a) Is the sample selection relevant?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Is the method of selection clearly described?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Is the context clearly described?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Is a relevant ethical discussion included?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Is the relationship between the researcher and the selected sample clearly described?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments on sample selection, patient characteristics, context, etc				
3. Data collection				
a) Is the data collection procedure clearly described?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Is the data collection relevant?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Has data saturation been achieved?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Has the researcher managed his own pre-understanding in relation to the data collection?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments on data collection, data saturation etc				
4. Analysis				
a) Is the analysis clearly described?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Is the method of analysis relevant in relation to the data collection procedure?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Has saturation in terms of analysis been achieved?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Has the researcher managed his own pre-understanding in relation to the analysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments on method of analysis, saturation etc				
5. Results				
a) Are the results logical?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Are the results comprehensible?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Are the results clearly described?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Are the results presented in relation to a theoretical framework?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Is a hypothesis, theory or model generated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Are the results transferable to a similar setting (context)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Are the results transferable to a different setting (context)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments on the clarity, adequacy etc of the results				

Appendix II. Criteria for assessment of scientific quality

High quality	Medium high quality	Low quality
Clearly described context (context)	Context not described clear (context)	Clearly described context (context)
Well-defined question	Issue not clearly described	Vaguely defined question
Well-written selection process, data collection, Transcription process and method of analysis	Some ambiguities in the description of the selection process, data collection, Transcription process and method of analysis	Unclear description selection, data collection, trans Transcription process and method of analysis
Documented methodology awareness	Some ambiguities in it documented methodological awareness	Poorly documented methodical awareness
Systematic, rigorous presentation of data	Unclear in the presentation of data	Unsystematic and minor rigorous data reporting
Anchor of interpretations in data detected	Some ambiguities though interpretations anchoring in data	Unclear anchoring of the interpretations in the data
Discussion of the interpretations credibility and reliability	Some ambiguities though the credibility of the interpretations and reliability	Discussion of the interpretations credibility and reliability is defective or missing
Contextualization of results in previous research	Unclear contextualization of results in previous research	Contextualization of results previous research is lacking or is undeveloped
Implications for relevant practice well formulated	Implications for relevant internships are not clearly described	Implications for relevant practice is lacking or unclear

Appendix III. Literature review matrices

Authors	Title	Purpose	Method	Participants	Result	Assessment
Chong and Poon (2011)	The lived experience of palliative homecare nurses in Singapore	The aim of this study was to understand homecare nurses in the context of the work that they perform	Hermeneutic phenomenology The study used purposeful sampling in which participants were selected based on the specific knowledge they possessed and their willingness to share.	Focus group discussion. 10 palliative home-care nurses (Singapore)	Nurses' experience: stress, hierarchy influences teamwork feeling of isolation at work. Emotional burden of care. Non- continuity care can cause problems for the palliative home care nurses.	Medium high quality
Danielsen, Sand, Rosland & Førland (2018)	Experiences and challenges of home care nurses and general practitioners in home - based palliative care – a qualitative study	To achieve more insight, through home care nurses and general practitioners, of conditions that facilitate or hamper more time at home and more home deaths for patients with terminal disease and short life expectancy.	Four focus groups and semi-structured question guides	19 participants: 7 home care nurses, 4 nurse assistance and 8 general practitioners (Norway)	There should be safer discharge routines and planning when hospitals transfer patients with terminal disease to their homes, good initial interdisciplinary collaboration meeting, supporting from family and extensive mentoring of care.	Medium high quality

Authors	Title	Purpose	Method	Participants	Result	Assessment
Funk, Stajduha and Purkis (2010)	An exploration of empowerment discourse of home-care nurses' account practice	To examine how home-care nurses talk about their practices with clients and families, the ways in which empowerment discourse operates in accounts of practice.	Interview 27 home-care nurses between 2006-2008. Analyzing nurses' perceptions about "empowerment"	27 home-care nurses. Nurses' characteristics are briefed in detail. (Canada)	Various experiences, perceptions of home-care nurses (HCN) about empowerment discourse. Nurses have positive attitudes about promoting empowerment. Nurses meet ethical dilemmas in handling "empowerment".	High quality
Holmdahl, Sävenstedt and Imoni (2014)	Parenteral nutrition in home-based palliative care: Swedish district nurses experiences	To describe the experiences of district nurses in caring for patients with home parenteral nutrition (HPN) in palliative care.	Semi-structured interviews	12 district nurses (Sweden)	There are three categories: all focus is on the infusion, alone without support and confidence in the relationship.	High quality

Authors	Title	Purpose	Method	Participants	Result	Assessment
Jack and O'Brien. (2010)	Dying at home: community nurses' views on the impact of informal carers on cancer patients' place of death	The aim of the study was to explore district nurses and community specialist palliative care nurses' perceptions and experiences of the factors that influenced hospital admission of patients with cancer in the final stages of life.	Semi-structured interview schedule to guide the discussion	8 community specialist palliative care nurses and 11 district nurses (United Kingdom)	Informal carers are burden for community nurses in providing care to the patients. Lacking ability, knowledge can be reason that influences patients' preferences of place of death.	Medium high quality
Law (2009)	'Bridging worlds': meeting the emotional needs of dying patients	To develop a grounded theory to explain how district nurses meet the emotional needs of dying patients in the community.	A 'classic' grounded theory study. Unstructured observations and semi-structured interviews	9 district nurses, nine patients and four family carers (United Kingdom)	Dying patients experience the dying world and the outside world. District nurses try to meet patients' emotional needs through bridging the dying and outside world. Nurses' experiences in encouraging patients to maintain connections with outside world.	High quality

Authors	Title	Purpose	Method	Participants	Result	Assessment
Marchessault, Legault and Martinez (2012)	Providing in-home palliative care within a generalist caseload: a chance for nurses to reflect on life and death	To ascertain and describe non-specialized homecare nurses' experiences of providing palliative care within a generalist caseload.	A Heideggerian interpretive phenomenological methodology Unstructured individual interviews in order to gain access to the comprehensive experiences of the nurses.	8 home- care nurses (Canada)	Nurses have positive attitudes in supporting the patients and their families. Have difficulty with the family's reaction and to inform patients about their health conditions. Dealing with the complexity of in-home palliative care Handling personal emotion by death and experiencing a variety of emotions intensely and receiving support.	Medium high quality

Authors	Title	Purpose	Method	Participants	Result	Assessment
Mojapelo, Usher and Mills (2016)	Effective pain management as part of palliative care for persons living with HIV/AIDS in a developing country: a qualitative study	To explore and understand nurses' experiences of managing pain for persons living with human immune virus/ acquired immune deficiency syndrome receiving palliative care at home in.	Semi-structured interviews	13 nurses who provide home-based care including palliative care (Botswana)	Nurses' experiences barriers that hinder nurses from advocating for patients. Nurses' concerning about doctors' attitudes in managing pain for patients at home.	Medium high quality
Stajduhar, Funk, Roberts, McLeod, Cloutier-Fisher, Wilkinson and Purkis (2010)	Home care nurses' decisions about the need for and amount of service at the end of life	To explore HCNs' decision-making about the need for and amount of service by clients and families at the end of life, through an analysis of their accounts of these decisions. HCNs' decisions are conceptualized as contextual: embedded in broader contexts that directly and indirectly affect access decisions.	Data collection was carried out with two interviewing phases. - General descriptions about daily decision making - Depp interview to get broad understanding about how nurses' perceptions	29 nurses were interviewed 27 nurses took part in full interview (Canada)	The study emphasizes factors that influence nurses' decision making: Different attitudes about relationships with clients and families. Workload stress and home care nursing recourse.	Medium high quality

Authors	Title	Purpose	Method	Participants	Result	Assessment
Tunnah, Jones and Johnstone (2012)	Stress in hospice at home nurses: a qualitative study of their experiences of their work and wellbeing.	To explore the feelings and experiences of hospice at home nurses when providing palliative nursing care for patients in the community. The study sought to identify key issues that contribute toward stress in hospice at home nurses working in primary care.	Semi-structured interview.	10 nurses (United Kingdom)	There are four superordinate themes: job satisfaction identified as an important determinant of the nurses' stress levels, stressors such as conflict with colleagues and difficulty communicating with the GPs, coping strategies to switch off after work and support from colleagues.	High quality