



# **Roles and Outcomes of Advanced Nurse Practitioner Providing Palliative Care for Neurological Patients - A scoping review**

Master's thesis

CARING SCIENCE

Author: Yana Heikkilä

Supervisor: Monika Koskinen

Åbo Akademi University

Faculty of Education and Welfare

Studies

Health Sciences

Department of Caring Science,

2024

## Abstract

ÅBO AKADEMI UNIVERSITY

Faculty of Education and Welfare Studies Department of  
Caring Science

Author:

Yana Heikkilä

Supervisor:

Monika Koskinen

---

Master's thesis

Tasks and outcomes of advanced nurse practitioner role in  
palliative care for neurological patients - A scoping review

CARING SCIENCE

---

Keywords:

advanced practice nursing, nursing roles, palliative care,  
neurological patients, scoping review

---

May 2024

Pages: 44    Appendices: 1

---

The purpose of this scoping review was to provide a comprehensive overview of the roles, tasks, and outcomes of advanced practice nursing in palliative care for neurological patients. By identifying seven relevant articles published between 2011 and 2023 from CINAHL and PubMed databases, and conducting an inductive content analysis, it's been synthesized valuable insights into the contributions of advanced nurse practitioners in the specialized area of healthcare. The results of this review highlight the multifaceted nature of advanced nurse practitioners' roles in palliative care settings for neurological patients, with responsibilities spanning management, education, coordination, and autonomous practice. The tasks identified, such as pain management, palliative care needs assessment, hospital discharge and admission, advanced care planning, and medication prescription. The outcomes observed in this review align with existing knowledge on the topic, indicating that advanced practice nurses facilitate faster access to services, reduce waiting times, promote cost efficiency, and enhance patient satisfaction. While the roles of advanced practice nurses in palliative care settings appear to be well-established in the United Kingdom and the United States, this review also highlights the need for further research to explore how these roles could be implemented and adapted in healthcare systems across other countries.

## Foreword

"All, everything that I understand, I understand only because I love."

- Leo Tolstoy

It's been a great journey! I truly enjoyed all ups and downs of it! I become a better and stronger person, I've discovered new places, traveled new countries, met lovely people, was humble and embraced changes! Writing a thesis was a journey on its own, which I feel very proud of! I would also like to thank my thesis supervisor and other teachers at Åbo Akademi University for this wonderful two-year journey!

I have not received any funding, scholarship, or grants during thesis process.

Yana Heikkilä

10.5.2023

## Table of content

Abstract .....	2
1 Introduction .....	5
2 Background.....	7
2.1 Neurological patients.....	9
2.2 Palliative care .....	11
2.3 Neuropalliative care.....	12
2.4 Advanced Practice Nursing .....	16
2.4.2 Clinical Nurse Specialist .....	18
2.4.3 The nurse practitioner .....	19
2.4.4 Differences and similarities between Advanced nurse practitioner, Clinical nurse specialist and Nurse practitioner .....	19
3 Previous research.....	22
4 Aim and research questions.....	24
5 Method.....	25
5.1 Design and context .....	25
5.2 Data collection and material .....	25
5.3 Selection process .....	26
5.4 Data analysis.....	29
6 Ethical considerations.....	33
7 Results .....	34
7.1 The roles of Advanced Nurse Practitioner .....	34
7.2 The outcomes of Advanced nurse practitioner providing palliative care to neurological patients.....	35
8 Discussion.....	37
9 Methodological considerations.....	39
10 Conclusion.....	42
References: .....	44

# 1 Introduction

Based on the WHO report “Leading Cause of Death Globally,” from the year 2000 to 2019, the number of deaths caused by neurological diseases, such as Stroke and Alzheimers, was rapidly increasing (World Health Organization, 2020b). Therefore, it is possible to conclude that the need for patients’ hospitalizations and palliative care services has increased over the years, creating the demand for specialized medical healthcare professionals in neurology and palliative care. Unfortunately, many patients suffering from neurological conditions do not receive supportive care from palliative care services within the current standards of healthcare (Kluger et al., 2023).

According to (Creutzfeldt et al., 2018), most neurological conditioners remain incurable, resulting in shortening the lifespan of a person, and have a significant negative impact on quality of life; patients with neurological conditions often suffer from pain, have physical, psychological, and spiritual difficulties in their everyday life. Palliative care should be integrated within neurology, becoming part of the ethos of neurology. Short-term and long-term strategies should be considered in healthcare systems in order to create a sustainable and meaningful change (Kluger et al., 2023). However, there is limited knowledge on integrating palliative care in neurology to its best ability (Creutzfeldt et al., 2018).

At the moment, people suffering from neurological conditions may be identified as a vulnerable group of patients. They are less likely to receive palliative care support compared to cancer patients (Kluger et al., 2023). A small proportion of neurological patients with non-malignant conditions receive palliative care support nationally and internationally. However, in reality, it is seldom that for this vulnerable group of patients, palliative care is offered (Creutzfeldt et al., 2018). Therefore, access to palliative care for all types of neurological patients, and not only with malignant conditions, can be identified as an area of the healthcare system that requires improvement.

We are living in a rapidly evolving world where people’s needs are the driving force for its development. Social, demographic, and economic factors are the main contributors that provoke change (European Environment Agency, 2015). Factors such as the aging population of a nation, economic reasons to lower medical health care costs, and shortened waiting time for patients to receive medical care were the main aspects leading to the creation of an Advanced practical nursing role model (Van Erp et al., 2021). Changes in the medical field are needed (Boman et al., 2019). The current trend is to shift even more responsibilities from doctors to nurses (Maier & Aiken, 2016).

An advanced nurse practitioner (ANP) healthcare role model is an internationally growing workforce. For instance, in the Netherlands, the growth of ANP's amount was from 140 in 2009 to 2749 in 2015. The model has been implemented and proven to work in countries such as the United States, Ireland, Canada, the United Kingdom, Australia, New Zealand, Spain, The Netherlands, Norway, Sweden, Finland, etcetera. The US is leading in the number of ANPs (including clinical nurse specialists and nurse practitioners) worldwide (Maier et al., 2016). In the Nordic countries, Sweden pioneered the development of an educational program for ANPs in 2003 (L. Fagerström, 2009). Nowadays, an APN is an internationally recognized professional role model for nurses (Kilpatrick et al., 2014).

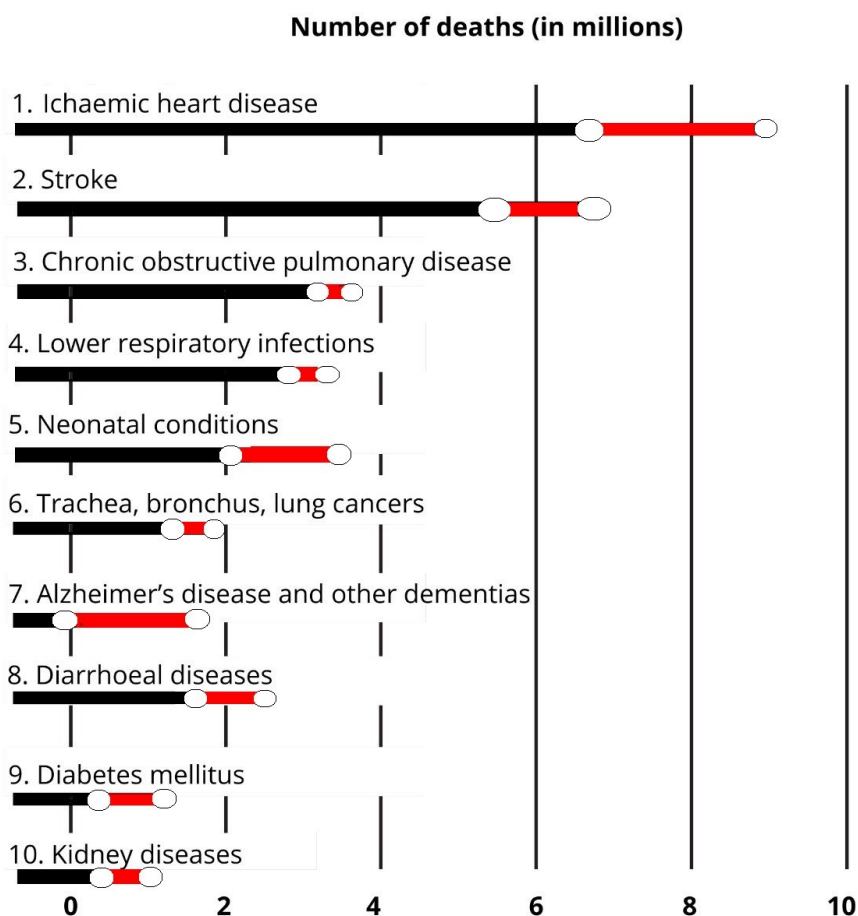
Due to a broad scope of practice, an ANP can be implemented on different levels of medical care. An ANP role has the ability to assess a patient's wide range of needs, such as physical, psychological, cognitive, social, and spiritual. The role can include coordinating care that addresses those patients' and caregivers' needs, with the main focus on improving quality of life (Bassah et al., 2023; Santos et al., 2023). Based on the report by Allen (2015) from the Parliamentary and Health Care Service Ombudsman, England, there are major problematic issues in palliative care: poor communication between healthcare professionals, poor patient symptom control, and inadequate care planning, with hospitals and general practitioner (GP) practices. Implementing an Advanced nurse practitioner (ANP) in palliative care specializing in neurological patients could improve the patient's care. There is extensive literature on the positive and beneficial outcomes of implementing ANP's role in the healthcare system.

The topic of this thesis was chosen based on the author's personal experience working with neurological patients for over eight years. During this time the author had observed how palliative care was provided to different types of neurological patients. It created the interest to conduct the research on the subject. This scoping review summarizes the existing knowledge on a topic. It focuses on tasks and outcomes of the Advanced nurse practitioner working in palliative care settings for neurological patients.

## 2 Background

One billion people across the globe have a neurologic illness, which results in more than 1 in 10 deaths caused by neurologic disease (Creutzfeldt et al., 2018). Stroke is the world's second leading cause of death, resulting in 11% of all deaths worldwide, see Table 4 (Kendall et al., 2018). In Sweden, suicide completion is increased among stroke patients. Similar findings were reported among the Danish population (Hesdorffer, 2016). Another neurological condition resulting in numerous deaths globally is Alzheimer's disease or other forms of dementia. In 2019, According to WHO, it was ranked as the seventh leading cause of death, see Table 1 (World Health Organization, 2020b).

Table 1. Leading causes of death globally from the year 2000 to 2019 (World Health Organization, 2020b).



The Global Atlas of Palliative Care at the End of Life was published in 2014 by the World Health Organization and The Worldwide Hospice Palliative Care Alliance for the first time. This publication aimed to estimate the need for palliative care globally (Connor et al., 2021). Based on the study

conducted by Bassah in 2023, about 56.8 million people worldwide require palliative care. The need is even more significant in low- and middle-income countries (LMICs), with 78% of total palliative care needs residing (Bassah et al., 2023). Between 2011 and 2017, the number of palliative care services worldwide increased from 16,000 to more than 25,000. However, the provided services cover less than 10% of current demand (Connor et al., 2021).

In over 30 countries, palliative care is recognized as a medical specialty or subspecialty. By 2011, over 73% of countries had few or no palliative care services available to people. Frequently, palliative care is seen as medical services only high-income countries can afford. Therefore, most palliative care services are found in high-income countries, followed by upper-middle-income countries (Connor et al., 2021). There is a gap between the demand for palliative care services and services being provided by health care systems. For instance, in Canada Ontario province, up to 40% of patients die without having received any palliative care services during their final year of life (Stilos et al., 2021).

Despite growing knowledge that multidimensional suffering is common for neurologic patients, the provision of palliative care is not sufficient. Early implementation of palliative care during illness trajectory is beneficial and can improve patient, family, and healthcare system outcomes (Kluger et al., 2023). Healthcare providers have increasingly recognized the importance of palliative care for neurological patients. It has resulted in many guidelines and educational programs designed for different neurological conditions. However, the knowledge of how and when to implement palliative care in neurological illness trajectory remains limited (Creutzfeldt et al., 2018).

The ANP role has an opportunity to contribute to the existing medical health care system. The role has a unique fluid boundary between nursing and medicine. It can be seen as a strength of the role, bridging traditional medicine and nursing discipline. Rather than replacing existing medical roles, the ANP role is seen to complement existing ones (Kennedy et al., 2015). In palliative care, the ANP role crosses many levels, including managing day-to-day care, working with other healthcare professionals, engaging in clinical and consultative activities, and managing patients' pain and medications. The role incorporates non-nursing specific tasks, such as physical examination, independent non- and medical prescribing, ordering and interpreting medical investigations, and accepting and processing admissions and discharges in palliative care (Kennedy et al., 2015).



## 2.1 Neurological patients

According to WHO (2016), a neurological disorder is a disease of a human's central and peripheral nervous system. The central and peripheral nervous systems include the brain, spinal cord, cranial and peripheral nerves, nerve roots, autonomic nervous system, neuromuscular junction, and muscles. The following diseases are classified as neurological disorders: Alzheimer's and other forms of dementia, epilepsy, cerebrovascular diseases including stroke, Parkinson's disease and other forms of parkinsonism, migraine and other headache disorders, multiple sclerosis, traumatic disorders of the nervous system caused by head trauma, brain tumors, neuroinfections, and neurological disorders as a result of malnutrition. Parasitic, viral, fungal, and bacterial infections can also affect the nervous system. Patients who are suffering from neurological diseases can be identified as neurological patients.

Neurological conditions often affect patients' core personhood and spiritual well-being. Consequently, those changes might require medical aid during the illness trajectory. It is important to emphasize a positive atmosphere, create opportunities to promote joy and find meaning that may help alleviate the patient's mental suffering (Kluger et al., 2023). Palliative care specialists providing care to neurological patients, their families, and care providers should understand this patient group's primary care-specific needs (Creutzfeldt et al., 2018). Different neurological conditions have different illness trajectories (see Table 2) (Brizzi & Creutzfeldt, 2018).

Table 2. Illness trajectory in neurologic conditions. (Brizzi & Creutzfeldt, 2018)

<b>Neurologic condition</b>	<b>Illness trajectory</b>
Amyotrophic lateral sclerosis	Rapid or prolonged decline
Brain tumors	Rapid or prolonged decline
Stroke	Acute decline followed by uncertain recovery
Multiple sclerosis and neuroinflammatory conditions	Episodic decline and recovery or prolonged decline
Dementia	Rapid or prolonged decline
Parkinson's disease	Prolonged decline

Traumatic brain/spine injury	Acute decline followed by uncertain recovery
Other neurodegenerative conditions	Varies

For instance, Parkinson’s disease illness trajectory has unpredictable periods of high needs when physical deterioration takes place. Such periods of high needs are challenging for both patients and caregivers. Overall, disease or impactful symptoms can be seen as an emotional burden to patients and their families (Tarolli & Holloway, 2020). Another incurable neurological condition, such as glioma, can be used as an example. Patients with gliomas are often referred to palliative care services late during their illness trajectory. Some responsibilities are often placed on caregivers to provide needed support to the patient due to glioma being a highly disabling disease. Potentially, that may result in stress, anxiety, depression, exhaustion, and other negative imprints on caregivers or/and family members (Pace et al., 2017). Depression is reported in 40 to 60% of caregivers of patients suffering from neurological conditions. Therefore, palliative care is provided to the patients and caregivers, reducing the psychological and physical burden of the disease (Brizzi & Creutzfeldt, 2018).

There is a strong link between neurological and psychiatric disorders, specifically psychosis and suicidal behavior. Suicidal behavior, attempts, and completion are primarily described in epilepsy, stroke, and memory problems, including Alzheimer’s disease and degenerative disorders. Among adults who have Parkinson’s disease, Alzheimer’s disease, essential tremor, and stroke, psychiatric disorders are relatively common (Hesdorffer, 2016). For instance, post-stroke depression (PSD) is the most recurrent mental illness, affecting 1 in 3 stroke survivors. PSD has a negative effect on rehabilitation outcomes (Werheid et al., 2022). Anxiety and depression are common in people suffering from neurological conditions, compared to other chronic diseases. Unfortunately, depression or anxiety is often under-recognized and undertreated (Kluger et al., 2023). Therefore, palliative care provided to neurological patients should also include psychological help, answering the specific needs of this patient’s group.

Many people with serious health conditions, chronic or acute illnesses, have unmet palliative care needs. Those patients who can be identified as coming from marginalized groups are most likely to have less access to palliative care (Bischoff et al., 2023). It is suggested that earlier integration and access to palliative care services during illness trajectory have significant benefits in symptom management, improving quality of life, psychosocial health, communication, decision-making

process, and overall patient satisfaction. However, early access to palliative care services is of concern to healthcare providers and on institutional levels (Tipton, 2021).

## **2.2 Palliative care**

Palliative care has a rich history of developing and evolving over the centuries. It takes its roots from ancient history. Caring for sick and dying people was often considered a moral responsibility in ancient societies. For instance, in ancient Greece, Hippocrates emphasized the importance of caring for the sick and eliminating their sufferings (Kleisiaris et al., 2014). Palliative care evolved in the Middle Ages, where religious orders and monasteries provided medical help for those who were severely ill and/or dying (Phipps, 1988). In modern days, a British nurse, Cicely Saunders, is often credited as a founder of the first modern hospice and for establishing the importance of the culture of palliative care in medicine (Richmond, 2005).

Between the 20th and 21st centuries, the concept of palliative care gained wider recognition beyond end-of-life care (Clark, 2016). The World Health Organization (WHO) advocated the implementation of palliative care into healthcare systems worldwide (World Health Organization, 2020a). For the past few decades, there has been a significant increase in research in the fields of palliative care, symptom management through illness trajectory, and psychosocial support for patients and their families (Aziz et al., 2012).

In research, the terms “palliative care,” “end-of-life care,” and “terminal care” are often used as synonyms. However, it is essential to emphasize that the term “palliative care” should not be used as a synonym for other terms in this thesis. According to (Zhukovsky, 2019), the term “palliative care” is derived from the Latin word “palliare”, which means “to cloak,” “is an interdisciplinary medical caregiving approach aimed to optimize quality of life and reduce suffering among people with serious, complex, and often terminal illnesses.”

In 2020, WHO defined palliative care as "an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness." Palliative care aims to prevent and relieve suffering through the early identification, correct assessment, and treatment of pain and other problems, whether physical, psychosocial, or spiritual (World Health Organization, 2020b). The primary aim of palliative care is not to prolong life, restore health, or cure the condition but to maintain the quality of life and a person's functioning (Pace et al., 2017).

Palliative care specialists suggested a switch from “Palliative care” term to “Supportive care” or “Complex-symptom management” (Creutzfeldt et al., 2018; The Lancet Neurology, 2021). Neutral terms may be culturally more acceptable since they remove the negative association with imminent death. It is possible that changing the term and eliminating the stigma of it might have a positive effect on both patients and healthcare providers (Connor et al., 2021). At times, some clinical staff members view the term “palliative care” as something related to patients who clearly are dying (Kendall et al., 2018). Lack of knowledge on the subject was widely reported to be a real barrier to providing high-quality palliative care, particularly among nurses and care providers. There is a clear need for more education concerning palliative care (Ferrell et al., 2020).

### 2.3 Neuropalliative care

Neuropalliative care is a relatively new field of clinical care that combines neurology and palliative care to improve the quality of care for people with neurological conditions (Brizzi & Creutzfeldt, 2018). The International Neuropalliative Care Society (INPCS) is newly established in 2020 (Kluger et al., 2023), aiming to promote the integration of palliative care within neurological services, improving the quality of life of neurological patients (The Lancet Neurology, 2021). According to INPCS, neurological patients differ from other patient groups; therefore, their need for palliative care also differs (The Lancet Neurology, 2021). There are three main observations of emerging neurology and palliative care:

- Patients with neurological conditions have significant palliative care needs.
- Neurological patients’ needs differ significantly from patients with other health conditions.
- Neurological patients’ needs are met insufficiently under current healthcare models.

(International Neuropalliative Care Society, 2021; Kluger et al., 2023)

Several models exist for integrating palliative care into neurology. According to Creutzfeldt (2018), those models exist both in inpatient and outpatient settings, as demonstrated in Table 3. It is essential to mention that models can coexist and work as a combination of approaches.

Table 3. Integration of palliative care into neurology. Models (Creutzfeldt et al., 2018)

Type of model	Care providers
Consultative model	<ul style="list-style-type: none"> <li>• A palliative care specialist consulted</li> </ul>

	<ul style="list-style-type: none"> <li>• Neurological treatment stays within neurologist practice</li> <li>• Patients referred to see palliative care specialist separately</li> </ul>
Integrated model	<ul style="list-style-type: none"> <li>• The palliative care approach is shared between primary care providers and specialty team</li> <li>• Outpatient settings: Collaboration between a neurologist, neuropalliative or palliative care specialist, and interdisciplinary team coexist in multidisciplinary clinic</li> </ul>
Primary neuropalliative care model	<ul style="list-style-type: none"> <li>• Neurologists, trained and educated in palliative care provide treatment themselves.</li> <li>• Outpatient settings: non-neurologists, such as primary care providers and/or geriatricians who take care of neurological patients</li> </ul>

The basis of the foundation for neuropalliative care is symptom management. Those symptoms can be divided into three main categories:

- Neurological physical symptoms
- Non-neurological physical symptoms
- Psychological and/or spiritual symptoms

Providing high neuropalliative care requires attention not only to neurological physical symptoms but also to non-neurological and emotional suffering (Brizzi & Creutzfeldt, 2018). A comprehensive symptom management analysis is outside the scope of this review. However, non-neurological symptoms are a part of neuropalliative care and are presented in Table 4.

Table 4. Psychological and physical symptoms of neurological patients (Brizzi & Creutzfeldt, 2018).

<b>Emotional/Spiritual symptoms</b>	<b>Physical symptoms</b>
Grief	Pain
Depression	Dry mouth/increase of saliva
Anxiety	Constipation

Spiritual suffering	Loss of appetite
Loss of dignity	Fatigue
Depersonalization	Insomnia

It is essential to provide screening for neurological patients for possible palliative care continuously needs to determine whether palliative care is appropriate for a specific patient (Bischoff et al., 2023; Creutzfeldt et al., 2018). Screening for palliative care needs can be done on different levels; see Table 5 (Kluger et al., 2023).

Table 5. Screening levels for palliative care needs (Kluger et al., 2023).

Stage of illness	Care providers	Tools for screening
Early stage of illness	Neurologist Primary caregiver/front-line care provider	Questionnaires Checklists Scales
Symptom progression Event-related triggers	Extended support team Specialist palliative care Social workers Mental health services Home health aides Rehabilitation Support groups	Palliative Outcome Scale Referrals to specialized teams
At the end-of-life stage	Hospice Hospital Nursing home Home	Identification of red flags (weight loss, rehospitalizations)

The screening measure can involve symptom management and advanced care planning for diseases like Dementia, Parkinson's disease, Amyotrophic lateral sclerosis, and emergency neurology (Creutzfeldt et al., 2018). There are tools available to perform palliative care screening. For instance, the 10-item questionnaire Palliative Assessment Screening Tool (PAST) (Flaherty et al., 2018) or the

13-question instrument The Screening for Palliative and End-of-Life Needs in the Emergency Department (SPEED) (Chang et al., 2022) are often used. A “surprise” question for a quick screening can be used: Would you be surprised if this patient died in the next year? If the answer is no, palliative care should be considered, and discussions with patients and family members should be initiated (Tipton, 2021).

Nowadays, medical societies prioritize a palliative approach for neurological patients in their guidelines. Neuropalliative care has the ability to address the unique needs of the patients affected by neurological incurable conditions (Kluger et al., 2023). Neurological patients face continuous physical and physiological losses during illness trajectory. Most of the time, medical interventions cannot help the patient’s condition. However, ANP services in neuropalliative care can positively affect a patient’s quality of life, regaining some control and dignity during decline periods of illness trajectory (Wang et al., 2016).

### **2.3.1 Advanced care planning**

Advanced care planning (ACP) in palliative care involves open communication about diagnosis and prognosis, treatment options, patient’s will and care priorities, and precise documentation (Kluger et al., 2023; Tipton, 2021). ACP conversations, or “Serious illness conversations” (SIC), can also focus on the exploration of patients' illness understanding, values, goals, and fears (Cretu et al., 2023). It is hard to make a correct prediction; however, an ANP can make a roadmap of possible illness trajectories to help the patient decide on the present (Kluger et al., 2023).

Often, an ANP is in the position of initiating a discussion with the patient about advance care planning (Tipton, 2021). An ANP is believed to be well prepared to hold high-quality conversations with patients, helping them to take the necessary steps in the decision-making process (Cretu et al., 2023). An ANP can provide information about existing services available to patients and their significant others through advanced care planning discussion. It can get overwhelming to the patient trying to deal with severe illness and looking for help from different sources. An ANP can navigate the patient, provide needed information, and help to relieve some burden from the patient's shoulders (Bischoff et al., 2023).

According to Cretu (2023), making advanced care planning conversations a routine part of all clinical encounters is recommended. Lower hospitalization rates, fewer intensive care unit admissions, reduction of unnecessary invasive procedures, and decreased hospital stay are the results of ANP’s

work (Wang et al., 2016). Advanced care planning, provided by ANP, can prevent patients from suffering unnecessarily. For instance, a patient can express his/her will not have medical interventions at the end of the illness trajectory. Medical interventions that do not improve the quality of life or survival can cause physical and emotional hardship, pain, or distress to patients and families (Kluger et al., 2023).

Early implementation of an advanced care plan in palliative approaches is often seen as preventing patients from receiving active treatment (Santos et al., 2023; Tipton, 2021) and withdrawal of treatment (Kendall et al., 2018). Unfortunately, till the present day, the term “palliative care” has a negative connotation or even stigma. Patients receiving palliative care are associated with end-of-life care, which is related to imminent death (Creutzfeldt et al., 2018). It gives the impression that the term palliative care, its aim, and its goal are not fully understood correctly. Therefore, implementing palliative care might be challenging based on a possible misunderstanding of the type of care and its strong association with death.

## **2.4 Advanced Practice Nursing**

In 2020, the World Health Organization (2020a) introduced a report calling for the more significant expansion and acknowledgment of all nursing roles, including advanced practical nursing. According to International Counseling of Nurses (ICN), nurses in advanced practice roles are often recognized as Advanced nurse practitioners (ANP). The ICN defines an ANP as “the expert with the knowledge base, complex decision-making skills, and clinical competencies for expanded practice” (International Council of Nurses, 2020). Advanced practice nurses have two typical roles: nurse practitioners (NPs) and clinical nurse specialists (CNSs). Both roles are internationally recognized (L. M. Fagerström, 2021). They ensure care delivery to the communities, treating patients with acute and chronic conditions and educating family members (Kilpatrick et al., 2023).

### **2.4.1 Advanced Nurse Practitioner**

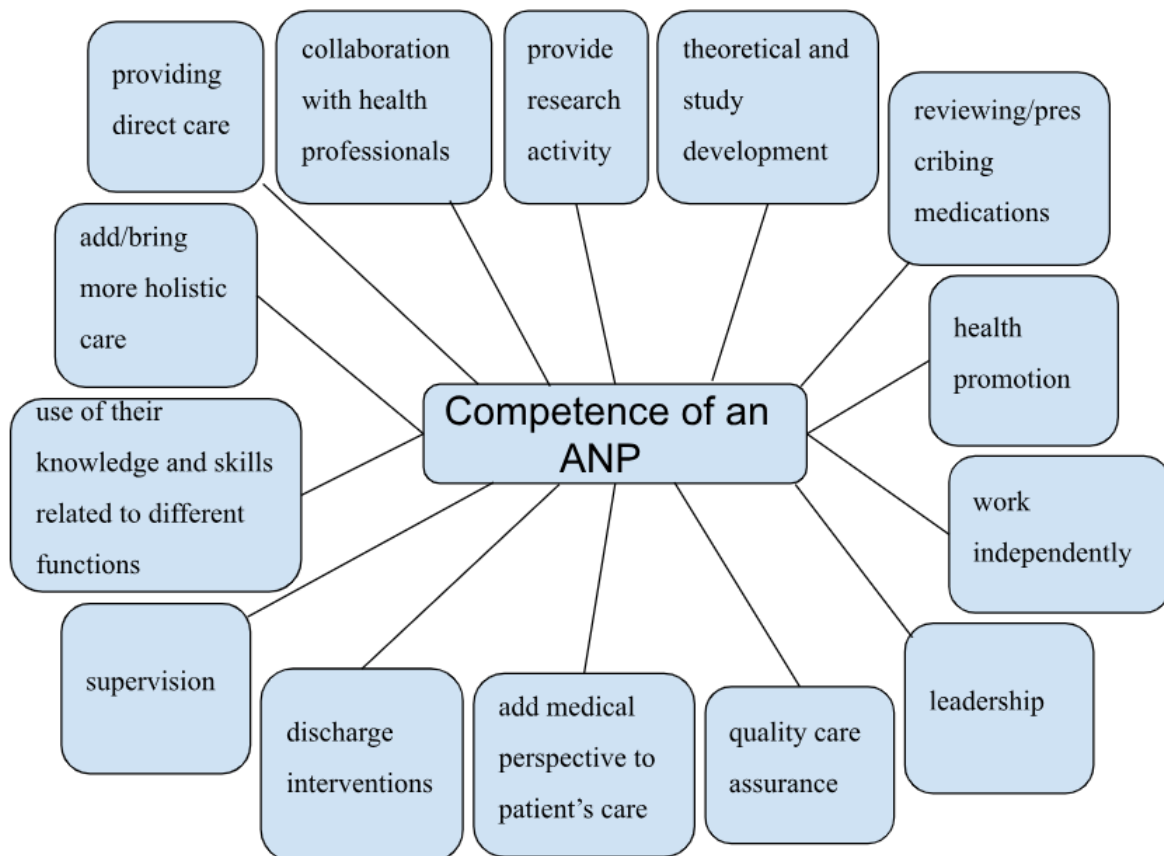
According to Boehning & Punsalan (2024), the roles of ANPs or NPs have evolved over time. An advanced nurse practitioner is a registered nurse with master’s and/or doctorate degrees and extra education and clinical training. ANPs are meant to provide medical health care to the fullest extent of their knowledge. A part of their scope of practice is to increase public healthcare access. Based on the International Council of Nurses, an ANP has the authority to diagnose, prescribe medications, and



order diagnostic tests (International Council of Nurses, 2020). However, the definition of an ANP role and the scope of practice might vary from country to country (Almost, 2021; Henni et al., 2021).

The ANP’s scope of practice is broad and demands a clear definition. The rights and responsibilities of a licensed nurse practitioner are defined by a country's laws, municipality, workplace, unit leadership, level of education, and work experience (Boman et. al., 2019b). The competence of ANPs is presented in Table 6. The alternative goal of the ANP's scope of practice is to improve patients’ medical health care (Holm Hansen et al., 2020).

Table 6. Competence of an ANP (Holm Hansen et al., 2020).



In the study “Advanced practice. APRNs Can Lead by Example When Integrating Palliative Care in Practice,” Tipton (2021) suggests that due to a lack of palliative care training among medical staff, an ANP can be implemented in primary, secondary, and tertiary levels of care (see Table 7).

Table 7. ANP role in primary, secondary, and tertiary levels of care (Tipton, 2021).

Type of care	ANP scope of practice
Primary care, specialized practice	<ul style="list-style-type: none"> <li>• Providing palliative care</li> <li>• Education</li> <li>• Symptom management</li> <li>• Advanced care planning</li> <li>• New referrals for palliative care</li> </ul>
Secondary medical and community centers	<ul style="list-style-type: none"> <li>• Consultations for complex and challenging palliative care cases</li> <li>• Providing acute care</li> <li>• Providing outpatient care</li> </ul>
Tertiary medical centers	<ul style="list-style-type: none"> <li>• Consultations in complex cases</li> <li>• Researching the field</li> <li>• Developing a new science in the palliative care field</li> </ul>

An ANP has a unique role within the medical field, offering multiple opportunities to improve patient-centered care and having a positive effect on patients and family members' quality of life. An ANP offers high-level clinical skills and practice, leadership skills, research management, and providing education to the target groups (Kennedy et al., 2015). In order to successfully implement an ANP role into palliative care services for neurological patients, it requires accurate planning, precise role tasks and responsibilities, strategic planning, support from the organizations, and legal recognition of the role (Fischer et al., 2022). Also, there is a need to expand the ANP role due to the national demand for person-centered care (Kennedy et al., 2015).

#### **2.4.2 Clinical Nurse Specialist**

The clinical nurse specialist (CNS) role was established over 70 years ago in The United States of America. It has developed over time, responding to the population's healthcare needs and socio-economic demands (Jokiniemi et al., 2023). According to the National Association of Clinical Nurse Specialists, by 2022, more than 90,000 CNSs will be working in the country (National Association of Clinical Nurse Specialists, 2022).

Basketter (2018) writes that CNS plays an essential role in patients' treatment throughout the illness trajectory. The key responsibilities include educating and supporting patients and their families, providing reliable holistic care, being trustworthy, having open communication during illness trajectory, and coordinating patient treatment. For instance, managing patient treatment might consist of clinical and patient assessments, providing pre-and post-treatment follow-up, managing treatment, and assessing possible side effects.

A CNS must obtain a master's or doctoral level of education from an accredited school or university to be recognized as a CNS. The education aims to prepare clinical nurse specialists to think critically at the advanced level in medical settings, provide support, and assist other healthcare professionals. A master's program or doctoral degree would prepare a CNS to be able to conduct research and incorporate it into clinical practice in various care settings according to patients' needs (International Council of Nurses, 2020).

### **2.4.3 The nurse practitioner**

In 2020, the International Council of Nurses defined a Nurse practitioner (NP) title as a generalist nurse who completed a minimum master's degree level of education and became an autonomous clinician. The education prepares NPs to diagnose and treat medical conditions according to evidence-based guidelines that include nursing principles that focus on treating the person as a whole rather than focusing only on the condition or disease (International Council of Nurses, 2020).

According to Professor L. M. Fagerström (2021), a nurse practitioner who is obtaining a master's degree level of education is competent to use his/her clinical knowledge and skills in medical practice. The NP has the authority to make independent decisions in assessing patient needs and stating the diagnosis and treatment. The title of NP determines the rights and responsibilities and the scope of practicing at which a nurse practitioner can perform his/her duties. However, the scope of practice may vary from that of a generalist nurse regarding the level of responsibility required for clinical, autonomous practice (Schober & Stewart, 2019).

### **2.4.4 Differences and similarities between Advanced nurse practitioner, Clinical nurse specialist and Nurse practitioner**

Similarities

In North America, “Advanced nurse practitioner” is an umbrella term that includes CNS and NP role models. However, in the United Kingdom, it has a different connotation and is viewed as a nursing practice at an advanced level. Nurse practitioners work below level as advanced practice nurses, with limited scope of practice (Cooper et al., 2019). There are some similarities in clinical tasks between Clinical nurse specialists, Nurse practitioners, and Advanced nurse practitioners. However, to gain wider recognition of ANP titles, it is essential to clearly define the main differences between the roles (L. M. Fagerström, 2021; International Council of Nurses, 2020).

Both roles of CNS and ANP have different historical paths of development. The roles were created due to the economic, historical, and public demand for health care services. CNS’s role was established before ANP with over a 30-year historical gap (Cooper et al., 2019). An ANP role was created from an NP pediatric role in 1965 (Silver et al., 1967). The following similarities can be observed in both roles:

- Direct patient care
- Leadership skills
- Patient education, including family members and health care professionals
- Developing and conducting research
- Administration duties
- Guidelines creation based on evidence-based sources

(Cooper et al., 2019)

According to Tsiachristas (2015), both roles have the right to receive and write referrals for clinical care.

### Differences

The World Health Organization, in 2020, called for greater recognition of all nursing roles, including ANPs, to meet healthcare needs better. The International Counseling of Nursing defines that there are two leading roles ANPs, including CNSs and NPs. They help to provide community care, as well as for patients with chronic and acute conditions and their families. The aim is to improve access to high-quality care and support/education for patients and their caregivers (Kilpatrick et al., 2014, 2023).

The roles of ANP, CNS, and NP can be found in all clinical fields of nursing (Cooper et al., 2019). The difference comes when an ANP role is mainly implemented in broader areas such as oncology, sexual health, emergency department, or cardiology. An ANP role is more generalist, being

competent in several different fields (Cooper et al., 2019; Tsiachristas et al., 2015). When it comes to CNS or NP scope of practice, it is usually defined by a specific disease or type of case, such as stroke, heart failure, or diabetes (Begley et al., 2013; Cooper et al., 2019).

Different studies on those roles report different outcomes. For instance, there are measured outcomes on ANP role scoring higher in patient satisfaction factor, when CNS had better results in evaluating patient's quality of life (Cooper et al., 2019; Tsiachristas et al., 2015). According to Begley's et al. (2013) study, patients reported greater confidence in ANPs as clinicians and in being treated with dignity and respect. Also, education about medications and clinical treatment provided by an ANP had a higher level of satisfaction among respondents. The study conducted by Comiskey in 2014 showed that the CNS role has better outcomes in patients' health and well-being. However, ANP work was extensively evaluated in specific aspects, such as patients experiencing anxiety and having a high trust in ANP as a medical health care professional (Comiskey et al., 2014).

Between ANP, CNS, and NP, an ANP's scope of practice contributed more to working within a multi-professional clinical team, developing curricula, and performing education at the master's level (Begley et al., 2013). According to the same study conducted by Begley, a CNS has an essential role in leadership within the healthcare professional team when an ANP is more likely to conduct professional research.

Possible differences in the scope of practices for those roles might be country-specific due to laws and roles' recognitions. For instance, in the Republic of Ireland, an ANP follows a different path of role legislation than CNSs and NPs (Begley et al., 2013). In Canada, an ANP has a broader scope of practice and responsibilities than a CNS. As in Australia, an ANP role is a legally protected status when CNS does not (Cooper et al., 2019). Educational demands for the roles might also be country specific. For example, in the Republic of Ireland or Canada, a master's level of education for an ANP is required, while in New Zealand, there is no standardized recognition for CNS (Dowling et al., 2013). As a result, the differences between ANP, CNS, and NP in the scope of practice responsibilities come from country-specific laws, legislations, recognitions, and clear definitions of the roles. However, those roles are seen as valuable members of multidisciplinary clinical teams.

### 3 Previous research

The research on the role of advanced nurse practitioners providing palliative care to neurological patients is somewhat limited. Only a few studies exist on a subject to this day. However, extensive research has been conducted about the role of an ANP in health care. Numerous studies suggest it has been proven beneficial to the patient's caregivers and cost-efficient for the medical healthcare system.

For instance, patients are highly satisfied with the care provided by an ANP. Surveys on patient satisfaction were taken in different countries, settings, and departments. As a result, they showed positive outcomes and higher numbers in patient contentment (Jackson et al., 2023; Lee, 2020; Santos et al., 2023). Cost-effectiveness is another positive outcome of an ANP work. For the past 50 years in the United States of America, different studies have been conducted to determine whether or not care provided by an ANP is cost-efficient for society. Implementing an ANP role into the medical healthcare system has proven cost-efficient (Abraham et al., 2019). For instance, similar studies have been performed in Europe and the Netherlands, where an ANP role was implemented over 20 years ago in the medical healthcare system. The results showed that an ANP providing care within a scope of practice is cost-efficient for society (Fund & Swanson-Hill, 2014).

The role of an ANP in palliative care settings has been explored during the past years. For instance, the role of ANP consists of providing an advanced care plan, including the patient's wishes and decision-making regarding the care, medical condition, prognosis, goals of care, limitations of care, place of care, social aspects, and family members' views (*What Is Palliative Care - THL*, 2023). Research, "The Advanced Practice Nurse: A valuable resource to increase timely access to palliative care for those in need," conducted by Stilos et al. (2021) within the Canadian settings, demonstrates that an ANP was responsible for the highest number of palliative care encounters in the Palliative Care Consultant team. It was higher than the physician group. Therefore, it is possible to conclude that an ANP plays a vital role in palliative care settings for patients suffering from life-limiting conditions.

The latest study in Australia found that general palliative care provided by an ANP has positive outcomes. The ANP role has a beneficial imprint on patient care, has a holistic and safe approach, and meets patient's needs in palliative care services. Furthermore, the study's results support the

outcomes of ANP services that meet patient expectations (Fischer et al., 2022). Another study demonstrates that ANP-led palliative care benefits healthcare services, resulting in lower admissions to an acute hospital (Fischer et al., 2022), re-hospitalizations, length of hospital stay, and healthcare costs (Bassah et al., 2023). Having an ANP role in palliative care services results in better patient pain management, supports better decision-making by patients and family members, and improves accessibility to palliative care services (Fischer et al., 2022).

## **4 Aim and research questions**

The purpose of this scoping review is to describe the roles and outcomes of advanced nurse practitioners providing palliative care to neurological patients.

The research questions are:

1. What are the roles of advanced nurse practitioners providing palliative care for neurological patients?
2. How does the role of advanced nurse practitioners impact outcomes when providing palliative care for neurological patients?



## **5 Method**

This study is a qualitative study and has an inductive approach. The methodological choices made are based on the study's purpose and research questions.

### **5.1 Design and context**

A scoping review is a type of literature review that gathers the existing literature on a particular topic. It addresses relatively broad topics without asking particular questions (Mak & Thomas, 2022). It is often conducted to identify the knowledge gap in a broad study area or to identify key concepts and theories (Mak & Thomas, 2022). A scoping review method was chosen due to scattered knowledge about advanced nurse practitioners providing palliative care for neurological patients. In 2005, Arksey and O'Malley introduced a six-stage theoretical framework for conducting a scoping review (Levac et al., 2010; Samuel, 2023). Later, authors such as Levac and Peters extended the original framework to nine steps (Levac et al., 2010; Peters et al., 2020). Nine-step approach to conducting scoping review is: (1) deciding to do a scoping review; (2) assembling the team; (3) identifying the research question; (4) identifying relevant articles; (5) article selection; (6) charting the data; (7) collating, summarizing, and reporting results; (8) consultation (optional); (9) structuring the manuscript (Samuel, 2023). The PRISMA-ScR was used to keep the research process's transparency, consistency, and quality. It encourages thorough documentation of the review process and findings, ultimately enhancing the utility and impact of scoping review research (Anderson et al., 2020).

### **5.2 Data collection and material**

Conducting a comprehensive search is crucial for the success and validity of a scoping review. In order to achieve comprehensiveness, time and resources should be constrained (Landerdahl Stridsberg et al., 2022). The search was conducted in both published and gray literature. The gray literature "is produced on all levels of government, academics, business, and industry in print and electronic formats" (Godin et al., 2015). It would include published studies from research institutes, short conference abstracts, theses and dissertations, ongoing research, and government and committee reports (Landerdahl Stridsberg et al., 2022). Databases, such as CINAHL, PubMed, and Google Scholar, were used to screen evidence-based literature. Primary and specialized healthcare settings were chosen since palliative care can be provided to neurological patients in both.

### 5.3 Selection process

The initial search including palliative care and an ANP role was conducted in databases such as CINAHL (EBSCOhost) and PubMed. 160 861 articles were found, including scoping reviews. A search on Google Scholar resulted in over 28 200 sources on the topic. In order to keep the search structured, a PICO Framework was applied, see Table 8.

Table 8. PICO Framework (L. Fagerström, 2012).

PICO	Classification
Participants:	Neurological patients in palliative care
Interventions:	Advanced nurse practitioner (ANP) Clinical nurse specialist (CNS) Nurse practitioner (NP)
Comparisons:	Not applicable
Outcomes:	Quality of care

Later on, the search words and their truncated forms were identified. Using a wide range of search words decreased the possibility of leaving out potential beneficial studies for the research.

Table 9. Key search terms are based on Table 8.

Population	Intervention	Comparison	Outcome
Neurology* Neuro* Neurological ward Neurological patients Palliative* Palliative care	Advanced Nurse Practitioner* ANP Clinical nurse specialist CNS Nurse practitioner* NP	Not applicable	Care outcome* Patient satisfaction Patient's family satisfaction Waiting time Cost-effectiveness* Interventions

Palliative patients	Role of ANP		Re-admission
End-of-life care	Role of CNS		Impact*
	Role of NP		Impact of care

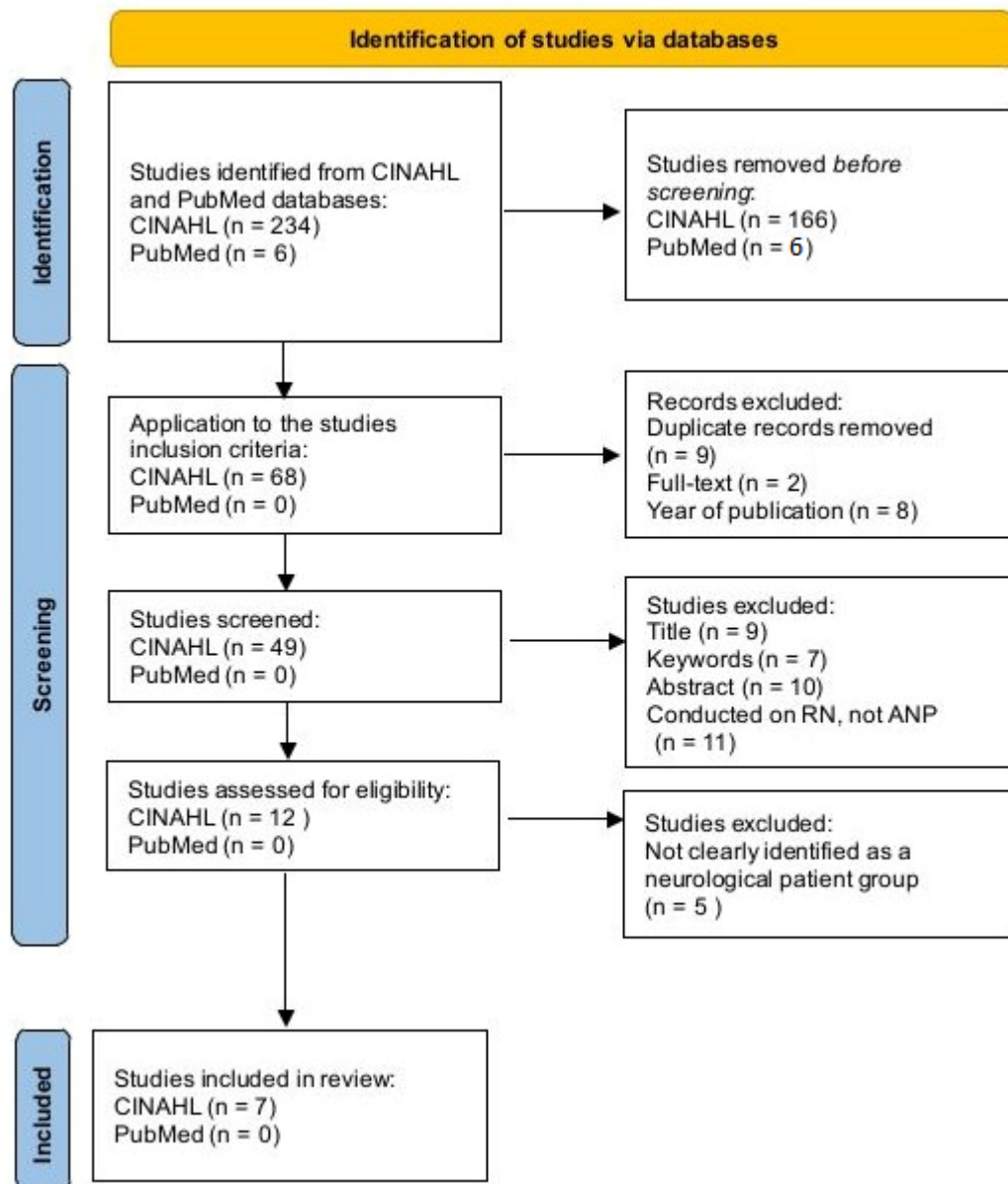
Inclusion criteria for the articles were: (1) published between 2011-2023; (2) written in English; (3) full-text available; (4) the content of the articles is relevant to the research question; (5) peer-reviewed articles, (6) ANP, CNS and NP terms are used as synonyms. The inclusion criteria aimed to manage the volume of literature and ensure that the most relevant and recent knowledge on a subject is available. During the initial search only articles, which were published between 2013-2023 were considered for analysis. However, it resulted in identifying six articles total. The decision was made to expand the years of publications to 2011-2023 in order to possibly gain more data. It resulted in finding one article more, which added valuable knowledge to the scoping review.

A search in Google Scholar was used to identify the great literature relevant to the thesis topic. The database has limited options for setting limiters. Therefore, the search in Google Scholar led to a very high number of search results. It created a challenge to identify relevant studies efficiently. The first thirty articles of the search were evaluated. However, most of the articles were not selected due to their irrelevance to the subject of the thesis and not meeting the inclusion criteria.

A primary search was conducted in both CINAHL and PubMed databases. Each database was analyzed one at a time. The search process began with application key terms; limiters were set to eliminate unrequited literature. Duplicates were removed from the results of the search during this stage. The final number of articles was 49. Therefore, all the articles were assessed according to their headings, keywords, and abstracts. The articles, which did not meet inclusion criteria were eliminated. The remaining seven articles were selected for future detailed analysis.

The literature search was conducted in January 2024 with a help of librarian. The total number of identified articles by CINAHL and PubMed was 240. The inclusion criteria were applied to the search, resulting in the exclusion of 172 articles. Of the remaining 68 articles, only 58 had a full-text review. The duplicates were removed, resulting in a total of about 49 articles. After screening the articles based on title, keywords, summary, or abstract, 12 articles were selected for the analysis. During the reading of selected articles 5 were excluded. In those studies, the group of patients suffering from long conditions were not clearly identified as neurological patients. The primary

search in CINAHL and PubMed databases identified 7 articles that met the inclusion criteria and were relevant to the research question. The PRISMA-Scr diagram (Figure 1) presents a screening process for the literature.



Note. Source: (Page et al., 2021)

Figure 1. The PRISMA-Scr diagram. Screening literature process.

The data extraction from the selected articles were following the JBL Manual for Evidence Synthesis guidelines developed by Peters et al. (2020). The data extraction results are presented in Appendix 1. Data extraction table. Data extraction was conducted by one author.

## 5.4 Data analysis

In order to systematically analyze the selected data (n = 7), inductive content analysis was chosen as a research method. This research method aims to identify patterns, themes, and categories (Elo & Kyngäs, 2008). The first step of analyzing the data was to read through the texts and assign codes relevant to the research sections of the text. The purpose of those codes is to capture the key concepts, ideas, or themes presented in the data. Once the first step of basic coding was complete, it was possible to start to group similar codes into categories based on their correlation with the meaning. The third step of the data analysis was to group related categories into higher-order headings. For this scoping review, higher-order headings were based on the research questions. These categories are different outcomes of advanced nurse practitioners providing palliative care for neurological patients and other stakeholders. The sub-categories below outcomes were patient satisfaction, cost-effectiveness, reduced hospital stay, better symptom control, and high-quality care delivery. The sub-categories below the outcomes included the role of advanced nurse practitioners in different healthcare settings. The subcategories below the tasks of an ANP were physical examination, advanced care planning, clinical care provider, education, and support. The research process was discussed and guided by the thesis supervisor.

Table 10. Data analysis table (Clevenger et al., 2018; Davis & Lou, 2011; Hussain et al., 2013; Kaasalainen et al., 2013; Madden et al., 2013; O'Mahony et al., 2017; Soper et al., 2023).

### Roles of an Advanced nurse practitioner

Relevant to the research sections of the text	Subcategories	Categories
Assessing psychological, social, and spiritual issues	assessing psychological symptoms	direct clinical care provider
Regular assessment and management of physical symptoms	assessment physical symptoms	direct clinical care provider
Medication adjustment according to the correct needs of the patient	medication adjustment	direct clinical care provider
Patient's screening for PC needs	patients' screening	direct clinical care provider
Providing complete comprehensive neurological examination	providing neurological examination	direct clinical care provider
Symptom management	symptom management	direct clinical care provider

Providing follow-up care	Follow up-care	direct clinical care provider
Providing clinical consultations	Clinical consultations	direct clinical care provider
Patient's PC consultations	PC consultations	direct clinical care provider

CNS interview patients about preferable place of care, treatment	preferable place of care	patient care coordinator
Clinic appointments, ED admissions; conducts scheduled, structured meetings; hospital discharges	admissions, schedules, meetings, discharges	patient care coordinator
Design an individualized care plan	design care plan	patient care coordinator
Coordinate care with multiple specialists	coordinate care	patient care coordinator
Coordinates the outpatient hospice referral	coordinate referrals	patient care coordinator
Improve access to care	improve access to care	patient care coordinator
Conduct interdisciplinary rounds	conduct interdisciplinary rounds	patient care coordinator
Creating advanced care plan	Creating care plan	patient care coordinator

Support patient's decision making		supporter
Providing support to staff members		supporter

Provided guidance, education to patients, family members, medical staff		educator
-------------------------------------------------------------------------	--	----------

Outcomes Advanced nurse practitioner providing palliative care to neurological patients

Relevant to the research sections of the text	Subcategories	Categories
-----------------------------------------------	---------------	------------

the CNSs, who were trained and specialized in providing palliative care to patients with ANC, acted as the patients' key workers	trained and specialized in palliative care	specialized high quality care
APRNs manage all primary care, potentially eliminating communication barriers between staff and providing less-fragmented care	eliminating communication barriers and less fragmented care	specialized high quality care
integration of palliative medicine clinicians into the operations improves quality of care in ICUs	improving quality of care	specialized high quality care
palliative care team provides patients and families with much needed support and improves outcomes	providing support	specialized high quality care
NP on the neuroscience ICU team led to a better representative from the unit, improved communication, and improved support for caregivers going through this difficult process.”	improving communication and support	specialized high quality care

there is some evidence that this resulted in improved patient outcomes, including a reduction in hospital admissions in the last year of life and an increased number of home and hospice deaths	reduction in hospital admissions	healthcare cost reduction
to avoid a potentially unnecessary visit, caregivers are instructed to contact an on-call APRN before visiting an ED	avoiding unnecessary visits	healthcare cost reduction
we found that the integration of a palliative care APN into the ICU could have saved approximately US\$224 500	direct savings	healthcare cost reduction
the NP may help to reduce costs and standardize care	cost reduction	healthcare cost reduction

there is some evidence that this resulted in increased number of home and hospice deaths	preferable place of death	improving patient's quality of life
The APN role in hospice has been shown to be integral and sustainable and to improve quality of life	improve quality of life	improving patient's quality of life
The findings of this study related to perceived outcomes of having NPs in LTC (e.g. improved better pain management	better pain management	improving patient's quality of life

integration of palliative care advanced practice nurses (APNs) into the routine rounding and case-based teaching of interdisciplinary ICU teams is one potential strategy to address the shortage of palliative medicine physicians and standardize decisions for referring patients to palliative medicine teams	APN integrated in the palliative care team	fastest access to care
decreased time from admission to the ICU until a palliative medicine consultation was conducted	decreased time from admission to consultation	fastest access to care
anticipation and initiation of appropriate referrals	initiation of referrals	fastest access to care
the NP has improved the accessibility and timeliness of care	improving accessibility to the care	fastest access to care
increase referral numbers to PC from this service	increased number of referrals	fastest access to care



## **6 Ethical considerations**

Legal and ethical issues are essential to modern research related to the subject and researcher (Yip et al., 2016). According to the guidelines of Åbo Akademi University (2022), there are no interactions with the research subjects. Therefore, an ethical assessment is not required to conduct a scoping review. The authors followed ethical norms based on the Finnish National Board guidelines (*Finnish National Board on Research Integrity TENK*, 2019). Collected data was reported and applied to research methods and data collection. The results were the conclusions of the scoping review and were presented without modifications. The authors of the study presented the research results without bringing their personal opinions on the subject. The literature results were tested credible by keeping the original materials and complete research records. Contribution to this work being credible is storing the research findings in accessible places for further knowledge and advanced science. The authors are open to criticism of the work and new ideas.

## **7 Results**

CINAHL and PubMed databases were used to collect the data. Seven articles met the selected criteria and were chosen for this thesis. The included articles were published between 2011 and 2023. The articles were conducted in the United States and the United Kingdom. This may demonstrate the existing role of advanced nurse practitioners providing palliative care to neurological patients in those countries. The articles provided inside knowledge on the outcomes of an ANP role implemented in palliative care settings for neurological patients. Clinical nurse specialist (n = 1), nurse practitioner (n = 3), or advanced nurse practitioner (n = 3) were the titles used in the analyzed literature. Most of the accepted studies for this scoping review had a quantitative design. This thesis used inductive content analysis to identify and form categories, describing the outcomes of an advanced nurse practitioner providing palliative care to neurological patients.

### **7.1 The roles of Advanced Nurse Practitioner**

Four leading roles of Advanced nurse practitioners providing palliative care to neurological patients were identified in the chosen data. The first role was clinical care provider. It is divided into direct and indirect care. Direct care was delivered in hospitals, outpatient clinics, home care, and hospice services (Clevenger et al., 2018; Kaasalainen et al., 2013; Madden et al., 2013). Direct care provided by an ANP included functional, emotional, and neuropsychiatric patient assessment and symptom-control interventions (Clevenger et al., 2018; Davis & Lou, 2011; Hussain et al., 2013; Kaasalainen et al., 2013). An ANP completes a comprehensive neurological exam and involves regular screening for new or changing symptoms, both physical and mental, as part of direct care (Davis & Lou, 2011). Indirect care, provided by an ANP, includes follow-up or counseling phone calls to ensure the continuity of the patient's care, the same as the patient's case management (Hussain et al., 2013; Madden et al., 2013).'

The second role of an ANP in palliative settings was that of a manager. ANP tasks included conducting scheduled structural meetings, hospital discharges, patient care coordination, phone calls to caregivers, and designing individualized care plans (Clevenger et al., 2018; Davis & Lou, 2011; O'Mahony et al., 2017). Besides that, an ANP was responsible for treatment monitoring, referral review, and identifying eligible patients for palliative care (O'Mahony et al., 2017). Written

documentation of patient reports on provided care is part of ANP manager tasks (Hussain et al., 2013; Madden et al., 2013). An ANP was responsible for continuously working with the system to improve patients' access to palliative care. Pronouncing patients' deaths and facilitating good deaths were assigned to an ANP duty (Kaasalainen et al., 2013).

Educator was a third identified role. An ANP specialized in palliative care for neurological patients can guide the physician regarding chemotherapy toxicity and the patient's supportive care. Due to an ANP being often present during physician's rounds and witnessing the physician's advice, she/he could later provide clinical reassurance to the patients or caregiver regarding the treatment by phone call (Madden et al., 2013). An ANP can provide counseling and education to patients, family members, and different levels of medical healthcare staff regarding diagnosis, treatment, or palliative care (Hussain et al., 2013; Kaasalainen et al., 2013; Soper et al., 2023). An ANP engages in discussions with patients and their families about goals of care to ensure an understanding of the medical treatment plan, potential risks, and benefits (Soper et al., 2023).

The fourth role of an ANP was supporter. An ANP acknowledges the patient's and family member's feelings (Madden et al., 2013). While working closely with the neurological patients and their families, ethics were considered to support them as they made decisions about appropriate care (Hussain et al., 2013; Kaasalainen et al., 2013; Soper et al., 2023).

## **7.2 The outcomes of Advanced nurse practitioner providing palliative care to neurological patients**

Different outcomes of an ANP providing palliative care to neurological patients were extracted from the data. Four leading outcomes were identified after data analysis: improving patient's quality of life, fastest access to care, providing specialized high-quality care, and healthcare cost reduction. The outcomes were presented from patients', medical healthcare system, caregivers and medical staff point of view. The outcome of healthcare cost reduction could be seen when patients, receiving palliative care provided by an ANP were likely have shorter hospital stay (Clevenger et al., 2018; Davis & Lou, 2011; Hussain et al., 2013; Kaasalainen et al., 2013; O'Mahony et al., 2017; Soper et al., 2023). Shorter hospital stays lowered healthcare costs both to patients and healthcare systems (Clevenger et al., 2018; O'Mahony et al., 2017). The outcome of the role resulted in avoidance of unnecessary patients' treatments, increase use of pain medications and better symptom management (Clevenger et al., 2018; Kaasalainen et al., 2013; O'Mahony et al., 2017; Soper et al., 2023).

Faster access to the care was presented in a result of an ANP work, that bigger number of patients have received palliative care and improved the accessibility and timeliness of care (Kaasalainen et al., 2013; O'Mahony et al., 2017). An ANP was able to establish a strong relationships with patients and their families, personalize and provide less-fragmented care (Clevenger et al., 2018; Hussain et al., 2013; Madden et al., 2013).

ANPs provide high quality care, which resulted in patients' quality of life was improved, improved communication and support between medical staff members, families and patients (Hussain et al., 2013; Kaasalainen et al., 2013; O'Mahony et al., 2017; Soper et al., 2023). ANPs providing palliative care to neurological patients resulted in better patient's life-changing decision making, focusing on his/her wishes and values, plan for their future, and navigate during difficult times (Davis & Lou, 2011; Hussain et al., 2013; Soper et al., 2023).

## 8 Discussion

It's notable that the roles identified in the scoping review for advanced nurse practitioners providing palliative care for neurological patients align closely with the broader description of advanced nurse practitioner roles outlined by the International Council of Nursing (2020), which includes clinical practice, education, leadership, and research. The roles identified in the reviewed literature - clinical care provider, manager, supporter, and educator - encompass key aspects of advanced practice nursing in palliative care settings.

While the research task wasn't explicitly identified in the literature review and results, it's important to consider potential reasons for its absence. It's possible that research responsibilities may not have been emphasized or documented extensively in the studies included in the review, or that they were subsumed within other roles such as clinical care provision or education. Additionally, variations in the scope and focus of the included studies may have influenced the prominence of research-related tasks in the findings.

Some of the advanced nurse practitioners are working independently in palliative care for neurological patients, for example prescribing and administering the medication for pain management or providing a follow up care (Madden et al., 2013). Also, APN's are capable of managing all primary care, potentially eliminating communication barriers between staff and providing less-fragmented care. An APN, specialized in primary care may deliver high-quality care to the growing population and their caregivers. The direct tasks would be patient's symptom management, medication adjustment, clinic appointments, emergency department admission, hospital discharge and conduct medical health care professional meetings (Clevenger et al., 2018).

An advanced nurse practitioner specialized in palliative care for neurological patients has a vast knowledge on a subject. An APN, as part of multidisciplinary team, working in ICU department can conduct a screening for neurological patients in need for palliative care. As a result of the ANP's work patient has a faster access to the care. Palliative care consultations were conducted faster to the patients rather than without an APN being part of the multidisciplinary team (O'Mahony et al., 2017). Interviewing patients about preferable place of care, possible treatments, and support patient's decision-making process are one of the direct tasks of APN in palliative care settings (Hussain et al.,

2013). Patients screening and consultations, conducting interviews provided by an APN resulted in lowering health care costs both for patients and health care organizations (O'Mahony et al., 2017). It lowered hospital admissions and hospital stay, withdraw unnecessary treatments and blood tests which are no longer beneficial to the patients, resulting in enhancing quality of life, elimination unnecessary sufferings to the patients and their caregivers (Clevenger et al., 2018; Davis & Lou, 2011; Hussain et al., 2013; Kaasalainen et al., 2013; Madden et al., 2013; O'Mahony et al., 2017; Soper et al., 2023).

The wider range of tasks undertaken by APNs in countries where the role has been established for a longer period of time suggests that there may be benefits to expanding the role of APNs, particularly in palliative care settings for neurological patients. The positive outcomes identified in the data analysis further support the potential advantages of incorporating APNs into such settings. The absence of negative impacts or outcomes associated with the ANP role in palliative care settings is noteworthy and suggests that the integration of APNs into healthcare teams can contribute positively to patient care and outcomes. This finding underscores the potential benefits of establishing APN roles in palliative care settings across different countries, not only for patients but also for healthcare providers.

The observation that the majority of the selected articles for the scoping review were published in the United States and Great Britain is significant, especially considering that these countries have a longer history of integrating the role of advanced nurse practitioners (APNs) into the healthcare system compared to some European countries. This historical context likely influences the breadth and scope of tasks performed by APNs in these regions, as noted by Fagerström (2012) and Lamb et al. (2018).

Policymakers and healthcare leaders in countries where the role of APNs is less established may consider the evidence presented in this scoping review as they explore opportunities to expand the role of APNs in palliative care and other healthcare settings. By leveraging the experiences and positive outcomes documented in regions with more established APN roles, these countries can potentially enhance patient care and address healthcare workforce needs effectively.

## **9 Methodological considerations**

The methodological approach employed in this scoping review raises several considerations. Typically, scoping reviews benefit from collaboration among multiple authors to ensure rigor and reduce the potential for biased decision-making. However, in this instance, the review was conducted by a single author, which may have introduced uncertainties in the decision-making process, particularly given the author's lack of prior experience in completing a scoping review or conducting inductive content analysis.

While the author consulted with a librarian during the search process and received guidance from the thesis supervisor throughout the writing process, the final methodological decisions rested solely with the author. This approach might have led to subjective interpretations or overlooked important considerations that could have been addressed through peer review and collaboration. In future endeavors, it would be beneficial to involve multiple authors with diverse expertise to enhance the methodological robustness and credibility of the scoping review. Additionally, seeking input from experienced researchers or methodologists could help mitigate potential biases and improve the overall quality of the review.

The utilization of articles dating back over ten years in the background and previous research sections of the review warrants attention. While some may question the relevance of older literature in a rapidly evolving field, the author's judgment in selecting these articles was validated during the analysis of included articles. This suggests that despite the passage of time, the insights gleaned from these older studies remain pertinent to the current discourse on advanced practice nursing.

In future research endeavors, it may be valuable to explore the reasons behind the perceived consistency in the tasks performed by advanced practice nurses over time. This could provide valuable insights into the evolving nature of the profession and inform strategies for optimizing role effectiveness in contemporary healthcare settings.

The challenges encountered during the search process underscore the complexities involved in conducting a thorough literature review, particularly for a single author with limited experience. While the author utilized what seemed to be the most obvious search terms, it's acknowledged that more appropriate terms may have existed, highlighting the importance of familiarity with search strategies and database functionality.

Limiting the search to CINAHL and PubMed may have inadvertently restricted access to potentially relevant literature, as evidenced by the lack of relevant articles identified through Google Scholar. The absence of robust limiters in Google Scholar could have contributed to the overwhelming volume of evidence encountered, making it challenging for a single author to sift through and assess all potentially relevant articles within the constraints of time and capacity.

In future endeavors, it may be beneficial for the author to seek guidance from experienced researchers to refine search strategies and explore alternative databases or search engines that offer more sophisticated limiters and search functionalities. Collaborating with colleagues or forming a research team could also help distribute the workload and enhance the comprehensiveness of the search process. Additionally, allocating sufficient time and resources for the literature search phase can help mitigate the risk of overlooking relevant studies due to time constraints.

The decision not to perform quality appraisal on the included articles aligns with the standard practice for scoping reviews, where the primary focus is on mapping the existing literature rather than assessing the quality of individual studies. Including various types of research studies and descriptive articles in the review reflects a broad approach to gathering relevant information on the topic of interest.

While all included articles met the predefined inclusion criteria, it's acknowledged that some may be more closely aligned with the specific focus of the review - describing the roles and tasks of advanced practice nurses providing palliative care for neurological patients - than others. This variability in relevance is not uncommon in scoping reviews, given the broad scope of inquiry and the diversity of literature encompassed.

One notable observation is that all included articles originated from the United States and the United Kingdom, which may introduce geographical bias and limit the generalizability of findings to other healthcare contexts. Exploring literature from a broader range of countries and healthcare systems could provide a more comprehensive understanding of advanced practice nursing roles in palliative care for neurological patients and offer insights into potential variations or similarities across different cultural and healthcare settings.

In future research endeavors, expanding the geographical scope of the literature search could help mitigate potential biases and enrich the breadth of perspectives represented in the review.



Additionally, considering the relevance of included articles to the specific focus of the review can enhance the clarity and depth of insights derived from the scoping exercise.

The discrepancy between the recommended educational preparations for advanced practice nursing, as defined by the International Council of Nurses (2020), and the lack of regulatory standardization in certain countries poses a notable challenge in interpreting the findings of the scoping review, particularly regarding the qualifications of participants in included studies. Given that the titles associated with advanced practice nursing, such as clinical nurse specialist and nurse practitioner, are not uniformly regulated across all countries, there is a risk that some participants in the reviewed articles may not meet the educational standards outlined by the International Council of Nurses (2020). This inconsistency in educational requirements could potentially impact the validity and generalizability of findings, as the roles and responsibilities of advanced practice nurses may vary based on their level of educational preparation and clinical training.

In light of this, it's essential for readers to critically evaluate the qualifications and credentials of participants in the reviewed studies and consider the implications of varying educational standards on the interpretation of results. Additionally, researchers conducting future scoping reviews in this area may need to exercise caution when synthesizing evidence from studies conducted in regions with disparate regulatory frameworks for advanced practice nursing titles and educational requirements.

## 10 Conclusion

The variation in the roles of advanced practice nurses providing palliative care to neurological patients globally, as highlighted in this scoping review, underscores the complexity of defining and standardizing these roles across different healthcare systems and countries. The United Kingdom and United States emerge as regions where the roles of APNs in palliative care settings are most clearly defined, with identified roles linked to coordination, counseling, management, and autonomous practice.

However, despite the clarity in roles observed in these countries, inconsistencies in titling and role delineation persist, posing challenges for accurately describing the roles of APNs, particularly in palliative care where responsibilities may overlap with those of other healthcare professionals. This lack of uniformity in titling and role definition can contribute to confusion among patients and colleagues and may hinder the optimal utilization of APNs within interdisciplinary healthcare teams. Nevertheless, it's noteworthy that the services provided by APNs are generally well-received by patients, with most expressing satisfaction with the care they receive.

While some patients may initially find the role of APNs unfamiliar or may have preferences for physician-led care, overall satisfaction suggests that APNs play a valuable role in delivering high-quality palliative care to neurological patients. In light of these findings, efforts to standardize and clarify the roles of APNs in palliative care, as well as to enhance interdisciplinary collaboration and communication, may help address challenges related to role ambiguity and improve patient outcomes and experiences. Additionally, patient education and engagement initiatives can help foster greater understanding and acceptance of the unique contributions of APNs within the palliative care team.

The findings from your scoping review affirm the existing understanding of the role of advanced practice nurses in palliative care for neurological patients. The evidence suggests that APNs can deliver safe and effective care, contributing to reduced waiting times, improved access to healthcare services, and enhanced patient satisfaction. These outcomes align with the broader body of knowledge on the subject, confirming the positive impact that APNs can have on patient care in palliative settings.

The ability of APNs to provide timely and high-quality care is particularly valuable in palliative care, where patients often have complex needs and require comprehensive support. By leveraging their advanced clinical skills, knowledge, and autonomy, APNs play a critical role in delivering holistic care that addresses the physical, emotional, and psychosocial aspects of patients' well-being.

Moving forward, it could be valuable for future research to explore the extent to which advanced nurse practitioners in palliative care for neurological patients engage in research activities, as this aspect plays a crucial role in advancing evidence-based practice and contributing to the knowledge base in the field. By addressing this gap, future studies can provide a more comprehensive understanding of the roles, tasks, and outcomes of advanced nurse practitioners in palliative care settings, thereby informing policy, practice, and education in this specialized area of healthcare.

Furthermore, the findings from this scoping review underscore the importance of continued investment in APN roles and the integration of APNs into interdisciplinary palliative care teams. By optimizing the utilization of APNs and recognizing their contributions to improving patient outcomes and experiences, healthcare systems can enhance the overall quality and effectiveness of palliative care services for neurological patients. Overall, the findings of this scoping review provide valuable support for the role of APNs in palliative care and reinforce the importance of ongoing research and practice in this area to further enhance patient care and outcomes.

## References:

- Åbo Akademi University. (2022). *Ethical assessment*. Åbo Akademi University Intranet. <https://abofi.sharepoint.com/sites/intra-en-research/SitePages/Ethical-assessment.aspx>
- Abraham, C. M., Norful, A. A., Stone, P. W., & Poghosyan, L. (2019). Cost-Effectiveness of Advanced Practice Nurses Compared to Physician-Led Care for Chronic Diseases: A Systematic Review. *Nursing Economic\$, 37*(6), 293–305.
- Allen, D. (2015). Poor end of life care is clear theme in ombudsman's report. *Nursing Management (2014+)*, *22*(4), 10. <https://doi.org/10.7748/nm.22.4.10.s9>
- Almost, J. (2021). *Regulated Nursing in Canada*. 165.
- Anderson, J. K., Howarth, E., Vainre, M., Humphrey, A., Jones, P. B., & Ford, T. J. (2020). Advancing methodology for scoping reviews: Recommendations arising from a scoping literature review (SLR) to inform transformation of Children and Adolescent Mental Health Services. *BMC Medical Research Methodology, 20*, 242. <https://doi.org/10.1186/s12874-020-01127-3>
- Aziz, N. M., Miller, J. L., & Curtis, J. R. (2012). Palliative and End of Life Care Research: Embracing New Opportunities. *Nursing Outlook, 60*(6), 384–390. <https://doi.org/10.1016/j.outlook.2012.08.006>
- Basketter, V., Benney, M., Causer, L., Fleure, L., Hames, D., Jones, S., Patel, K., & White, L. (2018). The role of the CNS in the mCRPC patient pathway. *British Journal of Nursing, 27*, S3–S8. <https://doi.org/10.12968/bjon.2018.27.Sup4b.S1>
- Bassah, N., Vaughn, L., & Santos Salas, A. (2023). Nurse-led adult palliative care models in low- and middle-income countries: A scoping review. *Journal of Advanced Nursing, 79*(11), 4112–4126. <https://doi.org/10.1111/jan.15646>
- Begley, C., Elliott, N., Lalor, J., Coyne, I., Higgins, A., & Comiskey, C. M. (2013). Differences between clinical specialist and advanced practitioner clinical practice, leadership, and research roles, responsibilities, and perceived outcomes (the SCAPE study). *Journal of Advanced Nursing, 69*(6), 1323–1337. <https://doi.org/10.1111/j.1365-2648.2012.06124.x>

- Bischoff, K. E., Vanegas, G., O’Riordan, D. L., Sumser, B., Long, J., Lin, J., Berkey, A. R., Kobayashi, E., Zapata, C., Rabow, M. W., & Pantilat, S. Z. (2023). A Systematic Approach to Assessing and Addressing Palliative Care Needs in an Outpatient Population. *Journal of Pain and Symptom Management*, *66*(3), 270–280.e8. <https://doi.org/10.1016/j.jpainsymman.2023.06.024>
- Boehning, A. P., & Punsalan, L. D. (2024). Advanced Practice Registered Nurse Roles. In *StatPearls*. StatPearls Publishing. <http://www.ncbi.nlm.nih.gov/books/NBK589698/>
- Boman, E., Ösp Egilsdottir, H., Levy-Malmberg, R., & Fagerström, L. (2019). Nurses’ understanding of a developing nurse practitioner role in the Norwegian emergency care context: A qualitative study. *Nordic Journal of Nursing Research*, *39*(1), 47–54. <https://doi.org/10.1177/2057158518783166>
- Brizzi, K., & Creutzfeldt, C. J. (2018). Neuropalliative Care: A Practical Guide for the Neurologist. *Seminars in Neurology*, *38*(5), 569–575. <https://doi.org/10.1055/s-0038-1668074>
- Chang, A., Espinosa, J., Lucerna, A., & Parikh, N. (2022). Palliative and end-of-life care in the emergency department. *Clinical and Experimental Emergency Medicine*, *9*(3), 253–256. <https://doi.org/10.15441/ceem.22.341>
- Clark, D. (2016). Palliative medicine: Historical record and challenges that remain. In D. Clark (Ed.), *To Comfort Always: A history of palliative medicine since the nineteenth century* (p. 0). Oxford University Press. <https://doi.org/10.1093/med/9780199674282.003.0007>
- Clevenger, C. K., Cellar, J., Kovaleva, M., Medders, L., & Hepburn, K. (2018). Integrated Memory Care Clinic: Design, Implementation, and Initial Results. *Journal of the American Geriatrics Society*, *66*(12), 2401–2407. <https://doi.org/10.1111/jgs.15528>
- Comiskey, C., Coyne, I., Lalor, J., & Begley, C. (2014). A national cross-sectional study measuring predictors for improved service user outcomes across clinical nurse or midwife specialist, advanced nurse practitioner and control sites. *Journal of Advanced Nursing*, *70*(5), 1128–1137. <https://doi.org/10.1111/jan.12273>

- Connor, S. R., Centeno, C., Garralda, E., Clelland, D., & Clark, D. (2021). Estimating the Number of Patients Receiving Specialized Palliative Care Globally in 2017. *Journal of Pain and Symptom Management*, *61*(4), 812–816. <https://doi.org/10.1016/j.jpainsymman.2020.09.036>
- Cooper, M. A., McDowell, J., & Raeside, L. (2019). The similarities and differences between advanced nurse practitioners and clinical nurse specialists. *British Journal of Nursing*, *28*(20), 1308–1314. <https://doi.org/10.12968/bjon.2019.28.20.1308>
- Cretu, E., Torabi, S., & Stilos, K. (2023). Palliative care Advanced Practice Nurse role in engaging in serious illness conversations. *Canadian Oncology Nursing Journal*, *33*(3), 377–382.
- Creutzfeldt, C. J., Kluger, B., Kelly, A. G., Lemmon, M., Hwang, D. Y., Galifianakis, N. B., Carver, A., Katz, M., Curtis, J. R., & Holloway, R. G. (2018). Neuropalliative care. *Neurology*, *91*(5), 217–226. <https://doi.org/10.1212/WNL.0000000000005916>
- Davis, M., & Lou, J.-S. (2011). Management of amyotrophic lateral sclerosis (ALS) by the family nurse practitioner: A timeline for anticipated referrals. *Journal of the American Academy of Nurse Practitioners*, *23*(9), 464–472. <https://doi.org/10.1111/j.1745-7599.2011.00628.x>
- Dowling, M., Beauchesne, M., Farrelly, F., & Murphy, K. (2013). Advanced practice nursing: A concept analysis. *International Journal of Nursing Practice*, *19*(2), 131–140. <https://doi.org/10.1111/ijn.12050>
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*(1), 107–115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
- European Environment Agency. (2015). *Driving force* [Term]. <https://www.eea.europa.eu/help/glossary/eea-glossary/driving-force>
- Fagerström, L. (2009). Developing the scope of practice and education for advanced practice nurses in Finland. *International Nursing Review*, *56*(2), 269–272. <https://doi.org/10.1111/j.1466-7657.2008.00673.x>
- Fagerström, L. (2012). The impact of advanced practice nursing in healthcare: Recipe for developing countries. *Annals of Neurosciences*, *19*(1), 1–2. <https://doi.org/10.5214/ans.0972.7531.180401>

Fagerström, L. M. (2021). *A Caring Advanced Practice Nursing Model: Theoretical Perspectives And Competency Domains* (1st ed. 2021) [Electronic resource]. Springer International Publishing : Imprint: Springer. <https://doi.org/10.1007/978-3-030-53555-1>

Ferrell, B., Malloy, P., Virani, R., Economou, D., & Mazanec, P. (2020). Preparing Oncology Advanced Practice RNs as Generalists in Palliative Care. *Oncology Nursing Forum*, *47*(2), 222–227. <https://doi.org/10.1188/20.ONF.222-227>

Finnish National Board on Research Integrity TENK. (2019). Finnish National Board on Research Integrity TENK. <https://tenk.fi/en/finnish-national-board-research-integrity-tenk>

Fischer, A., May, A., Lancaster, M., Alexander, K., & Good, P. (2022). Evaluation of a nurse practitioner role within a specialist palliative care service in Australia. *Progress in Palliative Care*, *30*(5), 295–304. <https://doi.org/10.1080/09699260.2021.1975397>

Flaherty, C., Fox, K., McDonah, D., & Murphy, J. (2018). Palliative Care Screening: Appraisal of a Tool to Identify Patients' Symptom Management and Advance Care Planning Needs. *Clinical Journal of Oncology Nursing*, *22*(4), E92–E96. <https://doi.org/10.1188/18.CJON.E92-E96>

Fund, M. E., & Swanson-Hill, A. (2014). Cost-Effectiveness of Nurse Practitioner Care. *Kansas Nurse*, *89*(1), 12–15.

Godin, K., Stapleton, J., Kirkpatrick, S. I., Hanning, R. M., & Leatherdale, S. T. (2015). Applying systematic review search methods to the grey literature: A case study examining guidelines for school-based breakfast programs in Canada. *Systematic Reviews*, *4*, 138. <https://doi.org/10.1186/s13643-015-0125-0>

Henni, S. H., Kirkevold, M., Antypas, K., & Foss, C. (2021). Perceptions of the scope of practice of nurse practitioners caring for older adults: Level of agreement among different healthcare providers. *Scandinavian Journal of Caring Sciences*, *35*(2), 492–501. <https://doi.org/10.1111/scs.12861>

Hesdorffer, D. C. (2016). Comorbidity between neurological illness and psychiatric disorders. *CNS Spectrums*, *21*(3), 230–238. <https://doi.org/10.1017/S1092852915000929>

- Holm Hansen, E., Bomann, E., Bing-Jonsson, P., & Fagerstrom, L. M. (2020). Introducing Nurse Practitioners Into Norwegian Primary Healthcare-Experiences and Learning. *Research and Theory for Nursing Practice*, 34(1), 21–34. <https://doi.org/10.1891/1541-6577.34.1.21>
- Hussain, J., Adams, D., & Campbell, C. (2013). End-of-life care in neurodegenerative conditions: Outcomes of a specialist palliative neurology service. *International Journal of Palliative Nursing*, 19(4), 162–169. <https://doi.org/10.12968/ijpn.2013.19.4.162>
- International Council of Nurses. (2020). Guidelines on advanced practice nursing. *April, 2020*, 44.
- International Neuropalliative Care Society. (2021). *Neuropalliative care*.
- Jackson, H., West, O., Austin, A., & Peal, K. (2023). Interventions to Improve Advanced Practitioner Work-Related Quality of Life and Patient Satisfaction. *JADPRO: Journal of the Advanced Practitioner in Oncology*, 14(1), 49–53. <https://doi.org/10.6004/jadpro.2023.14.1.4>
- Jokiniemi, K., Kärkkäinen, A., Korhonen, K., Pekkarinen, T., & Pietilä, A.-M. (2023). Outcomes and challenges of successful clinical nurse specialist role implementation: Participatory action research. *Nursing Open*, 10(2), 704–713. <https://doi.org/10.1002/nop2.1336>
- Kaasalainen, S., Ploeg, J., McAiney, C., Schindel Martin, L., Donald, F., Martin-Misener, R., Brazil, K., Taniguchi, A., Wickson-Griffiths, A., Carter, N., & Sangster-Gormley, E. (2013). Role of the nurse practitioner in providing palliative care in long-term care homes: International Journal of Palliative Nursing. *International Journal of Palliative Nursing*, 19(10), 477–485. <https://doi.org/10.12968/ijpn.2013.19.10.477>
- Kendall, M., Cowey, E., Mead, G., Barber, M., McAlpine, C., Stott, D. J., Boyd, K., & Murray, S. A. (2018). Outcomes, experiences and palliative care in major stroke: A multicentre, mixed-method, longitudinal study. *CMAJ: Canadian Medical Association Journal = Journal de l'Association Medicale Canadienne*, 190(9), E238–E246. <https://doi.org/10.1503/cmaj.170604>
- Kennedy, C., Brooks Young, P., Nicol, J., Campbell, K., & Gray Brunton, C. (2015). Fluid role boundaries: Exploring the contribution of the advanced nurse practitioner to multi-professional palliative care. *Journal of Clinical Nursing*, 24(21–22), 3296–3305. <https://doi.org/10.1111/jocn.12950>



- Kilpatrick, K., Kaasalainen, S., Donald, F., Reid, K., Carter, N., Bryant-Lukosius, D., Martin-Misener, R., Harbman, P., Marshall, D. A., Charbonneau-Smith, R., & DiCenso, A. (2014). The effectiveness and cost-effectiveness of clinical nurse specialists in outpatient roles: A systematic review. *Journal of Evaluation in Clinical Practice*, 20(6), 1106–1123. <https://doi.org/10.1111/jep.12219>
- Kilpatrick, K., Savard, I., Audet, L.-A., Kra-Friedman, A., Atallah, R., Jabbour, M., Zhou, W., Wheeler, K., Ladd, E., Gray, D. C., Henderson, C., Spies, L. A., McGrath, H., & Rogers, M. (2023). A global perspective of advanced practice nursing research: A review of systematic reviews protocol. *PLOS ONE*, 18(1), e0280726. <https://doi.org/10.1371/journal.pone.0280726>
- Kleisiaris, C. F., Sfakianakis, C., & Papathanasiou, I. V. (2014). Health care practices in ancient Greece: The Hippocratic ideal. *Journal of Medical Ethics and History of Medicine*, 7, 6.
- Kluger, B. M., Hudson, P., Hanson, L. C., Bužgovà, R., Creutzfeldt, C. J., Gursahani, R., Sumrall, M., White, C., Oliver, D. J., Pantilat, S. Z., & Miyasaki, J. (2023). Palliative care to support the needs of adults with neurological disease. *The Lancet Neurology*, 22(7), 619–631. [https://doi.org/10.1016/S1474-4422\(23\)00129-1](https://doi.org/10.1016/S1474-4422(23)00129-1)
- Lamb, A., Martin-Misener, R., Bryant-Lukosius, D., & Latimer, M. (2018). Describing the leadership capabilities of advanced practice nurses using a qualitative descriptive study. *Nursing Open*, 5(3), 400–413. <https://doi.org/10.1002/nop2.150>
- Landerdahl Stridsberg, S., Richardson, M. X., Redekop, K., Ehn, M., & Wamala Andersson, S. (2022). Gray Literature in Evaluating Effectiveness in Digital Health and Health and Welfare Technology: A Source Worth Considering. *Journal of Medical Internet Research*, 24(3), e29307. <https://doi.org/10.2196/29307>
- Lee, S. K. (2020). Diagnosis and Treatment of Status Epilepticus. *Journal of Epilepsy Research*, 10(2), 45–54. <https://doi.org/10.14581/jer.20008>
- Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science : IS*, 5, 69. <https://doi.org/10.1186/1748-5908-5-69>

- Madden, J. R., Hendricks-Ferguson, V. L., & Foreman, N. K. (2013). Neurologic Symptoms in Pediatric Brain Tumor Patients on Hospice: Continuous-Infusion Midazolam. *Journal of Hospice & Palliative Nursing*, 15(8), 435. <https://doi.org/10.1097/NJH.0b013e3182a57212>
- Maier, C. B., Barnes, H., Aiken, L. H., & Busse, R. (2016). Descriptive, cross-country analysis of the nurse practitioner workforce in six countries: Size, growth, physician substitution potential. *BMJ Open*, 6(9), e011901. <https://doi.org/10.1136/bmjopen-2016-011901>
- Mak, S., & Thomas, A. (2022). An Introduction to Scoping Reviews. *Journal of Graduate Medical Education*, 14(5), 561–564. <https://doi.org/10.4300/JGME-D-22-00620.1>
- National Association of Clinical Nurse Specialists, N. (2022, January 6). *CNS: Trends Look Good In The New Year*. <https://nacns.org/2022/01/2022-cns-trends-look-good-in-the-new-year/>
- O'Mahony, S., Johnson, T. J., Amer, S., McHugh, M. E., McHenry, J., Fosler, L., & Kvetan, V. (2017). Integration of Palliative Care Advanced Practice Nurses Into Intensive Care Unit Teams. *American Journal of Hospice and Palliative Medicine®*, 34(4), 330–334. <https://doi.org/10.1177/1049909115627425>
- Pace, A., Dirven, L., Koekkoek, J. A. F., Golla, H., Fleming, J., Rudà, R., Marosi, C., Rhun, E. L., Grant, R., Oliver, K., Oberg, I., Bulbeck, H. J., Rooney, A. G., Henriksson, R., Pasman, H. R. W., Oberndorfer, S., Weller, M., & Taphoorn, M. J. B. (2017). European Association for Neuro-Oncology (EANO) guidelines for palliative care in adults with glioma. *The Lancet Oncology*, 18(6), e330–e340. [https://doi.org/10.1016/S1470-2045\(17\)30345-5](https://doi.org/10.1016/S1470-2045(17)30345-5)
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., ... Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*, 372, n71. <https://doi.org/10.1136/bmj.n71>
- Peters, M. D. J., Marnie, C., Tricco, A. C., Pollock, D., Munn, Z., Alexander, L., McInerney, P., Godfrey, C. M., & Khalil, H. (2020). Updated methodological guidance for the conduct of scoping reviews. *JBIM Evidence Synthesis*, 18(10), 2119–2126. <https://doi.org/10.11124/JBIES-20-00167>

- Phipps, W. E. (1988). The origin of hospices/hospitals. *Death Studies*, 12(2), 91–99. <https://doi.org/10.1080/07481188808252226>
- Richmond, C. (2005). Dame Cicely Saunders. *BMJ: British Medical Journal*, 331(7510), 238.
- Samuel, A. (2023). Scoping Reviews: Expanding Methodological Approaches to Literature Reviews in Adult Education. *Adult Learning*, 10451595231201346. <https://doi.org/10.1177/10451595231201346>
- Santos, F. C. D., Snigurska, U. A., Keenan, G. M., Lucero, R. J., & Modave, F. (2023). Clinical Decision Support Systems for Palliative Care Management: A Scoping Review. *Journal of Pain and Symptom Management*, 66(2), e205–e218. <https://doi.org/10.1016/j.jpainsymman.2023.03.006>
- Schober, M., & Stewart, D. (2019). Developing a consistent approach to advanced practice nursing worldwide. *International Nursing Review*, 66(2), 151–153. <https://doi.org/10.1111/inr.12524>
- Silver, H. K., Ford, L. C., & Stearly, S. G. (1967). A Program to Increase Health Care for Children: The Pediatric Nurse Practitioner Program. *Pediatrics*, 39(5), 756. <https://doi.org/10.1542/peds.39.5.756>
- Soper, K., Reilly, M., & Krenzer, B. (2023). The Impact of Embedding a Palliative Care Advance Practice Provider on a Neuroscience Intensive Care Unit Service. *The Journal for Nurse Practitioners*, 19(4), 104542. <https://doi.org/10.1016/j.nurpra.2023.104542>
- Stilos, K. (Kalli), Huynh, L., & Wynnychuk, L. (2021). The Advance Practice Nurse: A valuable resource to increase timely access to palliative care for those in need. *Canadian Oncology Nursing Journal*, 31(1), 106–108.
- Tarolli, C. G., & Holloway, R. G. (2020). Palliative care and Parkinson's disease: Outpatient needs and models of care over the disease trajectory. *Annals of Palliative Medicine*, 9(Suppl 1), Article Suppl 1. <https://doi.org/10.21037/apm.2019.11.11>
- The Lancet Neurology. (2021). New hope for advancing neuropalliative care. *The Lancet. Neurology*, 20(6), 409. [https://doi.org/10.1016/S1474-4422\(21\)00142-3](https://doi.org/10.1016/S1474-4422(21)00142-3)

- Tipton, J. (2021). ADVANCED PRACTICE. APRNs Can Lead by Example When Integrating Palliative Care in Practice. *ONS Voice*, 36(11), 20–21.
- Tsiachristas, A., Wallenburg, I., Bond, C. M., Elliot, R. F., Busse, R., van Exel, J., Rutten-van Mólken, M. P., & de Bont, A. (2015). Costs and effects of new professional roles: Evidence from a literature review. *Health Policy*, 119(9), 1176–1187. <https://doi.org/10.1016/j.healthpol.2015.04.001>
- Van Erp, R. M. A., Van Doorn, A. L., Van Den Brink, G. T., Peters, J. W. B., Laurant, M. G. H., & Van Vught, A. J. (2021). Physician Assistants and Nurse Practitioners in Primary Care Plus: A Systematic Review. *International Journal of Integrated Care (IJIC)*, 21(1), 1–17. <https://doi.org/10.5334/ijic.5485>
- Wang, L. H., Elliott, M. A., Jung Henson, L., Gerena-Maldonado, E., Strom, S., Downing, S., Vetrovs, J., Kayihan, P., Paul, P., Kennedy, K., Benditt, J. O., & Weiss, M. D. (2016). Death with dignity in Washington patients with amyotrophic lateral sclerosis. *Neurology*, 87(20), 2117–2122. <https://doi.org/10.1212/WNL.0000000000003335>
- Werheid, K., Volz, M., Ladwig, S., & Hackett, M. (2022). Too Much and Too Little: Antidepressant Treatment in Stroke Survivors during the First Year. *Journal of Integrative Neuroscience*, 21(4), 108. <https://doi.org/10.31083/j.jin2104108>
- What is palliative care—THL*. (2023, September). Finnish Institute for Health and Welfare. <https://thl.fi/en/web/ageing/end-of-life-care/what-is-palliative-care>
- Wheeler, K. J., Miller, M., Pulcini, J., Gray, D., Ladd, E., & Rayens, M. K. (2022). Advanced Practice Nursing Roles, Regulation, Education, and Practice: A Global Study. *Annals of Global Health*, 88(1), 42. <https://doi.org/10.5334/aogh.3698>
- World Health Organization. (2016). *Mental health: Neurological disorders*. <https://www.who.int/news-room/questions-and-answers/item/mental-health-neurological-disorders#:~:text=Neurological%20disorders%20are%20diseases%20of,%2C%20neuromuscular%20junction%2C%20and%20muscles.>

World Health Organization. (2020a). *State of the world's nursing report 2020—Investing in education, jobs and leadership*. *Health Workforce*. <https://www.who.int/publications-detail-redirect/9789240003279>

World Health Organization. (2020b, December 9). *The top 10 causes of death*. <https://www.who.int/news-room/fact-sheets/detail/the-top-10-causes-of-death>

Yip, C., Han, N.-L. R., & Sng, B. L. (2016). Legal and ethical issues in research. *Indian Journal of Anaesthesia*, *60*(9), 684–688. <https://doi.org/10.4103/0019-5049.190627>

Zhukovsky, D. (2019). *Primer of Palliative Care*. American Association of Hospice and Palliative Medicine.

Author, year	Country	Professional title	Roles	Outcomes
Hussain et al. 2013	United Kingdom	Clinical nurse specialist	<p>regular assessment and management of physical symptoms, in addition to psychological, social, and spiritual issues</p> <p><b>direct clinical care provider</b></p> <p>CNS interview patients about preferable place of care, treatment, and support patient's decision making</p> <p><b>patient care coordinator</b></p>	<p>“the CNSs were able to provide support to 100% of the carers”</p> <p><b>- support provider</b></p> <p>“there is some evidence that this resulted in improved patient outcomes, including a reduction in hospital admissions in the last year of life and an increased number of home and hospice deaths”</p> <p><b>- lower hospitals admissions</b></p> <p><b>- healthcare cost reduction</b></p> <p><b>- fulfilling patient's wishes</b></p> <p>“the CNSs, who were trained and specialized in providing palliative care to patients with ANC, acted as the patients' key workers”</p> <p><b>- specialized high quality care</b></p>
Clevenger et al. 2018	United Kingdom	Advanced practice registered nurses	<p>patients' symptom management, medication adjustment</p> <p><b>direct clinical care provider</b></p>	<p>“to avoid a potentially unnecessary visit, caregivers are instructed to contact an on-call APRN before visiting an ED”</p> <p><b>- lower healthcare cost</b></p>

			<p>clinic appointments, ED admissions; conducts scheduled, structured meetings; hospital discharges</p> <p><b>patient care coordinator</b></p>	<p>“APRNs manage all primary care, potentially eliminating communication barriers between staff and providing less-fragmented care”</p> <ul style="list-style-type: none"> <li>- <b>promoting communication</b></li> <li>- <b>proving personalized care</b></li> </ul> <p>APRNs who specialize in dementia may deliver high-quality primary care to the growing population of PLWD and their caregivers</p> <ul style="list-style-type: none"> <li>- <b>enhance quality of health care</b></li> </ul>
O’Mahony et al. 2017	United States	Advanced nurse practitioner	<p>patient’s screening for PC needs; patient's symptom management</p> <p><b>direct clinical care provider</b></p>	<p>“integration of palliative care advanced practice nurses (APNs) into the routine rounding and case-based teaching of interdisciplinary ICU teams is one potential strategy to address the shortage of palliative medicine physicians and standardize decisions for referring patients to palliative medicine teams”</p> <ul style="list-style-type: none"> <li>- <b>addressing the shortage specialized workers;</b></li> <li>- <b>faster access to the care</b></li> </ul>

				<p>“we found that the integration of a palliative care APN into the ICU could have saved approximately US\$224 500”</p> <p><b>- lower healthcare cost</b></p> <p>“decreased time from admission to the ICU until a palliative medicine consultation was conducted”</p> <p><b>- faster access to the care</b></p> <p>“we demonstrated increased use of opioid medications and lower use of laboratory and radiological studies and ventilators in the cases”</p> <p><b>- better symptom management</b></p> <p>“ integration of palliative medicine clinicians into the operations improves quality of care in ICUs “</p> <p><b>- improving quality of care</b></p>
Davis et al. 2011	United States	Nurse practitioners	providing complete comprehensive neurological exam; symptom management; symptom screening	<p>“ the NP may help to reduce costs and standardize care”</p> <p><b>- lower healthcare cost</b></p> <p>“palliative care team provides patients and families with</p>



			<p><b>direct clinical care provider</b></p> <p>design an individualized care plan; coordinate care with multiple specialists</p> <p><b>patient care coordinator</b></p>	<p>much needed support and improves outcomes”</p> <p><b>- improving quality of care</b></p> <p>“anticipation and initiation of appropriate referrals”</p> <p><b>- faster access to the care</b></p>
Madden et al. 2013	United States	Advanced nurse practitioner	<p>symptom-management intervention; providing follow-up care</p> <p><b>direct clinical care provider</b></p> <p>provided guidance, education to patients, family members, medical staff</p> <p><b>educator</b></p> <p>coordinates the outpatient hospice referral</p> <p><b>patient care coordinator</b></p>	<p>“ the patient and family established a strong relationship with the APN who provided clinical care”</p> <p><b>- trust in ANP’s work and competence</b></p> <p>“The APN role in hospice has been shown to be integral and sustainable and to improve quality of life”</p> <p><b>- improving quality of life</b></p> <p>“an APN may help families navigate the EOL process that is known to be difficult”</p> <p><b>- improving patient’s outcomes</b></p>
Kaasalainen et al.	United Kingdom	Nurse practitioner	<p>patient, family members education</p>	<p>“NPs may act as an added resource for LTC nurses,</p>

2013			<p><b>educator</b> symptom management; providing clinical consultations</p> <p><b>direct clinical care provider</b></p> <p>improve access to care</p> <p><b>Patient care coordinator</b></p> <p>supporting staff</p> <p><b>supporter</b></p>	<p>supporting and mentoring them to improve their palliative care practices.”</p> <p>- <b>improving provided care</b></p> <p>“the NP has improved the accessibility and timeliness of care”</p> <p>- <b>faster access to the care</b></p> <p>“The findings of this study related to perceived outcomes of having NPs in LTC (e.g. improved accessibility, reduced hospital visits, better pain management, support for resident and family decision making) have been reported widely“</p> <p>- <b>faster access to the care</b></p> <p>- <b>cost efficiency</b></p> <p>- <b>better symptom management</b></p> <p>- <b>improved patients/family support</b></p>
Soper et al. 2023	United States	Nurse practitioner	<p>patient’s PC consultations</p> <p><b>care provider</b></p> <p>interdisciplinary rounds</p>	<p>“these benefits include improved communication related to prognosis and interventions, more focus on the patient’s wishes and values, helping families understand the</p>

			<p><b>coordinator</b>          providing support and education to staff members;          support patients's decision making</p> <p><b>educator and supporter</b></p> <p>creating advanced care plan</p> <p><b>patient care coordinator</b></p>	<p>viable options, and navigating difficult family relationships.”</p> <p><b>- improved understanding of illness, treatment</b></p> <p>“increase referral numbers to PC from this service and to provide patients and their caretakers with improved symptom management,”</p> <p><b>- faster access to the care</b></p> <p>“NP on the neuroscience ICU team led to a better representative from the unit, improved communication, and improved support for caregivers going through this difficult process.”</p> <p><b>- enhance quality of health care</b></p>
--	--	--	---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Appendix 1. Data extraction table.