

Patient Education in Palliative Care

Descriptive literature review

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Abstract

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Title of the thesis Patient Education in Palliative Care Descriptive literature review		
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Abstract <p>The purpose of this thesis was to discover and enhance knowledge of how patient education is carried out in palliative care through a descriptive literature review.</p> <p>The goal of this thesis was to help healthcare professionals, students, patients, and family members realise the significance of patient education in palliative care. The following aspects of the topic were considered: understanding the effects of patient education in palliative care, the necessity of communication, cultural perceptions, how effectively patients and their families can be prepared for death and healthcare personnel's understanding of palliative care.</p> <p>A literature review was conducted and data for the thesis was gathered from reliable scholarly sources and evidence-based articles. The study method was an exploratory approach to comprehend the topic and justifications to gain a deeper understanding. An inductive content analysis was used to analyse the data.</p> <p>The findings revealed that patient education in palliative care is critical for patients, family members, students, and healthcare professionals for patients to receive quality palliative care. However, nurses working in palliative care face challenges like language barriers in terms of cultural perceptions and inadequate communication skills to address the needs of the patients. To improve patient care, general recommendations for reducing the obstacles healthcare professionals and the common public confront in palliative care call for ongoing education programs.</p>		
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1 Introduction

According to the World Health Organization (2020), approximately 56.8 million individuals, including 25.7 million in the final year of existence, require palliative care every year. However, globally only 14% of those needing it have access to it. The need for it will only keep rising because the population ages and diseases will keep burdening the healthcare systems. To enhance access to palliative care experts in healthcare ought to be trained and the nations must launch proper sources, programme implementations, and strategies. A multi-professional team consisting of doctors, nurses, personnel of pharmacies, physiotherapies, paramedicine, and volunteer organisations plays an essential part in delivering services and care to palliative care clients.

Palliative care is the intense and holistic treatment of people diagnosed with a terminal illness. It aims to manage pain and enhance people's lives. Supporting friends and family members is also part of palliative care. Palliative care may be offered for several years. The final stage of palliative care is end-of-life care. It is given in the final weeks or days of life. The primary goals of palliative and end-of-life care are to alleviate pain and symptoms while also meeting physiological, cultural, emotional, and spiritual aspects. Multidisciplinary care is provided. Palliative care is a fundamental human right. (THL 2022.)

Palliative care patients with cardiovascular or respiratory disease, various cancers, AIDS as well as diabetes are the most common types of clients. In addition, kidney, liver, and neurological patients as well as multiple sclerosis, Parkinson's, rheumatoid arthritis, congenital anomalies, and tuberculosis are conditions that need to be cared for in palliative care. Palliative care is classified as a human right. One of the barriers to adequate palliative care globally is the lack of or incomplete training of professionals. (WHO 2020.)

Patient education is the central factor in the healthcare sector. The fundamental objective of patient education is to provide the patients and their loved ones with an understanding of their health and free interaction. This enables patients to express their wishes and allows them to understand the services that suit their needs. (Adapa et al. 2020.)

The purpose of the thesis is to find out about patient education in palliative care, how it is carried out, and what impact it has on patients, family members, and caregivers. The aim is to highlight the importance of patient education so that patients and healthcare professionals will understand its worth.

2 Key concepts

2.1 Palliative care

Palliative care is defined as holistic and active care of patients and their loved ones suffering from an illness that is life threatening or incurable. Palliative care aims to maintain quality of life and relieve physical, psychosocial, and existential suffering. Palliative care is a broader concept than just end-of-life care, which is also a part of palliative care and takes place in the proximity of assumed death. (Saarto et al. 2015, 10.)

The World Health Organization defines palliative care as a way of promoting a better life for sufferers, both grown-ups and paediatrics together with their loved ones, who are experiencing challenges related to severe sickness. It improves life and alleviates agony through early intervention, the right measures, and alleviation of pain and other complications such as physical, cognitive, or psychological. (WHO 2020.)

Palliative care includes dealing with symptoms, patient education about the sickness, survival tactics, and increased knowledge of the prognosis. Victims, their loved ones, and healthcare professionals gain an understanding of palliative care. (Harden & Schembri 2016.)

2.2 Patient education

Inadequate palliative care teaching to medical students within Europe is acknowledged as a serious obstacle to the incorporation of end-of-life in medical management. Several researchers have pointed out that healthcare undergraduates and several newly qualified doctors across the world attain insufficient lessons and training in end-of-life care. Healthcare undergraduates consider palliative care as a major subject to be taught during their studies, but it has been left unattended, hence they felt doubtful regarding end-of-life care provision. (Pieters et al. 2019.)

Patient education is a type of education that is organised by healthcare professionals who are educated in patient education and is aimed at assisting a patient or group of patients and families or family members to monitor their disease's intervention and prevent unnecessary preventable health problems while maintaining or enhancing their quality of life. Patient education is intended to teach patients and family members how to self-manage or adapt treatment to their specific disease, as well as coping skills and techniques. (Vargas-Schaffer & Cogan 2014.)

Patients with incurable conditions are the experts in caring for themselves, but they need to be educated to make the most of it for their own benefit. Patient education is one major part of the whole care administration. It must take into consideration that it is tailored to the patient's condition, the aim of care is common between the care provider and the patient, and the education is delivered according to the patient's schooling and cultural background, and at the most suitable education methods to the patient. (Slama-Chaudhry & Golay 2019.)

2.3 Nursing

Nursing has been described as holistic care and integrative care. Holistic care describes the features required by a caregiver to provide care. Such features include a joint workforce and in cooperation of other care providers in patient care. Holistic nursing acknowledges patients' whole being and uses of different ways to provide care in order to rehabilitate patients' health. Integrative nursing is defined as the knowhow of the practice that promotes patients' fitness and welfare, both patients' descent and neighbourhood are included in care through curative relation. The care follows nursing concepts and nursing theories and bestows operation instructions that can govern care within the clinical atmosphere. (Frisch & Rabinowitsch 2019.)

According to WHO nursing integrates caring independently or jointly with any aged people who are healthy or unwell in any kind of environment. The care can expand from an independent patient to a whole community. Nursing does not mean caring for sick or dying patients only but also comprises health promotion and illness prevention. Nurses are the key players in promoting, preventing, treating, and rehabilitating in primary healthcare.

Nursing can be defined as an evidence-based professional practice aiming at caring for a person and assisting, guiding, and supporting people in promoting health and adapting to live with the limitations caused by an illness (Terveysportti 2021). Nursing is seen as a skilful regulation that is dissimilar from other theoretical studies such as biology, ethnography, and finance. Though theory studies are involved in both scholastic and skilful studies, however, what distinguishes nursing from other studies is the additional clinical research that involves the sufferer and the care provider. Nursing also includes both craft and science that involve compassion and alleviation process. The research also shows that nursing conducive environment directly correlates to nursing quality care leading to contentment, fulfilment, and executive mode of care. (Smith & Liehr 2013, 5–9.)

3 Aim, purpose, and research questions

The aim of this thesis is to help healthcare professionals and students as well as patients and family members to understand the importance of patient education in palliative care.

The purpose of this thesis is to discover and enhance the knowledge of how patient education is carried out in palliative care through a descriptive literature review.

The following are the research questions of the thesis:

1. What is patient education in palliative care?
2. What is the impact of patient education?

4 Methodology

4.1 Literature review

A literature review is a method of summarising comprehensive information and interpreting research material on a particular topic. Analysing the material available on the topic assists the reader so that they do not need to access all the studies used in the report, but to learn from the review in which a lot of information is combined. It is the duty of healthcare professionals to keep on top of the latest findings in providing quality care. Reading just one study may not give the full picture of the topic and therefore the care may not be based on the most reliable information. Each study is looked at the review in perspective of each other thus providing a comprehensive view of the topic. The literature review consists of a research question for which answers are searched by a systematic approach, evaluation, and analysis of the literature. The conclusion of the review is produced, and the evaluation of the selected literature is explained. The literature review ends in the discussion section and provides recommendations for implementation. (Aveyard 2014, 2–4.)

A literature review is a breakdown of present scientific and theoretical information about a specific problem, including a formation of both what is known and what is unknown about the problem. A literature review may be carried out to sum up analysis insights for practice or to guide the development of analysis to enhance the evidence required to guide practice. This method provides critical information for scrutinising the existing literature segments of both qualitative and quantitative studies, analysing gathered literature, and reconstructing research findings to support evidence-based practice. A literature review on the detection and treatment of bed sores is described as an example of scientific information that is available to be implemented in practice. (Burns & Grove 2003, 110–111.)

A literature review comprises various structures; it consolidates the studies done by others, condemns earlier researchers' work, assembles gaps between comparable topics, and points out the main subject in the domain (Creswell 2014, 28).

According to Kangasniemi et al. (2013), a literature review includes primary and secondary materials/publications, and there are three types of literature review: descriptive, systematic, and meta-analysis. The descriptive literature review is widely used but its definition of methodical reasoning has historically been used partially conflicting in the literature, Descriptive literature review answers study questions in a narrative, descriptive manner. Its procedures are as follows:

- 1) Formulate a research question.
- 2) Select information.

- 3) Construct a descriptive.
- 4) Examine the generated outcomes.

4.2 Inclusion and exclusion criteria

The criteria for article selection are specified in Table 1. The general criteria are the language, publication date, whether free or payment is required, and if full text is available.

Table 1. Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Language either English or Finnish	Language other than English or Finnish
Publication date between 2013 and 2023	Publishing date before 2013
Free	Payment required for access
Full text available	Abstract available only

4.3 Content analysis

Deductive and inductive reasoning are methods used in understanding and forming a reason that supports the conclusion of a phenomenon studied. Deductive reasoning studies the subject starting from the overall and finishing at the specific while inductive reasoning moves vice versa. Inductive reasoning studies particular topics related to the subject and forms a common argument based on the combination of observations. (Gillis & Jackson 2002, 10.) Similarly, Polit and Beck (2014, 379 & 382) define deductive reasoning as forming a particular expectation from broader beliefs while inductive reasoning is the process of creating a broader understanding from specifics. According to the same authors (2014, 42), deductive reasoning is commonly practised in quantitative studies while inductive is used in qualitative research.

Conclusions on qualitative and quantitative analyses are accomplished on different grounds. Qualitative analysis results are formed by describing hypotheses based on observations of the research with the distinguished theoretical context enhanced by rational reasoning. The inductive reasoning process is used in qualitative analysis in which theories are formed from observations of a certain pattern. It is common that the results of the qualitative analysis do not produce a straightforward outcome but form a set of questions or theories that require quantitative analysis. (Boswell & Cannon 2014, 353.)

In this thesis, inductive content reasoning was used in data analysis. Appendix 7 displays the analysis performed.

4.4 Data search

The following databases were used in the data search for suitable articles to answer the research questions: Ebsco Cinahl, PubMed, Google Scholar, and Duodecim. Table 2 indicates the databases utilised, search terms and delimitations used, and the number of articles selected from each search result.

Table 2. Databases utilised

Database	Search terms	Delimitations	Results	Selected
EBSCO CINAHL	patient education AND palliative care	Full text, English, 2013-2023	105	5
EBSCO CINAHL	patient education AND palliative care AND nursing	Full text, English, 2013-2023	45	4
EBSCO CINAHL	palliative care or end- of-life care or terminal care or hospice care AND patient education or patient teaching or counselling or guidance or patient information AND nurse or nurses or nursing or nursing staff or healthcare professional	Full text, English, 2018-2023	77	2
PubMed	patient education AND palliative care AND nursing	Full text	144	3
PubMed	patient education AND palliative care	2018-2023, free full text, full text	112	1

Duodecim Oppiportti	potilasohjaus	palliativinen hoito	3	1
Google Scholar	potilasohjaus palliativinen	2013-2023	478	1
Google Scholar	patient education in palliative care	2019-2023	971000	1
Duodecim- lehti	Palliativinen hoito	2013-2023	103	2

5 Results

5.1 Impact of patient education in palliative care

According to Ansari et al. (2018), there is not adequate knowledge provided to patients suffering from cancer about their disease. This also applies to family members or others caring for the patients. The patients are not aware of the diagnosis, how the disease is likely to progress, what kind of complications are expected, and how they can get access not only for assistance but also for coping with the new situation. Education needs to be provided to patients on symptom management and coping skills.

Pelto et al. (2019) have brought up issues raised by cancer patients and their loved ones in areas where more training is required. These are pain management, pain medication, non-pharmaceutical pain relief as well as education on evidence-based pain management and training on pain assessment. In addition, to reduce various fears and beliefs patients and family members have, there is an interest in learning about the pain caused by cancer, the side effects of medications, and about safe dosage of pain relief medication. Also, the use and effect of various pain medications have been unclear to patients. Pain management education has eased the patient's perception of pain.

According to Chen et al. (2020), the end-of-life awareness programme encourages older adults with persistent health conditions, their relatives, and carers to change their attitudes towards death from one of avoidance to one of neutral acceptance and enhanced death competence. The effective support and health information that the death education programme offers also contribute to the decrease in anxiety surrounding mortality.

The patient strategies for engagement give elderly people psychological assistance as well as attention, thereby leading to an open discussion about death. Consequently, mortality education should not only discuss life and death but also give individuals useful advice on how to handle situations that are related to death. (Chen et al. 2020.)

It is critical to emphasise that the discourse is about the patient, not the nurses. To avoid the patients feeling abandoned, nurses should ensure that their patients are transitioned to a healthcare expert who can address their requirements while caring for them in the meantime. (Dahlin 2018.)

Goal-of-care dialogue was seen as a key element in the palliative care unit since it enables healthcare providers to have a greater knowledge of the patient's values, goals, and choices, especially for heart failure patients. Through these discussions, it may be possible

to link patients to additional health resources that will help them with unfulfilled palliative care needs and enhance their quality of life in general. (Doorenbos et al. 2016.)

Patients require professional guidance on their own care and symptom management to retain their mental state in balance. Interaction, listening, and guiding are essential factors in palliative care. No special psychotherapeutic skills are required in ordinary situations, patient guidance is sufficient. However, in more demanding cases it is necessary to consult a psychiatric unit for help. The patient and the carer should also comprehend how the care process goes and what are the means to manage symptoms in order to maintain trust and the feeling of staying in control. Good somatic symptom management, trust, and the care relationship create the foundation for the mental health of the patient. The aim is for the patient to be able to function according to their somatic capacities. Interaction based on active listening, education on the disease and treatment during all stages of cancer care are the focus to prevent anxiety and depression. Looking after mental health is one part of holistic palliative care. (Idman 2015.)

As stated by Chosich et al. (2020), regardless of multiple studies confirming the advantages of integrating palliative care into oncology there are still issues that prevent ideal application of palliative care. Some of the clear benefits of the integration have been seen as more satisfied patients with a better quality of life and fewer mental health symptoms. It is also found to prolong life. In addition, more beneficial cancer treatment scheduling, less assertive terminal stage care, improved resource management, improved support to caregivers and even financial advantages have been associated with providing palliative care along with oncological care.

Reasons for not getting into palliative care are not seen only among patients and their loved ones, but also among healthcare professionals. Findings indicate that palliative care is still heavily related to the end of life or even as being the last hope. Doctors may be hesitant to talk about palliative care with their patients because of its common unpleasant perception. On the other hand, patients can be reluctant or even not capable of fully comprehending their diagnosis. A common barrier to late referrals to palliative care is not knowing or comprehending what palliative care can offer and how it can improve the patient's life. (Chosich et al. 2020.)

Nyatanga (2015) emphasises that patients need to be given true and current education on their condition, care, and prognosis because it affects their palliative and end-of-life care outcomes. Decision-making is a process which produces a conclusion according to the information received. If patients cannot fully comprehend the information, they may choose the option that they are previously familiar with. Conclusions are affected by factors such

as what data is available at the time of decision-making, stereotypes of previously acquired information, and the probability of something taking place. For example, a patient may not want to go to the hospice because they don't have accurate information on modern hospices and have a mindset that if they go, they will die. Therefore, the education must be valid so that the patients can make the right decisions.

Nurses are in the best position to notice the patients who would be ideal candidates for palliative care despite the patient's exact chronic and non-curable illness. In fact, they are the patients' advocates to consult the appropriate health professionals with the patient's needs and possibly start the conversation with the patients about the care that they would benefit from the most. By educating the patients on how to sustain their quality of life regardless of the terminal illness, for instance, such as heart failure. There is evidence that by proper referral to appropriate services heart failure patients' admission to hospital care has been reduced. (Ivany and While 2013.)

According to Ivany and While (2013), research has shown that inadequate knowledge about heart failure and its inevitable progression bothers patients and therefore lowers their quality of life. In addition, insufficient attention to the patient's psychosocial requirements results in a decrease in their life quality. However, the patients would often be willing to accept an offer to discuss with a mental health professional (Cortis and Williams 2007, according to Ivany and While 2013.)

5.2 Importance of communication

The methods used in patient education have been satisfying. Sufficient time in the training session has created a peaceful learning environment. The language used in the training sessions has been easy to comprehend and the information has been delivered without professional jargon, which has strengthened the patient's feeling of being well cared for. Guidance has been provided using both oral and written instructions. The patients have indicated that they have found videos, voice recordings, and information from the internet supporting the education. Good interaction with the patient and considering the individual guidance requirements of the patient have reduced the worry about talking about the fears and prejudice relating to the disease and medication. (Pelto et al. 2019.)

The relationship between the nurse, patient, and family should be crucial to the death education programme. To discuss delicate subjects with patients and their family carers, nurses should first build a foundation of trust with patients. Since nurses typically interact with patients and their families the most when they are in the hospital, it is not difficult for them to build strong relationships with them. Patients and their families only feel safe to

address the subjects related to death for which they typically strive based on confidence. (Chen et al. 2020.)

According to Henoch et al. (2013), all medical personnel should undergo palliative care training since effective communication is crucial to both nurses and palliative therapy. Perspectives on caring for patients experiencing meaninglessness is a communication-related topic about nurses' reactions when a patient nearing the end of life declares that their life has become worthless, which is a statement of meaninglessness. The knowledge that death is near makes it necessary for nurses to have a conversation about fundamental issues with the patient.

When nurses interact with palliative patients, it is critical to comprehend their vocal or non-verbal signals of meaninglessness. Nurses should actively and freely listen to patients who are suffering at the end of their lives to support them. Talking about sad and challenging topics may enable patients to comprehend their sickness, which fosters hope, boosts faith, lessens suffering, and alleviates the patient's sense of being forsaken. (Henoch et al. 2013.)

Nyatanga (2017) explains that nurses can impact the patient's quality of life by creating a trusting and functioning relationship by sharing as much information as the patients want to hear on their diagnosis and what is expected to happen. By being proactive nurses can be educative to the right level and provide information on concerns that the patients have. What needs to be considered is that the information needs to be easy to understand and delivered in simple language avoiding professional terminology. Patients must be given enough time to digest the information delivered and not overload them with too much knowledge at the time. Patients are thus prepared to understand the progression of the disease and seek assistance at the ideal time.

Furthermore, patient education not only equips patients with information but also gives power to come to terms with dying. That in turn may result in self-reflecting the past or pondering life's purpose. Expressing empathy, for example by listening to the patient and their wishes, delivers a message that the patient is valued, and they are supported in their condition. It is the little things that produce a trusting connection between nurses and patients and impact the patient's quality of life positively. (Nyatanga 2017.)

Active listening is a skill that needs constant development among other areas of effective communication which mandates compassion and empathy of the health professional in the eyes of the patient. Professionals must observe the patients and be able to interpret when the limit for information has been reached and take an opportunity of the prime time to deliver it. When patients sense empathy, they will have the courage to seek answers to

issues that may be challenging and sensitive. The questions need to be responded to respectfully and honestly according to the nature of palliative care. (Nyatanga 2019.)

Hussain (2019) has also stated that nurses especially are at the frontline managing patients' mental symptoms due to facing the reality of their incurable disease and life coming to an end. The healthcare professionals must be equipped with proper know-how and boldness to initiate discussions about the issues causing anxious feelings in patients. The skills are also needed to guide the patients to stay in control of their own lives, form a clear picture of their situation, and accept what the future will bring. However, the nurses need to give space to the patients to lead the discussion according to their needs, not on the ideas of the nurses. A clear line needs to be drawn between the nurse's and the patient's own opinions. Again, the importance of language needs to be on the level that the patient understands, and no professional terminology should not be used. Active listening and the patient's body language help to guide the discussion to end in a way that both parties agree.

When an open and transparent connection has been created with a patient, health professionals are in the position to raise questions about preparing documents such as an enduring power of attorney, a will, and an advanced care plan. The patients must be aware of the possibility to make decisions on their care and how they want to live the rest of their lives. In other words, they can transcribe and take control of the remainder of their own life. In an accepting environment, patients may feel safe to open up about something they have not been able to say or even think about before. All this assists the patients to concentrate on living their lives to the maximum possible quality. (Hussain 2019.)

5.2.1 Cultural perceptions

According to Semlali et al. (2020), communication is a key component of palliative care, which strives to meet patients' medical, psychological, social, and spiritual needs at the end of life and during severe illness. Communication skills are thus critical in palliative care. When patients and relatives come from diverse cultural backgrounds, nurses in palliative care can face significant obstacles due to language barriers.

Cultural consideration is critical in palliative care when it comes to concerns like decision-making and symptom control. Nurses must be cross-culturally competent since cultural beliefs, values, and experiences impact each patient's definition of a good death. Cross-cultural competency and cultural sensitivity education contain a combination of knowledge, abilities, and attitudes that assist nurses in providing effective care to culturally diverse patients. Individuals have complicated ideas and methods of communication, which can often be conflicting, and cross-cultural education helps to illustrate how to deal with cultural

variety without prioritising one culture over another by focusing on individual patients and families. (Semlali et al. 2020.)

5.3 Before and after death

Education regarding efficient interactions, handling of challenging circumstances, and increased comprehension of the emotional requirements of patients and family members in palliative care could help nurses and other staff members determine the diverse types of grieving and loss encountered and offer suitable personalised condolence care. Grief care provided by the nurses should begin before a patient passes away and should be customised according to the patient's and family members' specific requirements. However, nurses should figure out the kind of support to provide and the level, considering the five phases of grief: denial, anger, bargaining, depression, and acceptance. (Johnson 2015.)

Nurses' confidence in providing palliative education would increase if they were familiar with bereavement theories, additionally, it would allow nurses to assess and understand that bereavement is a holistic process; thus, it is important to analyse each person's needs from a social, psychological, spiritual, and physical viewpoint. Spirituality is seen as a significant aspect of care and is connected to bereavement. (Johnson 2015.)

The palliative care team, especially the nurses, should assist patients in understanding end-of-life decisions, as well as ensure that patients are evaluated on various layers of spiritual, psychological, social, and emotional dimensions of care and that those requirements are satisfied. Nurses should help patients understand that advanced diseases and end-of-life concerns can be managed with a variety of pharmacologic and non-pharmacologic choices using current evidence-based practices. The palliative care staff should always be open and willing to have end-of-life conversations with patients to tackle any unresolved concerns and ensure that patients preserve dignity, respect, and the feeling that they will not be abandoned. (Dahlin 2018.)

While attending to a dying patient's needs, it is important to tell their loved ones about the changes that take place in the patient. They need to be explained what is happening, what is expected, and what medications are used in the patient's treatment. They can be guided on what they can do for their loved one and where they can get support themselves. It is important that the loved ones feel that they are given honest and truthful information. (Korhonen & Poukka 2013.) It is also good to remember that it is the responsibility of health professionals that a child whose parent is about to die will be noticed. A child requires truthful information about their parent's disease, treatment, prognosis, and approaching death on a level suitable for their age. (Marjamäki & Leppälä 2021) Korhonen and Poukka

(2013) add that because the family may have taken care of the patient's medications in the past, it is useful to explain to them why and how the medications will be reduced.

It is beneficial to talk to the loved ones about what takes place at the time of death and what needs to be done after breathing ceases. This will ease fears and prevent unnecessary procedures. Paying attention to loved ones is vital while caring for a dying patient. (Korhonen & Poukka 2013.)

It is a natural process for a cancer patient not to be able to eat food as the disease worsens and the patient approaches the end of life. Patients and their families find it difficult to accept or realise that they will never be able to eat normally again. Parenteral nutrition (PN) is given to patients who cannot tolerate oral or enteral feeding as part of standard medical practice. In critically unwell patients, PN treatment may assist in improving clinical outcomes. (Jung et al. 2020.)

The fluid treatment, intensive nutrition, or dextrose water fluid support in advanced cancer patients who cannot be nourished by the enteral route, according to Jung et al. (2020), improves the patient's quality of life. However, patients and relatives should be taught about the risks and benefits of parental nutrition at the end of life.

5.4 Healthcare workers understanding of palliative care

Palliative care is no longer limited to cancer patients nearing the end of their lives but also includes a wide range of other terminal illnesses, such as neurological diseases. Multiple sclerosis, amyotrophic lateral sclerosis, Parkinson's disease, and Alzheimer's disease are the most common neurodegenerative illnesses in the Western world. Patients and carers are unaware of the progression and accessible treatment and support packages. Patients with neurodegenerative diseases urgently require palliative care, and nurses and carers must be better prepared to deal with these diseases. Nurses must recognise that palliative care for neurological disorders differs from cancer care and requires further and refined investigation. (Dieplinger et al. 2017.)

Palliative care has an important part in healthcare systems around the world. Governments need to allow for sufficient education to health professionals delivering palliative care who in turn pass the information on to patients and family members. General awareness of palliative care can be spread by the means of media, communities, schools, and volunteers. Regardless of the awareness-raising efforts only 20 countries have stated that the public has moderate knowledge of palliative care services. (Ansari et al. 2018.)

According to evidence health professionals' palliative care skills are usually at a low level at the beginning of employment in palliative care. More training is required particularly on managing symptoms, communicating with the clients, and providing counselling. Adequate training is the key to the ability to deliver efficient services in palliative care. (Ansari et al. 2018.)

Healthcare professionals, especially nurses, must not only establish a supportive connection with the patient when providing palliative care but also acknowledge the individual's desire for self-determination, holistic treatment, and understanding of life's purpose. In a palliative care programme, the use of communication and information improves patient care. Continued education will advance medical professionals' understanding and enable nurses to effectively communicate with patients and families about mortality, treatment plans, procedures, and quality of life. Through communication, nurses are also able to find a suitable support network, allow patients to discuss their thoughts and emotions, and show empathy. (Isler 2017.)

According to Dahlin (2018), nurses must be willing to listen to their patients because it is their story and process. Listening detects the presence of spiritual or emotional discomfort, allowing nurses to address anxieties and concerns and tailor a care plan to the patient. Patients must understand that palliative care is always about patient-centred, family-focused care, and it is critical for them to understand how nursing fits into end-of-life discussions.

Patients suffering from neurodegenerative illnesses are treated differently than cancer patients. The study was able to identify several characteristics and problem areas in the care of patients with neurodegenerative diseases. There is a great need for support, including psychosocial and spiritual, not only for the patient but also for the carer. (Dieplinger et al. 2017.)

In the case of cancer, consultation regarding the condition and options, such as assistive services, financial support, and care options, occurs significantly sooner, frequently at the time of disease diagnosis or during hospitalisation. With neurodegenerative disorders, consultation services begin only when physical limits show and care dependency becomes too taxing on carers. As a result, patients with neurodegenerative disorders and their carers require early integration and the finest supportive care available. (Dieplinger et al. 2017.)

In addition, according to study findings, nurses who underwent palliative care training communication confidence grew greatly when caring for palliative cancer patients. Having a greater theoretical and practical understanding of existential themes, as well as the sharing of subjective experiences with peers during nurse group discussions, appear to be

beneficial factors in improving nurses' communicative confidence. Additionally, it makes it easier for nurses to talk to patients about life and death, which helps patients cope even in trying circumstances. (Hench et al. 2013.)

6 Discussion

6.1 Review of the results

The aim of this thesis is to help healthcare professionals, students, patients, and family members understand the importance of patient education in palliative care, while the purpose is to discover and enhance the knowledge of what patient education is and how it is carried out in palliative care. The study's objectives were met, and the results of the research questions could be projected from the findings of the analysis of the literature. The findings are examined through the context of the study subjects.

Based on the findings, Ansari (2018) and Pelto et al. (2019) addressed the patients' and their families' need for education on symptom and pain management. There is evidence that pain management education particularly has eased the patient's perception of pain. On pain medications especially there has been interest in the effect and side effects of pain relief medications and safe dosage. Non-pharmaceutical pain management and pain assessment are also issues that have been identified as beneficial. Professional guidance on the patient's own care and somatic symptom management assists them in retaining their mental state and enables them to function according to their capacities (Idman 2015). In addition, it has also been noted that the end-of-life awareness programme can decrease anxiety related to mortality by changing attitudes from avoiding the topic to accepting it neutrally (Chen et al. 2020).

In the larger community, there is a lack of information regarding patient education on palliative care, as well as a lack of recognition of who could provide palliative care settings and the multidisciplinary approach, showing a lack of knowledge of the variety of palliative care services. More information is needed in palliative care to alleviate negative emotions such as fear and hopelessness in patients who believe palliative care is primarily concerned with end-of-life care. (Chosich et al. 2020.)

Most of the selected articles show that at the final stage of life, patients tend to lose control of their being, tend to worry, become depressed and furious, and anticipate their foreseeable survival. As a result, healthcare professionals in palliative care need to focus their efforts more on alleviating pain and improving patients' quality of life. Managing and controlling uncomfortable symptoms such as pain, exhaustion, anxiety, and nausea/vomiting and offering special attention to patients' mental well-being. Challenges, such as pain, can sometimes exacerbate a patient's nervousness; hence, managing them can help alleviate the nervousness. Caring for the dying person's relatives can assist in comforting the patient and reducing their fears; it can even lead to a peaceful demise.

Consequently, families who witness a calm death may go through a less traumatic grief period. (Nyatanga 2019.)

The education given to the patients must be current and true because it will impact the outcome of the care. Patients must be able to make the right decisions based on valid information. (Nyatanga 2015). Pelto et al. (2019) point out that the language used in training patients must be easy to understand, the learning environment needs to be peaceful and sufficient time allowed for the session. Based on patients' feedback on top of oral and written instructions videos, voice recording, and internet supported education have been useful.

Most patients' future perspectives and aspirations are typically altered because of their final illness. One major effect is a loss of independence, which puts most patients in a position of reliance, lowering their sense of self-worth and confidence. During this stage, it is critical for palliative care nurses to demonstrate compassion for the patients and their current predicament. (Nyatanga 2017.) During the palliative and end-of-life stages of care, patients and their loved ones make lots of decisions. Nurses need to know how those decisions are made and what influences them. It is also essential to underline that decisions are the result of analysing the information at hand, the context in which the information is gained, and the source of the information. (Nyatanga 2015.)

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Hench et al. (2013) recommend that all medical personnel should receive training on palliative care. Findings reveal that not fully comprehending what palliative care is and how it can improve the patient's life is a common barrier in late referrals to palliative care. Also, the perception among patients and healthcare professionals that palliative care is the last hope or only related to end-of-life has been identified. (Chosich et al. 2020.) Hench et al. (2013) continue, that communication is crucial in palliative care and nurses should actively listen to patients talking about challenging issues such as when a patient declares a statement of feeling meaningless by vocal or non-vocal signals. Allowing patients to talk assists them to comprehend their sickness, decreases their suffering and alleviates their sense of being forsaken. Nyatanga (2017) adds that nurses expressing empathy deliver a message that the patient is noticed and supported in their condition. A trusting nurse-patient relationship has an impact on the patient's quality of life. Patients' families also feel

comfortable discussing delicate issues such as questions related to death when nurses have built a foundation of trust (Chen et al. 2020).

Furthermore, on communication, Nyatanga (2019) highlights that patients' questions must be answered respectfully and honestly. Health professionals must observe when the patient has reached the limit of information they can take in and if the time to deliver the information is the best. Professionals need the proper know-how and boldness to initiate difficult discussions that cause anxious feelings in patients, and at the same time keep in mind that the patients need to be allowed to lead the discussion (Hussain 2019). Palliative care staff should always be available to have discussions on end-of-life and tackle unresolved concerns patients may have (Dahlin 2018).

It is critical for healthcare practitioners delivering end-of-life care to carefully integrate cross-cultural teaching components into an internationally appropriate curriculum. Palliative care patients come from a variety of cultural, religious, and linguistic backgrounds. Patients would benefit more when cultural diversity is supported within palliative care because it will improve smooth collaboration among the professionals providing care, hence patients' culture and religion will be treated with dignity and respect. Culture needs to be considered particularly when it comes to decision making and symptom control in the delivery of effective care. Knowledge, abilities, and attitudes are part of cross-cultural competency and cultural sensitivity (Semlali et al 2020.)

Regardless of the patient's specific chronic and incurable illness, healthcare professionals, especially nurses, are in the best position to identify patients who are suitable for palliative care. Despite indications that patients value the opportunity to discuss their lives with a psychologist, healthcare practitioners, and carers', their psychosocial needs are left unaddressed. (Ivany & While 2013.)

Dahlin (2018) and Johnson (2015) discuss the aspects of spiritual, social, and psychological patient care. Spirituality is connected to bereavement and grieving, which are significant parts of palliative care. Nurses should be able to provide grief care customised to the patient's and their family members' requirements before the patient's death and consider all five phases of grief. Understanding bereavement as a holistic process and distinguishing denial, anger, bargaining, depression, and acceptance assist nurses in increasing their confidence in providing palliative education.

Lack of self-assurance and strong interpersonal abilities among nurses who provide care for grieving patients has become an issue. Pre- and post-registration training and instruction programmes should be suggested as a potential solution to the issue of a lack of confidence among nurses and other healthcare providers during palliative care. Patients in palliative

care benefit more when they are cared for by professionals who have undergone some palliative care programmes since they have confidence in themselves. (Hench et al. 2013.)

Nurses are not involved in writing prescriptions for patients, nor are they a part of the process once patients select physician-assisted death/physician-assisted suicide. However, nurses must be willing to listen to their patients since listening detects spiritual or emotional suffering, allowing nurses to address fear and worries and tailor a care plan for the patient. (Dahlin 2018.)

Many people lack access to palliative care services, which can enhance their quality of life. However, those patients who can afford palliative care frequently prefer to receive expensive, intensive medical treatment in place of palliative care, even though this therapy may not meaningfully extend life. Poor patient and family education about the progressive deterioration of patients' conditions, especially those suffering from heart failure, a lack of motivation amongst medical professionals and patients to address end-of-life preparation, and challenges predicting prognosis in heart failure are the primary explanations for an absence of aim-based care dialogues within palliative settings. (Doorenbos et al. 2016.)

Despite variations among cancer patients, the care of patients with neurodegenerative illnesses has a definite place in palliative care and should be able to extend in the future. It is critical to recognise that patients and carers require consultations and information about assistive at all stages of the disease, the critical importance of carer psychosocial support, and to formally address the differences in palliative care for neurodegenerative diseases. (Dieplinger et al. 2017.)

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When there are signs that death is about to approach, according to Korhonen & Poukka (2013), good guidance on the changes taking place in the dying patient, what happens at the time of death and what needs to be done after the final breath will ease fears of the loved ones. Marjamäki & Leppälä (2021) add the importance of encountering a child, who

must be given truthful information about the parent's condition and approaching death on a level suitable for their age.

The patient might have been cared for by their family members. They must be explained the reasons and how the patient's medications and unnecessary procedures are reduced during end-of-life care. (Korhonen & Poukka 2013.) It can be difficult for the patient and family to accept in case the patient cannot tolerate enteral feeding and need to transfer to parenteral nutrition if it assists in improving clinical outcomes (Jung et al. 2020).

Ansari et al. (2018) discover that health professional's palliative skills are at a low level when they start working in palliative care. Nurses' communication confidence grows when they undergo palliative care training. In addition, their theoretical and practical understanding of existential themes increased. (Hench et al. 2013.)

Also, governments need to realise that giving sufficient education to health professionals will have an impact on the quality of palliative care since nurses pass the education on to patients and family members. That in turn increases the general awareness of palliative care. Ansari et al. (2018) Medical professionals' understanding advances by providing continued education which trains nurses to discuss mortality, treatment plans, procedures, and quality of life with the patients (Isler 2017).

In summary, patient education in palliative care starts with health professionals' sufficient education and goes all the way down to the patients to improve their quality of life by nurses encountering the patients and their family members with respect and dignity. The care involves active listening and providing for the patients' needs while guiding them and their loved ones in the process. Effective communication in simple and understandable language, including cultural aspects, has a significant role in palliative care and creates a trusting nurse-patient relationship.

6.2 Thesis process

A group of three was formed based on the same interest in palliative care and the topic for the thesis was agreed on in autumn 2022. The plan was conducted in November, and the aim, purpose and research questions were set at the same time.

After the database search, which was started in April 2023 and continued into May and early autumn, each participant read the articles selected. The articles were evaluated based on whether they answered the thesis questions. Each participant had an equal opportunity to share their thoughts on each article. Those pieces that were agreed on as unsuitable were excluded. The final selection was done by meeting and discussing online in August.

The final data search results are shown in Table 2 under Chapter 4. The selected articles can be found in Appendix 1.

The quality of each article was evaluated using the appraisal tools of the Joan Briggs Institute. The scores of the appraisal are indicated in Appendix 7.

Inductive content analysis was performed by collecting phrases that formed answers to the thesis questions. The phrases were grouped to create sub-categories which in turn were arranged into upper categories as in Appendix 2.

The results section was written in August 2023. Each member of the thesis group took part in writing, and at the end, every paragraph was reviewed in an online meeting and grouped under suitable headings in mutual agreement. The discussion chapter and conclusion were also produced jointly in September and early October 2023.

6.3 Ethics and Reliability

The person conducting the research must be honest, careful, open, and respectful toward other researchers' work, and they must do the research in a planned manner. The responsibility of following good scientific practices belongs primarily to the researchers themselves. (Arene 2020.)

Research ethics is a broad concept that encompasses all ethical perspectives and survey questions to research and scientific studies. The Finnish Advisory Board on Research Integrity refers to collecting data in an ethically responsible and polite manner and taking steps to avoid forgery and lack of integrity in research. Research integrity emphasises truth and honesty to all researchers in their research work. (TENK 2012.)

While conducting the researcher's own research and disseminating its findings, the researcher takes into consideration the work and accomplishments of other researchers by honouring their efforts and properly citing their publications and giving them the merit, they deserve (TENK 2012).

The thesis is conducted as a literature review and therefore does not involve any significant ethical considerations. By proper citing, the theses give credit to the people who have done the research and can be considered as responsible work.

Data search was performed using reliable databases. Databases utilised were Ebsco Cinahl, PubMed, Google Scholar, and Duodecim. The search was limited to produce articles that were no older than ten years. Only quality articles by palliative care specialists were selected.

In addition, Joanne Briggs Institute (JBI) critical appraisal tools were used to evaluate the quality of the included studies. The articles were mutually appraised by all three members of the thesis group. The tools used were the JBI critical appraisal checklist for text and opinion papers (Appendix 3), for qualitative research (Appendix 4), for analytical cross-sectional studies (Appendix 5), and for systematic reviews and research syntheses (Appendix 6). The results of the appraisal can be seen in Appendix 7.

Joanne Briggs Institute is an organisation that specialises in producing and distributing evidence-based research, software, training, resources, and publications in the healthcare industry globally. JBI's goal is to transfer research outcomes into practice to improve clinical decision making which will result in better health outcomes across the world. JBI's systematic review methods cover diverse questions and study designs and therefore can service literature contributors in planning, implementing, and writing systematic papers, which assist healthcare professionals and those using healthcare systems worldwide. (Aromataris & Munn 2020.)

6.4 Further research

According to the findings of the thesis, patient education has a standing in palliative care which improves patients' quality of life. However, the common public seems to relate palliative care to terminal care and thinks it is the last hope when curative care is not anymore available. We would recommend further research to be done on the question of how the attitude and understanding of palliative care could be changed to be more positive for people to feel more comfortable receiving it.

7 Conclusion

The common public needs education on what palliative care is. The common belief that it is related only to those in the final stage of their life should be corrected. More people will benefit from palliative care if only they have a clear understanding of what it can offer.

Palliative care is most beneficial when started early. Many patients with qualifying diagnoses believe that it is the last resort when all other hope has been utilised. The patients can have their say on their treatment options, place of care, and wishes for the time they are not able to communicate their wishes anymore. These factors need to be discussed when creating their advanced care plan. Adequate patient education has a positive impact on patients in palliative care by improving their quality of life.

It is important to note that palliative care information needs to be delivered at the right time and in the right quantity, not overloading the patients or family members with too much information at one time. Effective communication skills will ease the fear and anxiety and create a trusting care relationship.

Findings obtained from the review show that cancer patients have a sufficient level of knowledge of palliative care and a better grasp of it, and they do not have negative impressions of the care provided, which indicates that they benefit from it. The failure to successfully integrate palliative care is also considered a result of the stigma attached to death and ageing.

Furthermore, the results indicate that healthcare professionals require more training in palliative care skills. Particularly, pain management, communication skills and how to deal with difficult situations are areas that lack the most. It was also noted that patients' carers and family members would like to get more guidance on managing pain with pharmaceutical and non-pharmaceutical methods as well as education on pain medications.

References

- Adapa, K., Jain, S., Kanwar, R., Zaman, T., Taneja, T., Walker, J. & Mazu, L. 2020. Augmented reality in patient education and health literacy: a scoping review protocol. Retrieved on 1 November 2022. Available at [e038416.full.pdf \(bmj.com\)](#)
- Ansari, M., Rassouli, M., Akbari, M., Abbaszadeh, A. & Sari, A. 2018. Educational needs on palliative care for cancer patients in Iran: a SWOT analysis. *International Journal of Community Based Nursing & Midwifery*. Retrieved on 23 April 2023. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5845115/>
- Arene. 2020. Ammattikorkeakoulujen opinnäytetöiden eettiset suositukset. Retrieved on 15 November 2022. Available at https://www.arene.fi/wp-content/uploads/Raportit/2020/AMMATTIKORKEAKOULUJEN%20OPINNÄYTETÖIDEN%20EETTISET%20SUOSITUKSET%202020.pdf?_t=1578480382
- Aromataris, E. & Munn, Z. 2020. *JBIManual for evidence synthesis*. Joanne Briggs Institute. Retrieved on 18 September 2023. Available at <https://jbi-global-wiki.refined.site/space/MANUAL>.
- Aveyard, H. 2014. *Doing a literature review in health and social care*. Third edition. Berkshire: Open University Press.
- Boswell, C. & Cannon, S. 2014. *Introduction to nursing research: incorporating evidence-based practice*. Third edition. Burlington: Jones & Bartlett Learning.
- Burns, N. & Grove, S. 2003. *Understanding Nursing Research*. Third edition. Philadelphia: Saunders.
- Chen, W., Ma, H., Wang, X. & Chen, J. 2020. Effects of a death education intervention for older people with chronic disease and family caregivers: a quasi-experimental study. *Asian nurse res (Korean soc nurse sci)*. Retrieved on 15 June 2023 Available at <https://pubmed.ncbi.nlm.nih.gov/32858214/>
- Chosich, B., Burgess, M., Earnest, A., Franco, M., Runacres, F., William, L., Poon, P. & Yoong, J. 2020. Cancer patients' perceptions of palliative care. *Supportive Care in Cancer*, Vol. 28 (3) 1207-1214. Retrieved on 23 April 2023. Available at <https://doi.org/10.1007/s00520-019-04917-8>
- Creswell, J.W. 2014. *Research design: qualitative, quantitative, and mixed methods approach*. Fourth edition. California: SAGE Publications.

- Dahlin, C. 2018. How can nurses can help patients understand end-of-life options? *Oncology Nursing Society Voice*. Retrieved on 28 August 2023. Available on <https://search-ebSCOhost-com.ezproxy.saimia.fi/login.aspx?direct=true&db=c8h&AN=130639374&site=ehost-live>
- Dieplinger, A., Sari Kundt, F. & Lorenzl, S. 2017. Palliative care nursing for patients with neurological diseases: what makes the difference? *British Journal of Nursing*, Vol 26 (6). Retrieved on 20 July 2023. Available at <https://web-s-ebSCOhost-com.ezproxy.saimia.fi/ehost/pdfviewer/pdfviewer?vid=0&sid=cc483852-c6c7-4b55-9334-af7250dfec36%40redis>
- Doorenbos, A., Levy, C., Curtis, R., & Dougherty, M. 2016. An intervention to enhance goals-of-care communication between heart failure patients and heart failure providers. *Journal of pain symptom management*. Retrieved on 11 July 2023. Available at <https://pubmed.ncbi.nlm.nih.gov/27401505/>
- Frisch, N. & Rabinowitsch, D. 2019. What's in a definition? Holistic nursing, integrative healthcare, and integrative nursing: report of an integrated literature review. *Journal of holistic nursing*. Vol. 37 (3), 260–272. Retrieved on 9 March 2023. Available at <https://journals-sagepub-com.ezproxy.saimia.fi/doi/epub/10.1177/0898010119860685>
- Harden, K. & Schembri, J. 2016. Early intervention with transplantation recipients to improve access to and knowledge of palliative care. *Clinical journal of oncology nursing*. Vol. 20 (4), E88–E92. Retrieved on 7 November 2022. Available at DOI 10.1188/16.CJON.E88–E92m
- Henoch, I., Danielson, E., Strang, S., Browall, M. & Melin-Johansson, C. 2013. Training intervention for healthcare staff in the provision of existential support to patients with cancer: a randomized, controlled study. *Journal of pain and symptom management*. Retrieved on June 26. Available at <https://pubmed.ncbi.nlm.nih.gov/23764108/>
- Hussain, F. 2019. Using a frame of reference for talking to patients about death and dying. *British Journal of Nursing*, Vol 28 (16), 1069–1075. Retrieved on 28 May 2023. Available at <https://web-s-ebSCOhost-com.ezproxy.saimia.fi/ehost/pdfviewer/pdfviewer?vid=0&sid=c0b8fd6d-0d92-4681-9fff-2cacc56ceb91%40redis>
- Idman, I. 2015. Psykososiaalinen tuki ja psyykkisten oireiden hoito syöpäpotilailla. *Duodecim Oppiportti*. Retrieved on 5 August 2023. Available at https://www.oppiportti.fi/op/pli00132/do?p_haku=palliativinen%20potilasohjaus#q=palliativinen%20potilasohjaus

- Isler, A. 2017. Palliative and Hospice Care versus Standard Care on Quality of Life and Suffering. *Kentucky Nurse*, Vol. 65 (3), 6–7. Retrieved on 16 July 2023. Available at <https://search-ebshost-com.ezproxy.saimia.fi/login.aspx?direct=true&db=c8h&AN=123942369&site=ehost-live>
- Ivany, E. & While, A. 2013. Understanding the palliative care needs of heart failure patients. *British Journal of Community Nursing*, Vol 18 (9), 441–445. Retrieved on 23 April 2023. Available at doi:10.12968/bjcn.2013.18.9.441
- Johnson, A. 2015. Analysing the role played by district and community nurses in bereavement support. *British Journal of Community Nursing*, Vol. 20 (6), 272–277. Retrieved on 16 July 2023. Available at <https://web-s-ebshost-com.ezproxy.saimia.fi/ehost/detail/detail?vid=1&sid=8f159f43-91b3-442a-b0c7-934b48985b1d%40redis&bdata=JnNpdGU9ZWwhvc3QtbGl2ZQ%3d%3d#AN=109794482&db=c8h>
- Jung, K., Oh, S., Jun, H., Song, B., Park, K., Oh, S., Kim, J. & Park, E. 2020. Effect of education on preference of parenteral nutrition for patients in palliative care unit: quantitative and qualitative study with an anthropological approach. *Annals of palliative medicine*, Vol. 9 (5), 2793–2799. Retrieved on 23 April 2023 Available at <https://doi.org/10.21037/apm-20-269>
- Kangasniemi, M., Utriainen, K., Ahonen, S., Pietilä, A. & Jääskeläinen, P. 2013. Kuvaileva kirjallisuuskatsaus: eteneminen tutkimuskysymyksestä jäsenettyyn tietoon. *Hoitotiede*. Vol. 25, No. 4. Retrieved on 16 November 2022. Available at <https://www.proquest.com/docview/1469873650?fromopenview=true&pq-origsite=gscholar>
- Korhonen, T. & Poukka, P. 2013. Kuolevan potilaan hoito. *Duodecim*. Retrieved on 21 August 2023. Available at <https://www.duodecimlehti.fi/lehti/2013/4/duo10821?keyword=palliativinen%20hoito>
- Marjamäki, E. & Leppälä, L. 2021. Kuolemaa lähestyvä potilas - miten keskustelen lapsen kanssa? *Duodecim*. Retrieved on 21 August 2023. Available at <https://www.duodecimlehti.fi/lehti/2021/21/duo16514?keyword=palliativinen%20hoito>
- Nyatanga, B. 2015. Decision making in palliative and end-of-life care. *British Journal of Community Nursing*, Vol. 20 (9), 462. Retrieved on 23 April 2023. Available at <https://doi.org/10.12968/bjcn.2015.20.9.462>

Nyatanga, B. 2017. The small things matter in end-of-life care: a personal reflection. *British Journal of Community Nursing*, Vol. 22 (3), 152. Retrieved on 23 April 2023. Available at doi:10.12968/bjcn.2017.22.3.152

Nyatanga, B. 2019. Put life into their days, and not days into their life. *British Journal of Community Nursing*, Vol 24 (12), 610. Retrieved on 28 May 2023. Available at <https://web-s-ebshost-com.ezproxy.saimia.fi/ehost/pdfviewer/pdfviewer?vid=0&sid=9bcbfa23-075c-4446-bd3c-da5d434e3ce6%40redis>

Pelto, A., Hökkä, M. & Kajula, O., Kaakkinen, M. 2019. Kivunhoidon ohjaus syöpää sairastavan potilaan ja hänen läheisensä kuvaamana palliatiivisessa hoidossa – integroitu kirjallisuuskatsaus. *Tutkiva hoitotyö*. Retrieved on 2 August 2023. Available at <http://jultika.oulu.fi/files/nbnfi-fe2019082124966.pdf>

Pieters, J., Dalmans, D., Verstegen, D., Warmenhoven, F., Courtens, A., Merieke, J. & Everdingen, M. 2019. Palliative care education in the undergraduate medical curricula: Students' view on the importance of, their confidence in, and knowledge of palliative care. Retrieved 10 November 2022. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6712798/>

Saarto, T., Hänninen, J., Antikainen, R. & Vainio, A. 2015. *Palliatiivinen hoito*. 3. edition. Helsinki: Duodecim.

Semlali, I., Tamches, E., Singy, P. & Weber, O. 2020. Introducing cross-cultural education in palliative care: focus groups with experts on practical strategies. *BCM Palliative Care*. Retrieved on 1 September 2023. Available at <https://doi.org/10.1186/s12904-020-00678-y>

Slama-Chaudhry, A. & Golay, A. 2019. Patient education and self-management support for chronic disease: methodology for implementing patient-tailored therapeutic programmes. *Public health panorama*, Vol. 5 (2–3), 123–367. Retrieved on 28 August 2023. Available at <https://apps.who.int/iris/bitstream/handle/10665/330106/php-5-2-3-357-361-eng.pdf?sequence=1&isAllowed=y>

Smith, M. & Liehr, P. 2013. *Middle range theory for Nursing*. Third edition E-book. New York: Springer publications. Accessed on 29th March 2023. Available at <https://ebookcentral.proquest.com/lib/lab-ebooks/detail.action?docID=1182694>

TENK Finnish Advisory Board on Research integrity. 2012. Responsible conduct of research and procedures for handling allegations of misconduct in Finland. Retrieved on 15 November 2022. Available at https://tenk.fi/sites/tenk.fi/files/HTK_ohje_2012.pdf

Terveysportti. 2021. Sanakirjat: Lääketieteen termit. Retrieved on 25 March 2023. Available at <https://www.terveysportti.fi/apps/sanakirjat/0/hoitoty%C3%B6>

THL. 2022. What is Palliative Care. Retrieved on 16 November 2022. Available at <https://thl.fi/en/web/ageing/end-of-life-care/what-is-palliative-care>

Vargas-Schaffer, G. & Cogan, J. 2014. Patient therapeutic education: placing the patient at the centre of the WHO analgesic ladder. *Can Fam Physician*. Retrieved on 12 April 2023. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3952757/>

WHO. Nursing and midwifery. Retrieved on 25 March 2023. Available at https://www.who.int/health-topics/nursing#tab=tab_1

WHO. 2020. Palliative care. Retrieved on 8 November 2022. Available at <https://www.who.int/news-room/fact-sheets/detail/palliative-care>

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Appendix 1. Studies included in the literature review

Authors, publication, year	Purpose of the study	Research design	Main results
<p>Ansari, M., Rassouli, M., Akbari, M., Abbaszadeh, A. & Sari, A.</p> <p>2018.</p> <p>Educational needs on palliative care for cancer patients in Iran: a SWOT analysis.</p>	<p>The study surveys the need for education of palliative care associates for cancer patients in Iran.</p>	<p>A qualitative study.</p> <p>Semi-structured interviews with cancer patients, their family caregivers, healthcare providers, experts and policy makers were analysed in the form of SWOT.</p>	<p>Policy makers need to recognise the opportunities, weaknesses and threats while creating tactics to bring palliative care education to the required level. Also, awareness of palliative care must be raised in the public using various avenues.</p>
<p>Chen, W., Ma, H., Wang, X. & Chen, J.</p> <p>2020.</p> <p>Effects of a death education intervention for older people with chronic disease and family caregivers: a quasi-experimental study.</p>	<p>The study investigates the effectiveness of a structured death education program for older adults with chronic illness and their family caregivers.</p>	<p>Quasi-experimental study.</p>	<p>The study shows the importance of death education for older adults with chronic diseases and their families to promote the development of palliative care and the quality of end-of-life.</p>
<p>Chosich, B., Burgess, M., Earnest, A., Franco, M., Runacres, F., William, L., Poon, P. & Yoong, J.</p> <p>2020.</p> <p>Cancer patients' perceptions of palliative care.</p>	<p>The survey was conducted to study the current understanding and experiences of palliative care among cancer patients which has remained negative regardless of early integration of palliative care and oncology.</p>	<p>Cross-sectional survey.</p> <p>A questionnaire handed out to cancer patients admitted to a cancer ward.</p>	<p>The study discovered positive results on the knowledge and experiences of palliative care but points out the need for improved patient and public education.</p>

<p>Dahlin, C. 2018.</p> <p>How can nurses can help patients understand end-of-life options?</p>	<p>The study shows the role of nurses when a patient requests an assisted death.</p>	<p>Article.</p>	<p>The study shows that the request for an assisted death by the patient is not part of palliative care rather the nurses should know how to approach a patient who requests for an assisted death.</p>
<p>Dieplinger, A., Sari Kundt, F. & Lorenzl, S. 2017.</p> <p>Palliative care nursing for patients with neurological diseases: what makes the difference?</p>	<p>The article explains the reason why neurogenerative patients must be included in palliative care against the common misconception that the care is only for oncological patients.</p>	<p>Article. Peer reviewed.</p>	<p>The article highlights the importance of referring neurogenerative patients to palliative care at an early stage of the disease. It is essential to provide psychosocial support, particularly to caregivers who play in big role in the patient's normal routine. Palliative care can benefit neurogenerative patients who often have difficulties with verbal and non-verbal communication.</p>
<p>Doorenbos, A., Levy, C., Curtis, R., & Dougherty, M. 2016.</p> <p>An intervention to enhance goals-of-care communication between heart failure patients and heart failure providers.</p>	<p>The study was done to determine the effects of a goals-of-care intervention, quality of communication between patients and providers, referrals to palliative care services and completion of advance care directives.</p>	<p>Cross sectional study.</p>	<p>The goal of care intervention results in more conversations and higher-quality communication between HF patients and providers without increasing anxiety or depression.</p>
<p>Henoch, I., Danielson, E., Strang S., Browall, M. & Melin-Johansson, C. 2013.</p> <p>Training intervention for healthcare staff in provision of existential support to patients with cancer.</p>	<p>The goal of the study was to determine the effects of nurses training interventions on their confidence in communication and their attitude towards caring for dying patients.</p>	<p>A randomised, controlled trial with a training intervention comprising theoretical training in existential issues combined with individual and group reflection.</p>	<p>The study results show that short-term training with reflection improves the confidence of healthcare staff when communicating, which is important for healthcare managers with limited resources.</p>

<p>Hussain, F. 2019.</p> <p>Using a frame of reference for talking to patients about death and dying.</p>	<p>The article concentrates on the importance of talking openly to patients at the end of life about death and dying.</p>	<p>Article. Peer reviewed.</p>	<p>The article explains that conversations at the end of life can be difficult, particularly if the patient is experiencing mental distress along with their terminal illness. Several factors can disrupt a constructive and supportive conversation around death and dying.</p>
<p>Idman, I. 2015.</p> <p>Psykososiaalinen tuki ja psyykkisten oireiden hoito syöpäpotilailla.</p>	<p>The article provides information on the mental health symptoms of cancer patients and how to alleviate them.</p>	<p>Article.</p>	<p>The article raises the importance of psychosocial support. It states that interaction based on active listening is essential in preventing depression and anxiety, which are common mental health symptoms of cancer patients.</p>
<p>Isler, A. 2017.</p> <p>Palliative and hospice care versus standard care on quality of and suffering.</p>	<p>The article focuses on the impact of standard care on the quality of life and suffering of patients in palliative care.</p>	<p>Article. Peer reviewed.</p>	<p>The article explains the importance of support and religiosity in palliative care, which helps patients manage their lives with confidence. Barriers to social support could include feelings of sickness, an unwilling support system, and depression.</p>
<p>Ivany, E. & While, A. 2013.</p> <p>Understanding the palliative care needs of heart failure patients.</p>	<p>The study focuses on heart failure patients' unmet communication and education needs that could be met effectively by specialist palliative care services.</p>	<p>Systematic review.</p>	<p>The study highlights the need for training nurses in palliative care as key assets in the management of heart failure.</p>
<p>Johnson, A. 2015.</p> <p>Analysing the role played by district and community nurses in bereavement support.</p>	<p>The study aims to explore the provision of bereavement care from a district nurse's perspective.</p>	<p>Article.</p>	<p>The study results suggest an awareness of bereavement care and knowing the types and stages of bereavement was seen as beneficial, hence improving confidence towards its delivery.</p>

<p>Jung, K., Oh, S., Jun, H., Song, B., Park, K., Oh, S., Kim, J. & Park, E.</p> <p>2020.</p> <p>Effect of education on preference of parenteral nutrition for patients in palliative care unit: quantitative and qualitative study with an anthropological approach.</p>	<p>The article through the quantitative and qualitative study analyses how parental nutrition during palliative care can improve the quality of life of a patient.</p>	<p>Prospective quantitative and qualitative study.</p>	<p>The study shows that patients and family members should be educated about the benefits and risks of parental nutrition in end-of-life care.</p>
<p>Korhonen, T. & Poukka, P.</p> <p>2013.</p> <p>Kuolevan potilaan hoito.</p>	<p>The article discusses issues that need to be considered while caring for a dying patient.</p>	<p>Article.</p>	<p>The article explains that good symptom management, communication, and consideration of the patient's family members have an enormous part in looking after a dying patient.</p>
<p>Marjamäki, E. & Leppälä, L.</p> <p>2021.</p> <p>Kuolemaa lähestyvä potilas - miten keskustelen lapsen kanssa?</p>	<p>The article brings out the importance of paying attention to a child whose parent is about to die, and how to discuss with them so that they can comprehend the situation.</p>	<p>Article. Peer reviewed.</p>	<p>The article prompts that children require truthful information about their parent's condition and approaching death at an age-appropriate level.</p>
<p>Nyatanga, B.</p> <p>2015.</p> <p>Decision making in palliative care and end-of-life care.</p>	<p>The article explains what is behind the decisions that are made by patients and families in palliative care and end of life.</p>	<p>Article.</p>	<p>The article highlights the importance of providing adequate information on which the patients and families can base their decisions concerning palliative and end-of-life care.</p>
<p>Nyatanga, B.</p> <p>2017.</p> <p>The small things matter in end-of-life care - a personal reflection.</p>	<p>The article describes how nurses can impact the patient's quality of life by being proactive and using their psychosocial skills.</p>	<p>Article.</p>	<p>The article points out how little gestures increase a patient's understanding of their disease and create a trusting relationship between a nurse and a patient.</p>

<p>Nyatanga, B. 2019.</p> <p>Put life into their days, not days into their life.</p>	<p>The article discusses some principal issues for community nurses to consider in enhancing the lives of dying patients.</p>	<p>Article. Peer reviewed.</p>	<p>The study explains compassionate care through communication, the need for health professionals to understand how much information the patient needs and when to share it, and the integration of palliative care into existing services.</p>
<p>Pelto, A., Hökkä, M. & Kajula, O., Kaakkinen, M. 2019.</p> <p>Kivunhoidon ohjaus syöpää sairastavan potilaan ja hänen läheisensä kuvaamana palliativisessa hoidossa – integroitu kirjallisuuskatsaus.</p>	<p>The review describes perceptions of pain education among cancer patients and their caregivers in palliative care.</p>	<p>Integrative literature review.</p>	<p>The review explains that patients find pain education satisfying, but wish to receive more information on pain, pain medications and their side effects, and non-pharmaceutical pain management.</p>
<p>Semlali, I., Tamches, E., Singy, P. & Weber, O. 2020.</p> <p>Introducing cross-cultural education in palliative care: focus groups with experts on practical strategies.</p>	<p>The purpose of the reflective article is to provide interested educators and decision makers with ideas for how to implement cross-cultural training in palliative care.</p>	<p>Thematic content analysis.</p>	<p>The article offers new insights into cross-cultural courses in palliative and end-of-life care and shows how well clinicians working in end-of-life settings are prepared to take care of linguistically and culturally diverse patients.</p>

Appendix 2. Inductive analysis content

Simplified phrases	Sub-category	Upper category
<p>A better understanding of palliative care leads to positive emotions</p> <p>Patient centred care</p> <p>Nurses' role in therapeutic relationship and patient self-determination</p> <p>Patient's spiritual habits allowed, providing a chaplain</p> <p>Recognition of boundaries between the patient's issues and the views of the nurse</p> <p>In ordinary situations, patient guidance is sufficient, and no special psychotherapeutic skills are required</p> <p>Education on pain management, pain assessment and side effects of medications</p> <p>Advanced care plan</p> <p>Decrease in anxiety</p> <p>Increase in quality of life</p> <p>Ensuring assurance</p>	<p>IMPACT</p>	<p>PATIENT EDUCATION</p>
<p>Requirement for information on prognosis and complications,</p> <p>Need for support in adapting to condition, managing symptoms and coping</p> <p>Carers expect guidance on how to manage symptoms</p> <p>Patients worried about worsening physical abilities</p>	<p>DISEASE MANAGEMENT</p>	
<p>Knowledge can rise by reflecting on life and looking for purpose</p> <p>Facing reality and existence</p> <p>Allow the patient to show emotions with professionals and family members</p> <p>A strong patient-nurse relationship creates trust and improves the quality of life</p> <p>Little gestures assist in staying connected with life</p> <p>Acting when recognising psychosocial issues in patients or their careers and offering</p>	<p>EMOTIONAL SUPPORT</p>	

<p>assistance (discussion or referral to specialist care)</p> <p>Education on psychological well-being decreases anxiety and medical symptoms</p> <p>Support to family members at the end of life</p>		
<p>Not able or willing to accept diagnosis</p> <p>Better understanding correlates with better acceptance or reception of services</p>	DENIAL	
<p>Proactive discussion, asking questions on how much the patient wants to know and if they want to know something else</p> <p>Clear information delivery, not all in bulk, and giving patients time to process</p> <p>Truthful information according to the age level</p> <p>Children expect to receive information on their parent's disease, but also to feel that they are paid attention to</p> <p>Active listening particularly</p> <p>Communicating compassionately manifests as empathy to the patient</p> <p>Amount of information given</p> <p>Good communication skills</p> <p>Patients' sensitive questions</p> <p>Poor public awareness</p> <p>Interaction, listening, and guiding are essential factors</p>	INFORMATION DELIVERY	COMMUNICATION
<p>Missed opportunities in the terminal phase</p> <p>Association of palliative care as end-of-life care or 'no hope left'</p> <p>The general public needs to be educated better</p> <p>Raising public awareness</p>	MISCONCEPTIONS	
<p>Information accuracy</p> <p>Timing of providing information</p> <p>Previous prototype knowledge</p> <p>Fear of dying if admitted to hospice</p> <p>First recognisable alternative</p>	DECISIONS	

<p>Language barrier</p> <p>Cross-cultural training</p> <p>Cultural stereotyping of patients</p>	<p>CULTURE</p>	
<p>Explaining family, the reasons for discontinuing medications</p> <p>Guidance to family on what is happening at the time of death</p> <p>Ensuring assurance of patients</p> <p>Patients understanding of pharmacologic and non-pharmacological choices</p> <p>Importance of telling family members truthful information about their dying patient</p> <p>Effectiveness of fluid treatment in patients approaching death</p>	<p>PREPARING FOR DEATH</p>	<p>BEFORE AND AFTER DEATH</p>
<p>Identify grief and its five stages</p> <p>Psychological support at the time of death</p> <p>Routine follow-up of the bereaved helps to anticipate the need for extra mental support</p>	<p>BEREAVEMENT</p>	
<p>Referrals to care given late</p> <p>Lack of knowledge among professionals</p> <p>Not willing or able to deliver bad news or discuss palliative care</p> <p>Inadequate skills and training</p>	<p>LACK OF TRAINING</p>	<p>HEALTHCARE PROFESSIONALS UNDERSTANDING</p>
<p>Need to improve education, communication, research, policies and service delivery</p> <p>Train nurses to deal in challenging situations and how to communicate</p> <p>Training and innovative service delivery</p> <p>Earlier integration of palliative care</p> <p>Demand to be trained in counselling, communication and managing symptoms</p> <p>Propose proper education in universities</p>	<p>POTENTIAL RESOLUTION</p>	

JBI CRITICAL APPRAISAL CHECKLIST FOR TEXT AND OPINION PAPERS

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not applicable
1. Is the source of the opinion clearly identified?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Does the source of opinion have standing in the field of expertise?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Are the interests of the relevant population the central focus of the opinion?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there reference to the extant literature?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is any incongruence with the literature/sources logically defended?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include Exclude Seek further info

Comments (Including reason for exclusion)

JBI CRITICAL APPRAISAL CHECKLIST FOR QUALITATIVE RESEARCH

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include Exclude Seek further info

Comments (Including reason for exclusion)

JBI CRITICAL APPRAISAL CHECKLIST FOR ANALYTICAL CROSS SECTIONAL STUDIES

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not applicable
1. Were the criteria for inclusion in the sample clearly defined?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Were the study subjects and the setting described in detail?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Was the exposure measured in a valid and reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Were objective, standard criteria used for measurement of the condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Were confounding factors identified?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Were strategies to deal with confounding factors stated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Were the outcomes measured in a valid and reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Was appropriate statistical analysis used?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include Exclude Seek further info

Comments (Including reason for exclusion)

JBI CRITICAL APPRAISAL CHECKLIST FOR SYSTEMATIC REVIEWS AND RESEARCH SYNTHESSES

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not applicable
1. Is the review question clearly and explicitly stated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Were the inclusion criteria appropriate for the review question?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Was the search strategy appropriate?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Were the sources and resources used to search for studies adequate?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Were the criteria for appraising studies appropriate?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Was critical appraisal conducted by two or more reviewers independently?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Were there methods to minimize errors in data extraction?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Were the methods used to combine studies appropriate?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Was the likelihood of publication bias assessed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Were recommendations for policy and/or practice supported by the reported data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Were the specific directives for new research appropriate?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include Exclude Seek further info

Comments (Including reason for exclusion)

Appendix 7. Critical appraisal results

Study		Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Total
Ansari et al. 2018	+	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10
Chen et al. 2020	%	Y	Y	Y	Y	Y	Y	Y	Y				8/8
Chosich et al. 2020	%	Y	Y	Y	Y	N	X	Y	Y				6/8
Dahlin 2018	±	Y	Y	Y	Y	Y	X						5/6
Dieplinger et al. 2017	±	Y	Y	Y	Y	Y	Y						6/6
Doorenbos et al. 2016	%	Y	Y	Y	Y	N	N	Y	Y				6/8
Henoch et al. 2013	%	N	Y	Y	Y	Y	Y	Y	Y				7/8
Hussain 2019	±	Y	Y	Y	Y	Y	?						5/6
Idman 2015	±	Y	Y	Y	Y	Y	Y						6/6
Isler 2017	±	Y	Y	Y	Y	Y	Y						6/6
Ivany & White 2013	\$	Y	Y	Y	Y	?	?	Y	Y	?	Y	?	7/11
Johnson 2015	±	Y	Y	Y	Y	Y	Y						6/6
Jung et al. 2020	+	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y		10/10
Korhonen & Poukka 2013	±	Y	Y	Y	Y	Y	Y						6/6
Marjamäki & Leppälä 2021	±	Y	Y	Y	Y	Y	Y						6/6

Nyatanga 2015	¤	Y	Y	Y	Y	Y	Y						6/6
Nyatanga 2017	¤	Y	Y	Y	Y	Y	Y						6/6
Nyatanga 2019	¤	Y	Y	Y	Y	Y	Y						6/6
Pelto et al. 2019	%	Y	Y	Y	Y	Y	Y	?	Y	Y	Y	Y	10/11
Semlali et al. 2020	+	Y	Y	Y	?	Y	Y	Y	Y	Y	Y	Y	9/10

Q = question, Y = yes, N = no, ? = unclear, X = not applicable

JBIC critical appraisal checklist for qualitative research (+) / analytical cross-sectional studies (%) / systematic reviews and research (\$) / text and opinion papers (¤)