

Beatrice Ngina Kibatha

**COUNSELING AND PALLIATIVE CARE FOR PATIENTS WITH
PANCREATIC CANCER: A LITERATURE REVIEW**

**Thesis
CENTRIA UNIVERSITY OF APPLIED SCIENCES
Bachelor of Health Care, Nursing
March 2019**

ABSTRACT

| | | |
|--|---------------------------|---|
| Centria University of Applied Sciences (Kokkola Campus) | Date March 2019 | Author Beatrice Ngina Kibatha |
| Degree programme Bachelor of Health Care, Nursing | | |
| Name of thesis Counseling and Palliative Care for Patients with Pancreatic Cancer: A Literature Review | | |
| Instructor Marjo Tilus- Sandelin | | Pages 40 + appendices 6 |
| Supervisor Anita Hollanti | | |
| <p>Pancreatic cancer is the fourth leading prevalent cause of cancer deaths. Palliative care is an approach that improves the quality of life of patients associated with a life-threatening illness.</p> <p>The purpose of this thesis was to find out the role of the nurse by focusing on the counseling and palliative care offered to the cancer patients. The goal was to find out the importance of improving the quality of life for the cancer patient and to provide the nurses with knowledge regarding the different approaches of counseling in the palliative care of a pancreatic cancer patient thus improving the quality of life.</p> <p>A literature review study method was used to articulate knowledge to nurses regarding the importance of counseling and palliative care of a pancreatic cancer patient and the importance of improving the quality of life for the patient.</p> <p>The findings of this thesis discussed more on the role of the nurse and the importance of improving the quality of life to the patient. Quality of life in cancer is achieved by breaking down information to the patient in a sensitive manner. This entails providing information about the cancer and creating awareness and education.</p> <p>The roles of the nurse include; providing proactive communication, offering support to the patient through symptom management and care planning techniques, providing a comprehensive assessment when it comes to elderly cancer patients, regulating pain by implementing both pharmacological and non-pharmacologically pain interventions, providing sexual health education and counseling the patient on chemotherapy and radiotherapy treatments, fatigue, constipation, nutritional supplementation techniques, dietary counselling and exercise programs.</p> | | |
| Key words Content analysis, counselling, nurse role, palliative care, pancreatic cancer, quality of life. | | |

ABSTRACT**TABLE OF CONTENTS**

| | | |
|----------|---|-----------|
| 1 | INTRODUCTION | 4 |
| 2 | QUALITY OF LIFE IN PANCREATIC CANCER CARE | 5 |
| 2.1 | Pancreatic cancer | 5 |
| 2.2 | Palliative care..... | 6 |
| 2.3 | Counseling..... | 11 |
| 2.4 | Quality of life | 14 |
| 3 | PURPOSE AND RESEARCH QUESTION..... | 16 |
| 4 | METHODOLOGY | 17 |
| 4.1 | Literature Review..... | 17 |
| 4.2 | Data Collection | 17 |
| 4.3 | Inclusion and Exclusion Criteria | 18 |
| 4.4 | Data Analysis | 19 |
| 5 | ETHICAL CONSIDERATIONS AND VALIDITY..... | 21 |
| 6 | FINDINGS..... | 22 |
| 6.1 | The role of the nurse in counseling | 22 |
| 6.2 | Role of the nurse in palliative care..... | 26 |
| 6.3 | The importance of improving the quality of life to the patient..... | 29 |
| 7 | DISCUSSION AND CONCLUSION | 30 |
| 7.1 | Discussion of findings..... | 30 |
| 7.2 | Discussion of method..... | 33 |
| 7.3 | Conclusions and recommendations | 33 |
| 7.4 | Learning experiences | 34 |
| 8 | REFERENCES | 36 |
| 9 | APPENDICES..... | 41 |

1 INTRODUCTION

Pancreatic cancer is the fourth leading prevalent cause of cancer deaths in both men and women. The risk factors of pancreatic cancer are obesity, imbalance of energy, smoking, diet such as processed red meat, as well as diet high in energy and fat and low in fiber, diabetes, cirrhosis, and exposure to certain chemicals and genetic mutation which occurs in nearly 10% of the patients per one study (Shi, Hruban & Klein 2009). Pancreatic cancer malignancy is world widely equivalent to that of prostate cancer, colorectal cancer and breast cancer. Therapies integrated in the management of pancreatic cancer have little benefit, thus the patient has an immensely low prognosis (Zhang, Dhakal, Gross, Lang, Kadlubar, Harnack & Anderson (2010). Pancreatic cancer has no early warning signs, so higher percentage of detection arises when the cancer has diversely spread to an advanced disease. Chemotherapy and radiotherapy have been the approved sources of treatment for a long time but the survival rate with their use is 5% because pancreatic cancer has a poor diagnosis (Obeid 2016.)

According to Gooden & White (2013), patients with pancreatic cancer have a short survival time, therefore, efficient and adequate psychosocial support and counseling is important to facilitate best quality of life in palliative care. Nurses play a vast role in the palliative care by paying attention to patient assessment, patient education, organization of patient care, symptom management of symptoms, counselling and supportive care. Palliative care for the pancreatic cancer patients' is necessary to improve their quality of life by decreasing patient aggression because of psycho-social thinking and anxiety. This helps to ease the suffering by correct assessment, supporting both physically and psycho-socially and counseling them and the ones closest to them, that is, the family. According to Nitipir, Barbu, Moțatu, Filipescu & Popescu (2017), patients who have been diagnosed with pancreatic cancer, need to be assessed entirely of their symptom concerns, their cognitive status, and social support. Initiation to palliative care services helps to boost the pancreatic cancer patients' analytics and condition of the care result.

The purpose of this thesis is to find out the role of the nurse by focusing on the counseling and palliative care offered to the cancer patients. The goal is to find out the importance of improving the quality of life for the cancer patient and provide the nurses with relevant knowledge regarding the different approaches of counseling in the palliative care of a pancreatic cancer patient to improve the quality of life. The study method used was a literature review.

2 QUALITY OF LIFE IN PANCREATIC CANCER CARE

In this thesis, the writer is concentrating on the general quality of life focusing on counseling and the palliative care of a patient with pancreatic cancer. According to vast research conducted previously, patients who have been diagnosed with pancreatic cancer have a 5% survival rate of 5 years, and ongoing clinical trials have been conducted to develop new combination of drugs, and other radiation therapy methods to improve the survival rate of the patient (Obeid 2016.) These topics have been discussed below in relation to the nursing intervention.

2.1 Pancreatic cancer

According to World Health Organization (2017), cancer is a universal term for a broad class of diseases that can affect various parts of the body. Common terms used with cancers are neoplasms and malignant tumors. Cancer is the fast formation of abnormal cells from normal cells, growing ahead of their typical boundaries and attacking the adjacent parts of the body and extending to other organs thereby metastasizing and leading to death. The number of cancer cases is rising rapidly globally. Cancer is caused by foreign agents that are classified as: physical carcinogens such as ultraviolet and ionizing radiation, biological carcinogens like virus, bacteria or parasitic infections and chemical carcinogens such as aflatoxin (food contaminants), arsenic (drinking water contaminants) and asbestos (naturally occurring silicate minerals.) Carcinogens are agents that cause cancer.

The pancreas is a secretory gland located on the posterior to the stomach. The head of the pancreas lies near the duodenum. About 75% of all pancreatic cancers occur within the head or neck of pancreas. According to Zhang et al. (2010), pancreatic cancer usually arises from the exocrine pancreas which is physically exposed to high levels of insulin due to its adjacency to the endocrine pancreas. It is quite difficult to detect the cancer in the pancreas because of its physical location in between the stomach and colon and near the liver and no screening tests are available yet for identifying the early stage of the pancreatic cancer. It is usually identified at the rapid progressive stage. Health physical examinations are carried out by the oncologist, whereby patients with advanced pancreatic cancer usually have jaundice that is painless, and the abdomen is full, and it is conspicuous (Obeid 2016). The other signs and symptoms of pancreatic cancer are loss of weight, vomiting, nausea, fatigue and persistent back pains. Weight loss in patients with pancreatic cancer occurs slowly and continuously (Obeid 2016.)

2.2 Palliative care

Palliative care is an approach that improves the quality of life of patients with life-threatening illness, which in this case is pancreatic cancer. According to the World Health Organization, 34% of adult cancer patients require palliative care (World Health Organization 2017). It is whereby other beneficial treatments like surgery, radiotherapy, chemotherapy or a combination of the three treatments are not possible but where treatments may have anti-cancer activity to recover cancer related symptoms. Palliative treatment decision is suggested when curative treatment is not possible but where treatments may have enough anticancer activity to better the cancer-related symptoms. (Watson, Hoy, Lucas & Wells 2009)

In most circumstances, improvement of symptoms comes with the shrinking of the tumor which is detectable clinically or by radiological methods such as CT scan or MRI. It is progressively more recognized that there may be a palliative benefit even in the absence of tumor shrinkage. As the primary purpose of therapy is to improve quality of life, such treatments should be well tolerated with a low incidence of acute side-effects. Long-term toxicities are generally not relevant. In certain instances, the similarity between radical and palliative treatment may not be entirely well defined. As a matter of fact, the goals of treatment may change as the disease progresses. (Watson et al. 2009)

Nurses are a part of the primary care and palliative care teams which are involved in management of problems presented in palliative care. Palliative care has various aspects which include basic needs such as: pain management, nutritional support and psychosocial wellbeing. A nurse plays a crucial role in the palliative care for cancer patients whose disease is advanced, rapidly progressive and fatal in the long run. The nurse is equipped with the necessary knowledge and skills that will affect the patient's care at the end of life. For patients with pancreatic cancer, it is a means of managing distress and symptoms which will be discussed later in the thesis. There is a fundamental change of emphasis in decision making away from a focus on prolonging life towards decisions that balance comfort and the individual wishes with treatments that might prolong life. (Walker, Colledge, Ralston & Penman 2014)

According to Mot Dictionaries (2017), physical support is the support given by the health care professionals to various individuals with different physical needs. Pancreatic cancer patients need support for their physical health to cope with the health problems which include nutrition deficiencies, weakness and weight loss, pain, nausea and vomiting. This physical support helps them to carry on with their day

to day activities with ease. Incorporating nutritional, weight loss and pain intervention helps to improve the social support for the patients' physical health offered by the nurses.

Patients with pancreatic cancer face difficulty when managing gut symptoms, complicated dietary issues and managing symptoms of pancreatic exocrine insufficiency leading to malabsorption. This is because of a lack of prescription of enzyme supplements and diet guidelines. Pancreatic exocrine insufficiency is when the pancreas does not produce enough enzymes that the body needs to break down and absorb nutrients and is caused by damage to the pancreas similar in cancer. Pancreatic exocrine insufficiency leads to abdominal discomfort after feeding, bloating, pain, diarrhea and indigestion of fats thus leading to weight loss. (Gooden & White 2013)

Pancreas is located deep within the gut and with no screening tests available yet, it is hard to detect the gut symptoms. The gut symptoms usually are ongoing, and they also result to continued pain and in acute cases, it can present nausea and vomiting, severe pain and obstructive jaundice. This puts the patient at a higher risk of psychosocial distress because of digestive symptoms. The patients' isolate themselves socially because of the negative impact of the symptoms. Patients' fear the leakage from the diarrhea and sometimes the washrooms are not readily available and this instills fear to the patient. Malabsorption and fat indigestion cause feces to be pale, smelly and long and it can be difficult to flush them sometimes, creating a need to break them into small pieces. (Gooden & White 2013)

Nutritionists' are important because they can provide information to patients regarding the medications they could use when battling with the pain of malabsorption, the effects of pancreatic exocrine insufficiency and its treatment. They are responsible for ensuring proper diet of the patient as pancreatic cancer comes with a degree of anorexia and weight loss. This involves giving the patient appetite stimulators and pancreatic enzyme supplements which assist to boost the digestion and absorption of nutrients in the body for those with pancreatic insufficiency, which have been shown to improve the quality of life and maintain weight. (Gooden & White 2013)

Nurses should carry out periodic assessments regarding the dietary requirements and advices, following up the patients' diet, evaluating the pancreatic exocrine, its supplementary therapy and the required guidelines assistance. Eating serves multiple functions such as maintaining energy, providing nutrition and a chance to interact in social activities for patients. The care takers should also be involved in the process of providing dietary information because sometimes they struggle to find out what is the best food for their loved ones to keep their weight normal. The nurse's consistency of providing enough

knowledge about different foods in the diet is very important. This will cut down frustrations, anger and feelings of giving up for both the patient and the care takers. (Gooden & White 2013)

Pain is an undesirable sensory and sensitive experience, combined with certain or likely tissue damage. Physical pain is caused by nerve stimulation (WHO 2017). Cancer pain affects more than 30% of patients under anti-neoplastic therapy whereas about 70% of the patients experience moderate to severe pain due to the cancer in the later phases of the illness (Grossman & Nesbit, 2014). Cancer pain greatly impairs quality of life and more often it is poorly managed. Cancer pain can be caused by direct tumor involvement, therapy or an illness unrelated to the malignancy. Pancreatic cancer causes abdominal pain more often by invasion to adjacent organs but also the tumor may spread to the surrounding nerves thus causing back pain. (American Cancer Society, 2017)

According to WHO (2018) and Terveyskylä (2018), cancer pain has different stages. In normal circumstances, cancer pain does not completely tell how severe the cancer has advanced or how long the pain will continue. In the early stages of pancreatic cancer, it begins already in the early stages of the metastasis. Pain is more common when the cancer tumor is close to nerve tissue. The pain at the detection phase of the cancer is not always constant, because the first treatment normally helps but surgery for the pancreatic cancer can relieve it almost entirely. In the advanced stages of cancer, most of the patients suffer from pain resulting from the cancer metastases stretching around the nerve tissues. Pain experienced from the cancer patient is not only linked to the cancer tumor itself but to some patients' the cancer treatment, that is, radiotherapy, chemotherapy and anti-cancer drugs also play a role in prolonging the cancer pain. Long term pain from headaches, back pain, joint tenderness as well as discomforts.

The nurse has an obligation to the patient when it comes to the management of pain and this includes;

Knowing the patient

The nurse needs to establish a professional rapport as a healthcare giver with the patient and he/she should understand what the patient is suffering from, the kind of pain the patient is going through and the expectations of the patient when it comes to the pain management. This is achieved by including the nurse in the pain assessment team at polyclinics or at the hospital where the patient is seeking help. The assessment, is usually multidimensional, and it includes the severity, chronicity, location and associated factors with the pain. (Niederhuber 2014)

Knowing the medication

According to Glavin (2010), more of often than not, the nurse is tasked with the administration of drugs to the patient after prescription by the doctor. The nurse should understand the schedule for the medications for effectiveness and routes of administrations. Nurses are also required to know the adverse effects of some of the medications such as opioids as they may cause respiratory depression and the contraindications on non-opioid drugs such as acetaminophen drugs in patients with hypersensitivity. Medication errors have adverse effects that are life-threatening to the patient and could lead to death as well as psycho-social trauma to the nurse.

When cancer patient experiences pain, there should be available pain medicines to be administered and the easiest way to administer is oral unless the patient is not able to swallow, then the drugs can be administered in other ways. The orally administered drugs should be administered in this order level: non- opioids (aspirin and paracetamol), mild opioids (codeine), then strong opioids (morphine) until the patient is free of pain. In order to calm fears and anxiety, supplementary drugs like adjuvants could be used (World Health Organization 2019).

Records and response to management

Nurses also play part in keeping the records of the interventional procedures that are undertaken to improve the quality of life of the patient. These records are a source of information for future reference but also play a crucial role in evaluating the patient response to the pain management protocol employed. For example, it sheds light to the level of opioid concentration the patient tolerates and thus indication for a higher dose. A study conducted, showed that patients with active cancer were more responsive to pain management at polyclinics by analyzing score charts for the individual patients (Jennings, Cassel, Fletcher, Wang, Archer, Skoro, Nevena, Yanni & Del Fabbro 2014).

In order to keep cancer patient free from pain, pain medications must be given by the clock, which means at least every 3 to 6 hours, rather than on request. This three-step approach of dispensing the right drug in the right dose at the right time is economical and normally it is 80 to 90% effective. Surgical intervention on the nerves that result to the pain or the most affected pain triggers, could result to additional pain relief if drugs are not entirely effective (World Health Organization 2019).

Understanding pain management issues

Pain management issues are diverse and ultimately affect the patient as well as the nurse as a healthcare giver. During the assessment of the pain, it is difficult to come to a practical conclusion particularly with patients who are non-verbal or have communication difficulties. Some patients, for example, opioid

abusers may exaggerate pain for secondary gains which include addiction at the healthcare facilities, therefore, creating difficulty in knowing whether their pain level is true or false thereby complicating the situation for the nurse. (Vallow, Zhang, Greenberg, Reynolds, White & Birnbaum 2006)

Outcomes and satisfaction of pain management

According to Glowacki (2015), pain management is a universal requirement and its outcomes are beneficial and highly desired. Patients receiving the pain intervention will have improved function, that is, with the pain alleviated they can be released from hospital and resume social-economic activities such as work. It also promotes good health as uncontrolled pain has serious consequences such as delayed healing, increased stress, decreased appetite, disrupted sleep and anxiety and depression. The pain intervention also increases the comfort of the patient to a level which is acceptable and aids in the psychosocial wellbeing of the patient. The patient's viewpoint of the management of symptoms such as pain form the core basis of satisfaction of the intervention and is jointly determined by the attitude of the nurse towards the patient during the process. These further impacts on whether the method employed is active or not (George & Hirsch 2005).

Non-pharmacological ways of easing cancer pain

Non-pharmacological pain interventions are alternatives for pain management which have been proven to help alongside with the use of medications bearing in mind the patients' specific needs as well as responses to the different pain intervention methods. These non-pharmacological methods are usually used when there is a problem with pain medication titration especially when the patient tends to drift towards addiction, or the dosage increase does not necessarily help in the pain management. Examples of non-pharmacological pain interventions that could be used include acupuncture to ease nausea, vomiting and neuropathic pain, cognitive behavioral therapy to psychosocially help with anxiety and insomnia with individualized care (Taverner 2015.)

According to Terveyskylä (2018), active relaxation and having a conscious presence balances the treatment of cancer pain. When the body tension decreases and the awareness of the painless areas of the body increases, it is usually easier to experience cancer pain. Relaxation exercises can assist in relieving body tension and pain. When the muscles relax, it is easier to calm the mind. Some patients find the exercises that relieve tension in the body useful to relieve the discomfort caused by the cancer pain. There are many relaxation exercises which the cancer patient can learn under the guidance of a nurse.

Exercises for conscious engagement create the attitude of conscious presence which in turn aids to strengthen the ability to be present in the moment. This can be used to relieve stress, for example, due to heavy memories or future troubles. Some of the exercises include learning how to focus on different parts of your body. By listening to body sensations, a person is present at that moment. Some of the patients find the exercises useful to relieve the cancer pain. When the patient becomes aware of the painless areas of the body, it is easier to tolerate pain. Taking advantage of positive stimuli to direct attention away from pain, for example, listening to music, watching TV, reading or other comfort can be used to control the cancer pain. Good stimulus for pain management are those that take the complete attention (Terveyskylä 2018.)

2.3 Counseling

Counseling of patients battling with pancreatic cancer can be understood as the manner used to aid the patients' reactions to their mixed emotions regarding their life situation with pancreatic cancer in a healthy manner. It is not necessarily meant to solve problems, but it creates a secure and helpful environment for the patients to air their views and concerns. Counseling programs usually combine structured information and practical advice. The credibility of counseling in a patient with pancreatic cancer situation helps them to learn to live with the disease. Towers & Diffley (2011) discuss how counseling can range considerably in several ways which include aiding the individual to come into terms with the cancer occurrence or establishing ways of managing the experience that they encounter. This form of therapy relieves patient of anxiety and depression individually.

In counseling, the nurse should let the patient initiate the conversation where they talk about their view of the pancreas cancer, and their expectations after the diagnosis. The nurse then offers advice to the patient by giving facts about the cancer stages, the financing of the treatments used and their advantages like chemotherapy, surgery or radiotherapy. In this way, the patient is effectively equipped to their individual decision making and exploration of options, effective communication with both the health care and the family members. Communication is effective because the patient has enough information, and this makes it easy for him or her to make their family understand the crisis or necessary changes that might happen like the chemotherapy. (DeKort, Pols, Richel, Koedoot & Willems 2010)

Oncology nurses offer cancer treatment counseling based on what is best for the patient. The oncology nurse can help the pancreatic cancer patient decide between chemotherapy and/or adjuvant chemo-radiation of the pancreatic cancer after resection of the pancreatic cancer. Usually the resection of pancreatic cancer is done to remove the tumor on the pancreas in early stage pancreatic cancer. The survival rate of the patient usually increases when a resection of pancreatic cancer is done together with an adjuvant therapy with chemo-radiation. The chemo-radiation is the standard optimal care for pancreatic cancer patients and is done post operatively in a surgical resection that is curative to prevent the metastases of the cancer cells. Oncology nurses recommend patients an adjuvant therapy with both chemo-radiation and chemotherapy. (Iott, Corsini & Miller 2008)

An evidence review study carried out by Iott et al. (2008) to patients with a resected pancreatic cancer showed that their overall survival rate increased. The median survival for patients who underwent resection surgery alone was 19.2 months and patients who underwent both resection surgery with an adjuvant therapy was 25.2 months. Another evidence review study carried out by Swartz (2006), showed that the median survival for patients with adjuvant treatment after surgery was 20.8 months and for patients who underwent resection surgery was 13 months. These two randomized studies clearly showed that chemo-radiation done post-operatively improves the survival of the pancreatic cancer patient.

It is very necessary for the patient to understand that the challenges they face psychologically are not out of this world. Assessing the patient effectively and aiding them to manage their individual concerns is important because it makes the patient not look like a set of symptoms. Sometimes the patient is in denial especially when the pancreatic cancer is diagnosed at stage 4 where surgery is a risk. This not uncommon. Guaranteeing the patient that he/she can control and change various elements in their life despite how progressive the cancer has been, is important because they learn how to set realistic intentions. (Towers & Diffley 2011) Counseling the pancreatic cancer patient on the need for physical activity and exercise is necessary. Physical activity is a series of body movements involving the skeletal muscles which need energy. Exercise is part of physical activity which is organized and conducted every now and then and its goal is to improve the physical fitness of a certain individual. (World Health Organization 2017)

According to Ali, Osmany, Khan & Mishra (2014), physical activity aids in reducing anxiety and depression, fatigue, improving the emotional well-being of the patient and helping the social functioning of the patient. The nurse can organize walks or exercise participation programs for the patient and their fellow peer support group members which will make them mingle and interact. In this way they can also

share their different approaches of how they are managing their well-being. Interacting with the society helps improving ones' body image as they balance their body energy levels thus reducing obesity or cholesterol related problems. Nurse should educate the pancreatic cancer patient about the essential intensity, duration, frequency and types of exercise programs that he/she can involve themselves in for an optimum and continuous desirable effect.

Counseling for the patient usually comes with a choice. There are three types of counseling which are; individual counseling, couples or family counseling and group counseling. Individual counseling is based on the patient with pancreatic cancer, and they have a one on one conversation with the counsellor sharing their views and concerns. Couple or family counseling is based on a session with a couple or the family members of the patient affected by pancreatic cancer where the counsellor aids on various issues that may raise a conflict or crisis. The couple or the family members acquire ways of dealing with the issue and supporting the patient constantly. Group or peer counseling involves individuals who have pancreatic cancer at the same time or at different pancreatic cancer stage. The counsellor is always the head of the discussion and the patients acquire helpful information from both the counsellor and the group's understanding. (American Society of Clinical Oncology 2015-2017)

Therapeutic listening and emotional support minimize chances of fear, anxiety and depression which the patient may develop as they try to come to terms with the diagnosed cancer. Rosenstein (2011), writes that 15%-50% of patients with cancer develop depressive symptoms and that 5-20% will meet various diagnostic criteria for Major Depressive Disorder (MDD). According to Satin, Linden & Philips (2009), via a met analysis, it showed that patients with depressive symptoms had a 26% higher mortality risk and those with Major Depressive Disorder (MDD) had a 39% higher mortality out of the 9417 patients. Costelloe & Nelson (2004), discuss that peer and psychosocial support are valued by patients for considerable benefits and they report it on the patients' evaluation forms. Individual patients give feedback on the need to include other patients with similar diagnosis, that is, pancreatic cancer or treatment. The bond that is conceived from the palliative care hospice with its patients helps to enhance the capability to offer peer support. This helps patients to reach out and consult other pancreatic patients and offer them psychosocial support and, in this manner, the pancreatic cancer patients can express their emotions and feelings regarding their body image, sexuality, effects in their personal lives and coping mechanisms in a safe environment without fear straining their families.

The nurse, therefore, is of importance in ensuring the patients welfare psychologically by providing a shoulder to lean on. Patient education of the illness is of importance as it helps them understand the

situation and facilitates decision making, for example, in treatment options available and new therapies. The nursing professionals also play a very important role in recognizing and managing adverse effects that may arise from these therapies. The nurse who is the caregiver, has a fundamental responsibility to give palliative care to the patient which may include providing a compassionate and therapeutic presence to the patient and the family and advocating for resources that support patients and family in choosing preferred environment for dignified death. (Cancer Nurses Association 2012) They also offer a link between primary and secondary care.

2.4 Quality of life

Patients with pancreatic cancer undergo extensive physical and emotional challenges because they identify the cancer as a life-threatening illness. In most cases these pancreatic cancer patients tend to try to solve their symptom problems by themselves using their own social resources and this increases their psychological concerns. They are faced with depression and the fear of dying which usually diminishes the patient's quality of life, their comfort and consent to treatment. Death is the end of life of a living individual. The quality of life is improved by the coping mechanism of the patient with pancreatic cancer based on how they will deal with the disease. (Ali et al. 2014)

Pancreatic cancer patients face death anxiety because they tend to feel that life will be over at some point in time. This death anxiety is because of general anxiety brought about by loss of jobs, finances, relatives or caretakers and one's self-perception. In other words, it is because of fear. Coping is how people react to stressful situations through their conducts, approaches and notions. Efficient coping eases the dilemma and lowers the emotional distress. How a patient copes with pancreatic cancer can have a deep impact on their physical, social and psychological health. (Ali et al. 2014) Coping helps to preserve the emotional condition of the pancreatic cancer patient allowing their psychological changes to insensitive circumstances (Ali et al. 2014).

There are three different types of coping mechanisms in the literature of psycho-oncology namely; active behavioral coping which include discernable behavioral ways of dealing precisely with the cancer and its effects, for example, leaning on others for support, secondly, active cognitive coping which includes one self's mental outlook, conduct, and notion about the pancreatic cancer and thirdly, avoidance coping which attributes to strongly trying to refrain from the problem or lowering the emotional strain by utilizing diversions (Nadine, Jordana, Bettina, Phyllis, Margaret, Kristine, Graham & Scott 2012). Nurses

can help the patient put into action different approaches to help them cope with the pancreatic cancer by advising them on what measures they can take. These important measures which the pancreatic cancer patient needs to keep in mind include: dealing with the reality of the pancreatic cancer, speaking out their emotions, pursuing support from other people, retaining their self-esteem and embracing their viewpoints and attitudes. (Ali et al. 2014)

3 PURPOSE AND RESEARCH QUESTION

The purpose of this thesis is to find out the role of the nurse in the counseling and palliative care offered to patients battling with pancreatic cancer and the importance of improving the quality of life for the patient. The goal of this thesis is providing nurses with knowledge regarding the different approaches of counseling in the palliative care of a pancreatic cancer patient to improve the quality of life.

The research question is:

1. What is the role of the nurse in the counseling and palliative care of a patient with pancreatic cancer and what is the importance of improving the quality of life?

4 METHODOLOGY

This chapter highlights the approach used to conduct the thesis study. It focuses primarily on the literature review, the inclusion and exclusion criteria, the data collection and the data analysis. The literature review carried out was primarily on web-based publication materials and previous evidence based scientific studies to answer to the research problems.

4.1 Literature Review

According to Aveyard (2010), literature review is an extensive evaluation and explanation of literature that focuses on a specific topic. Its aim is to analyze and assess the existing literature on the study topic to show a gap on the existing research and support ones planned research aim. It basically combines the texts with current information including the theoretical and methodological input to a certain topic by developing a research question and finding answers. A literature review is important because new understandings and discoveries are acquired by reviewing various researches in a specific area of study, thus giving a clearer understanding by comparing the different findings and statistical data if any.

According to Hedges & Williams (2015), a literature review should not rule out studies because of the results differing from the preferences or expectations of the author. The literature review should always be up to date and comprehensively accurate. The author should first acquire a research topic, gather knowledge from various literature, classify the research and finally illustrate the findings. The disadvantage of literature review is that sometimes there are pieces of literature that do not coincide with the main body of research which could be because of media reports, thereby falsifying information changing it for fit a certain story, therefore one should always refer to the original research rather than research reports. (Aveyard 2010)

4.2 Data Collection

The data retrieval methods used in this literature review are based on search and selection of materials using the limit of years, databases, keywords and screenings such as: titles, abstracts and full texts. The year limit for the used is about ten years. The keywords used in the study are counseling, palliative care, pancreatic cancer, patients, nurses and quality of life. The basic search words result that have been used

in the selection of material are counseling and palliative care for patients with pancreatic cancer and the quality of life. The databases that have been used to retrieve data are scientific academic databases which are; Sage Premier, Cinahl, Ovid and Academic Search Elite (EBSCO). The dependable web publications, World Health Organization, American and Canadian Cancer Associations and Cancer Society of Finland, have been used in the theoretical framework.

All the academic journals used in this literature review are based on health sciences. The evidence-based knowledge covered in this literature was collected from consistent scientific database sources like Academic Search Elite (EBSCO), Cinahl and Ovid. The web publications that include World Health Organization, Cancer Society and Cancer Association were used to add additional information in the theoretical framework. The in-text and the final references have been used beginning from the introduction to the conclusion so that the reader follows the author. Various ideas and opinions from the scientific academic journals used have been balanced, convenient and appropriate search approaches have been used to find the crucial evidence for this literature review topic, and the data collected is related to counseling and palliative care all through the entire thesis.

Initially, 35 research articles were acquired for the research findings, and finally the researcher narrowed down to 18 scientific articles to answer the research question. The articles were analyzed based on content analysis method and also the full availability of the research article while focusing on the research question.

4.3 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria were used to filter out data materials from various search engines used, thereby giving accurate and precise number of articles. The filtering was used to determine which literature co-relates with the research question and which does not to avoid distractions. The inclusion criteria has relevant, accurate and up to date information whereas the exclusion criteria have information that is outdated and out of synchrony with the research problem. The table below was used to simplify the criteria applied by the author.

TABLE 1. Inclusion and Exclusion Criteria

| Inclusion criteria | Exclusion criteria |
|---|---|
| Research articles less than ten years old. | Research articles older than ten years. |
| Research articles in English | Research articles written in other languages other than English. |
| Research articles related to nursing and pancreatic cancer. | Research articles not related to nursing and pancreatic cancer. |
| Research articles related to counseling and palliative care of a pancreatic cancer patient. | Research articles not related to counseling and palliative care of a pancreatic cancer patient. |
| Research articles available in full text. | Research articles not available in full text. |
| Materials based on scientific research evidence. | Materials not based on scientific research evidence. |

4.4 Data Analysis

According to Holloway (2013), data analysis is an extensive process of synchronizing research data that has been collected by a researcher after collecting the data, organizing it, merging it and sorting it strategically. It is done to polish the data acquired from various databases to provide meaningful information by avoiding distortion of information from the collected data. Its purpose is to answer the research question from the information collected from the research topic. The purpose of the data analysis concept is to organize the acquired data into categories with the same subject. In this literature review, content analysis has been used to answer the research question based on the role of the nurse in the counseling and palliative care of a pancreatic cancer patient.

Content analysis has been used in this literature review to answer the research question in an increased understanding to give more quality information in the conclusion part. The selection of articles was based on counseling and palliative care for patients with pancreatic cancer and they have been expounded more to answer the research question and fulfill the thesis goal. Single words and multiple words from search selection have been incorporated in the analysis process (Holloway, 2013). The content analysis was based on the sources of information. This included, scientific academic databases, the time frame of the data acquired, its relevancy are from ten years old, and on the research topics which are counseling, palliative care, quality of care and pancreatic cancer all based on a nursing perspective.

Inductive content analysis has been used as the data analysis method in this thesis process to organize the qualitative data. This process involves open coding by using written materials, and writing down notes and headings, grouping the gathered data, creating categories and identifying themes by simplifying data, thereby creating a valid argument with particular instances into a generalized conclusion. (Elo & Kyngäs 2008)

TABLE 2: Example of content analysis method

| Article | Direct quotation | Attribute | Sub-category | Main-category |
|---------|--|---|--|-----------------|
| 15 | Learning the views of people affected by pancreatic cancer to better and improve the treatment options. | Identifying patients' needs and priorities. | Supporting patients' needs and priorities psychosocially | Counseling |
| 11 | Patient recounted psychosocial problems were termed as predictors of a wish for psycho-oncology support. | Need for psychosocial support for coping with cancer. | | |
| 12 | Cancer support a patients' care plan to improve communication between the nurse and the patient. | Using care plan improves communication. | Using a care plan to reduce hospital admissions considering patients' desires. | Quality of life |
| 2 | Having a palliative treatment aim and being older were considerably connected with less hospital admissions. | Reduction of hospital admissions and respecting the patient's desires | | |

The description of articles has been mentioned in the appendices, at the conclusion of the thesis. All the articles used for the content data analysis have been compiled together in an appendices table.

5 ETHICAL CONSIDERATIONS AND VALIDITY

Ethical considerations are a major key in research in terms of accounting for the research results precisely by keeping the original meaning valid and creating authentic results. In this literature review ethical considerations have been upheld. According to Broomfield (2017), a researcher has to have the ability to consider various issues regarding research ethics when gathering research materials, for example, the researcher has to be able to use the modern technology which involve computers when trying to find reliable and scientific resources and focusing on reliable academic sources.

No quotes have been copied or plagiarized thus all copyright and publication rules have been followed. The words that have been used in writing have been changed and summarized but the same meaning from the authors has remained (Doody & Noonan 2017). All references in use have been put down as both in text and conclusion in the final reference page. The information that has been used from the scientific databases has free access for easy retrieval by the readers and further referencing.

Based on validity of information used in this literature review, the academic journals and articles are from scientific databases. A clear picture of the research subject question and answers has been provided in a nursing perspective without the use of random references from unreliable facts (Aveyard 2010). The information in use has been credible and the references from the scientific databases have free access. Updated information sources have been achieved through the inclusion and exclusion criteria. The academic journals and articles have responded authentically to the research question.

6 FINDINGS

In accordance to the research question, the purpose of this thesis is to find out the role of the nurse in the counseling and palliative care offered to patients battling with pancreatic cancer and the importance of improving the quality of life for the patient with the goal of providing nurses with knowledge regarding the different approaches of counseling in the palliative care of a pancreatic cancer patient to improve the quality of life.

According to the research articles used based on the validity of information, the author arose with certain topics that are based on the crucial findings for counseling in the palliative care of the patient with pancreatic cancer and how to improve the quality of life for the patient with pancreatic cancer.

6.1 The role of the nurse in counseling

Proactive communication is an essential tool when conveying information from the patient to the nurses. Above half of pancreatic cancer patients currently with metastatic disease at diagnosis are on a median survival of about 9 to 11 weeks and with a 1-year survival rate of only 24%. The diagnosis of pancreatic cancer ought to prompt the immediate start of palliative care, and this is because some of the patients with pancreatic cancer may deteriorate and die suddenly. Having proactive communication with the patient, which includes, talking about suppressing curative and life-prolonging treatments and diagnostic as a way to prevent hospitalizations. The aim of palliative treatment is to lessen hospital admissions and reduce the hospital mortality, by supporting the patient to stay at the place they prefer as long as possible. To accomplish this, the accessibility of community-based palliative care is very significant in order to support the patients' wishes and care needs (Oosterveld-Vlug, Donker, Atsma, Brom, Man, Groenewoud & Philipsen 2017).

Provision of support for neurotoxicity which includes; paresthesia and dysesthesias in upper and lower extremities, problems with fine motor function, problems with controlling their bladder function and cold-induced paresthesia were commonly mentioned to have a negative effect on daily activities and the quality of life in cancer patients treated with chemotherapy. It is essential for nurses to communicate with patients by asking them about the problems they face in relation to neurotoxicity and counsel the patient on the impact they have on daily activities and how to go about them because as of now,

there are hardly any treatments or preventive interventions available. The cancer patients should, however, be sufficiently educated about the possible side effects of their treatment. The CINQ (Chemotherapy Induced Neurotoxicity Questionnaire) would be a useful and likely measure to favor the evaluation of patients' suffering from neuropathy symptoms. (Driessen, Kleine-Bolt, Vingerhoets, Mols, & Vreugdenhil 2011)

According to Polakowski (2015), a survivorship care planning is of importance regarding addressing the health and wellness subjects referring to the patients dealing with pancreatic cancer. The survivorship care starts with an assessment which carries on to developing a care plan which helps the nurse counsel the patient on certain topics involving cognitive function, sexual function, sleep disorders, exercise, fatigue, infections, pain, anxiety and depression. A survivorship care plan should have an abstract of the treatment received by the patient, screenings, the health maintenance and possible side effects. (Morgan 2009)

Polkowski (2015), goes on to mention that the use of this care plan by the nurses has helped in the development of better communication as there is a collaborative plan between the patient and the nurses. It has also aided to notice the side effects and complications of the patient regarding the therapies as it is done through an easy questionnaire they fill in every hospital visit. It enables both the patient and the nurses to play an active role in the care of the pancreatic cancer. Having an electronic health record saves time and energy of accessing and documenting the patients care plan, which averages the creation time of the survivorship care plan to 3 minutes thereby improving the patient's satisfaction. Involving both the patients and the nurses in assessing the presenting symptoms, challenges them to play an active role in the care and facilitating proper treatment.

Sexual health education is advised to help cancer patients go through their day-to-day activities that involving psychological emotions as patients with pancreatic cancer have a low survival rate. Anti-cancer treatments and their side effects can result to the psychosocial stress thereby affecting an individual's sexual response cycle and their body image. The radiation and the chemotherapy agents interfering with sexual functioning and infertility. The role of the nurses is offering effective support by initiating discussions regarding sexuality issues and fertility options. An example is supporting sperm banking for adolescent men or fertility treatments for young couples with pancreatic cancer which helps in supporting their likelihood of having a family of their own. (Kotronoulas, Papadopoulou, & Patiraki 2009)

The result of pancreatic cancer in expressing one's sexuality, sexual functioning, and fertility can make an immense impact and even change one's position in a relationship, family or the society due to low self-esteem. As a nurse, bringing up these sexual health issues reassures a positive look on the patients' survival, rebuilds the patient's sex life and helps the patient to be ready with future sex problems. Oncology nurses presume that sexuality helps conquer distress and fear and achieve life through enabling human interaction in times of misery and anxiety as they patient is in palliative care as well. (Kotronoulas et al. 2009)

According to Kotronoulas et al. (2009), sexual health education and counseling can be done at the time of diagnosis of the pancreatic cancer, through-out the cancer treatment or during the recovery, as sexuality reveals itself in various ways, times and different conditions and sexual concerns will always exist. Nurses are more aware of the available resources to offer to the patient. This include self-help groups, counselors, sexual aids, and fertility preservation facilities. Patients who are dealing with advanced stage of pancreatic cancer may tend to lack interest or the readiness to discuss these issues and the options because they think that their poor health status is a barrier, and in such situations, it would be complete if the nurse participates in the conversation.

Fatigue is one of the side effects of pancreatic cancer. It affects the patient physically, psychologically, socially, spiritually, and cognitively which affects the patient's ability to work, psychosocial and physical functioning as well as the patient's dedication to pancreatic cancer treatment. The quality of life reduces because of fatigue in that the patient losses commitment to meaningful life activities. Nurses help the patient manage fatigue by evaluating the level of fatigue and the outcome on the patient during the active cancer treatment and in the follow up visits. Exercise helps to manage cancer related fatigue and nurses promote exercise programs to improve mobility, fatigue, sleep quality and the quality of life. (Huether, Abbott, Cullen, Gaarde 2016)

Nurses educate and counsel the patients on various kinds of exercise programs that suit them individually or as a group to improve the quality of life. These include walking, cycling and yoga among others. Regular exercise is conducted for about two to three days in a week. Support group exercises with the supervision of a nurse who counsels them on the different exercise programs to work with to improve the participation and commitment. Physical exercise alleviates pain, anxiety, depression and has positive effects on the composition of the body by reducing body mass index (BMI) and body weight, thus improving the individuals' body image and self-esteem. It also increases the optimum oxygen consumption and improves sexuality. (Huether et al. 2016)

According to Huether et al. (2016), the role of the nurses is to create awareness and interest by promoting the advantages, the outcome of exercise, and enduring the education of the exercise programs, building knowledge and commitment by having support core groups for the patients and providing resources and equipment for the exercise, promoting action and adoption by offering interventions for cognitive behaviors, energy conservation measures, and mindfulness stress reduction strategies and psychoeducation. Huether et al. (2016), goes on to mention that after the assessment of the fatigue levels, nurses can equip the patient with verbal education in conjunction with written handouts that explain and review different methods of managing energy through expanding physical activity.

Cachexia can have an overwhelming influence on the quality of life, symptom load, and a patient's sense of dignity. It is a severe complication, as weight loss throughout cancer treatment is correlated with additional chemotherapy-related side effects, less fulfilled phases of chemotherapy, as well as reduced survival ratios. Certain rising consideration to indications signifying the adverse effect of cachexia on the quality of life to individuals with cancer is essential to acquire a scale that focuses on the fears of the patients with cancer that is exclusive to anorexia and cachexia. A suitable scale needs to have comprehensive psychometric properties be manageable, and monitor cachexia associated outcomes on quality of life over time. (Suzuki, Asakawa, Amitani, Nakamura & Inui 2013)

Nurses counsels the patient with pancreatic cancer on how to deal with cachexia which is a major problem affecting patients who have upper gastrointestinal cancer. As mentioned in the theoretical framework, cachexia is when the body is weak and wasted because of severe chronic illness with cancer being one of the conditions. (Hagmann, Cramer, Kestenbaum, Durazo, Downey, Russell, Geluz, Ma & Roeland 2018) The body has imbalanced levels of certain nutrients resulting in weight loss and wastage of muscles involuntarily. This makes the patients suffer from malabsorption and the narrowing of the gastrointestinal tract because of the pancreatic cancer. When the patient with pancreatic cancer is in an advanced stage as the disease is rapidly progressing with symptoms such as abdominal pain, nausea, vomiting, taste abnormalities, inability to for intake of natural nutrition, fatigue, narrowing of the gastrointestinal tract, malabsorption and maldigestion, it results in cancer related anorexia-cachexia. (Pelzer, Arnold, Goevercin, Stieler, Doerken, Riess, & Oettle 2010)

According to Wilkes & Allen (2018), cancer specific assessment and nutritional screening are conducted by both the doctor and the nurse to identify the risk for malnutrition, nutrient deficiency and nutrient toxicities. Both physical appearance like monitoring weight and functional status of the body like the

ability to eat, gastrointestinal changes such as constipation, nausea and vomiting are part of the assessment, therefore the scores for severity and non- severity of malnutrition are obtained. The role of the nurse is to give nutritional recommendations and interventions to meet the objectives of the nutritional therapy which are retaining enough calories, proteins, fluids, and general nutrition status through monitoring, preventing or managing nutrition related problems emerging from the cancer or the cancer treatment.

Nurses counsel and educate patients verbally during the clinical visits in their chemotherapy or radiation treatment, or through phone appointment check-ups. Questions are asked to the patient and the nurses fill up the answers according to the patients understanding, with a technique called teach-back. This is whereby the nurses gauge the patient's understanding and general knowledge and as the answers are provided by the patient, the nurse goes on to provide more knowledge to the patient about the topic of the question. When the patient is diagnosed with pancreatic cancer, the nurse involves both the patient and his/her family in educating them about the effect cancer has on the nutritional status, and the potential side effects of the cancer treatment. The nurse encourages both parties on the preventative approaches. (Wilkes & Allen 2018)

Wilkes & Allen (2018), continue to mention that nurses give dietary counseling by educating the patient with pancreatic cancer on the importance of maintaining a good nutritional status. Nurse advises the patient on eating a healthy diet with enough protein intake and to hydrate frequently to maintain a normal fluid status before, during and after the treatment. The patient is recommended to do at least 150 minutes of moderate physical activity weekly to survive long-term. Nurse ensure that with malnourished patients during the completion of treatment have an enough intake of protein calories by having 6 meals in a day with enough hydration to improve the patient's tolerance of the treatment. The patients who do not match with nutritional requirements should not use traditional oral supplements as they have a high fructose content and the gastrointestinal effect of carrageenan. Carrageenan is an additive that emulsifies and preserves foods and evidence-based information states that it causes inflammation and gastrointestinal ulcers.

6.2 Role of the nurse in palliative care

Comprehensive assessment is advised to be used when nursing elderly cancer patients, it involves using a geriatric assessment or predictive chemotherapy toxicity tools, as the foundation for formulating an optimal therapy program. Factors such as the efficient status of major organs, social support, patient's preference, presence of comorbidities, and life expectancy should be paid attention to when preparing an optimal treatment program. When dealing with elderly cancer patients, it is essential to balance the risk of dying from cancer alongside the risk of dying from a possible comorbidity or from a treatment-caused complication. Nurses should put more focus on managing the complications than treating, to prevent the manifestation of the complications. Nutritional support, maintenance of internal homeostasis, management of several complications such as pain, infection, and jaundice, protection of organ functioning, and the mental intervention are important features of a complete and efficient realization for cancer patients. Attention to organ protection is a major element of full cancer management in elderly cancer patients. (Wan, Xu, Wu, Wu, Liao, Xu & Wang 2018)

Regulation of pain helps in improving the quality of life for the patient affected by cancer. Cancer pain can be eased successfully by giving opioids alone or combining them with corticosteroids which are adjuvant analgesics. Corticosteroids are commonly used for improving the quality of life, controlling and improving the symptoms. The nurse should administer the lowest effective dose and they should regularly follow up and assess patients to know the benefits and the risks that come with the pain therapy. In cases whereby, the general condition of a patient worsens, and the patient is not able to take medications orally, it is suggested not to stop the treatment immediately but instead, the nurse can continue giving the medications through the subcutaneous route. (Leppert & Buss 2012)

Ideal management of cancer pain can be attained by developing and implementing interventions. Medication ought not be the only way of managing pain, non-pharmacological pain interventions for patients and nurses can aid to manage and treat pain effectively. For efficient treatment to be attained, a regular, sufficient self-report of pain intensity assessment is necessary. Nurses should work towards a pain assessment method to accurately identify and monitor a patient's specific pain in clinical practice. Nurses should urge and support patients to be active and functional when it comes to the management of their pain. Nurses should attend training programs with the use of pain diaries with patients to monitor the pain of the patients. This will help to expand the patient related results. Fatigue, sleep disorders and anorexia usually come hand in hand with pain, which impair the quality of life of the patient, therefore, communication between the nurse and the patient with pancreatic cancer will help to improve the quality of care and life for the patient. (Jara, Barco, Gravalos, Hoyos, Hernandez, Munoz, Quintanar, Meana, Rodriguez & Penas 2017)

Nurses offering symptom management workbooks to patients dealing with pancreatic cancer to document their ups and downs/ symptoms in the journey with pancreatic cancer helps them to have information at hand regarding their own health thus empowering, motivating and improving the care and quality of life for the patients palliatively. This symptom management workbook includes questions put together for the patient to be asked during the appointments, their medication log, their health profile and their symptoms logs thus reducing the confusion, and it comes in handy during homecare visits by the nurses. This idea of a symptom management workbook improves the communication between the patient and the nurse based on individualized care in that every health log is in one place and not cluttered and this helps with the physical recovery and coping of the patient with the support of the nurse palliatively. (Banks 2012)

As a nurse, understanding the patient's symptom transition helps to categorize the overall symptom work up and treatment in an evidence-based approach to management. This essential primary step lets the nurse to critically evaluate the symptom analysis so that options are centered on the therapeutic usefulness while reducing suffering palliatively and financial deadlines. Comparable to the pain assessment method, one can get a broad symptom assessment and cooperate with the team to commence the progress of the patient as an individual. Alternative objective is to bring into line the patients' goals with the treatment plan. Oncology nurses commonly have a immense persona concern of the patient's values, home life, and support system. The whole patient must be well-thought-out when initializing a complete workup and treatment plan centered on the symptom management workbook. Nurses serve on the lead, appealing and supporting for the patients' needs based on their symptoms. (Hagmann, Cramer, Kestenbaum, Durazo, Downey, Russell, Geluz, Ma & Roeland 2018)

Nutritional supplementation in different ways can be used to artificially supplement the nutrition of the patient with pancreatic cancer who is in palliative care. These are enteral and parenteral nutrition. Parenteral nutrition is prepared intravenously by inserting a tube directly into the veins to pass in the nutrients. Enteral nutrition is prepared by use of a feeding tube. Artificial nutrition reduces symptoms such as overload of fluid in the body and difficulty in breathing because of choking or the inability to eat/chew. Palliatively, parenteral food is slowed down to a halt when the patient is close to death and the pain medication is only mechanism that is continued. In this case, supporting the relatives is important and relieving their anxiety because of the visible signs of deteriorating health of the patient in the end of life care. In most cases, the relatives tend to be more affected emotionally than the patients' themselves. (Simanek, Henry, Weixler, Hammerl-Ferrari, Geissler & Watzke 2012)

6.3 The importance of improving the quality of life to the patient

Patients with pancreatic cancer tend to have a clear understanding that there is not enough research done to give the essential knowledge regarding the cause of pancreatic cancer and the significance of the benefits of discovering the pancreatic cancer at an early phase. Most patients' worries were for the crucial demand for the developments in the early discovery and proper diagnosis of pancreatic cancer not only for them but for their loved ones, and other potential people. In most cases, patients got the diagnosis when it was too late because there were no symptoms showing that the pancreas has a tumor. Some of the patients mentioned that there could be a setback with the early detection of the pancreatic cancer tumor for asymptomatic patients. The solution to this was that the body system and the genes need to be thoroughly checked for faults that have never been identified, because preferably it has been known that all cancers are as a result of genetic failure. (Saunders, Gooden, Robotin & Mumford 2009)

According to Saunders et al. (2009), most patients express distress based on disbelief from clinical communication whereby the nurse or physician breaks down the information insensitively. An example, is when the health care professional tells the patient that their probable chance of living is up to 6 months, in other words, it's telling the patient that in 6 months they will be dead. This psychologically affects the patient because they had life plans of maybe to 96 years, nonetheless someone just crashes their hope. This leads to loss of positivity in life, lack of self-esteem and lack of motivation in life because eventually they know that they have a limited time frame to live. Another percentage of patients mentioned that, offering a solution to the problem, which in this case is pancreatic cancer, led to a negative conclusion as the nurses tend to ignore and brush off the conversation by mentioning that the conversation regarding pancreatic cancer is never a good one and they should just believe what the doctor is saying without making complaints because in accordance to protocol, nothing will be changed.

Availability of public information in written text is really handy for the patient with pancreatic cancer and their loved ones as well potential patients, as this creates awareness and education. The patient should be provided with reliable information on the cancer itself, where it is located, how it affects the body and the wellbeing of the patient and the various effective treatments available. This will reduce the impulsive decisions by the patient, for example, going overseas to seek treatment. This public information will save on the cost of travelling because patients tend to travel to look for better alternatives of treatments and ways to deal with the cancer. This will also help to save lives in the future. (Saunders et al. 2009)

7 DISCUSSION AND CONCLUSION

Pancreatic cancer is a disease that has the lowest survival rate of 5% in 5 years. Education through providing information that is necessary in regard to the treatment of the patient with pancreatic cancer in the stages of pancreatic cancer is important because this will ease the support and counseling given by the nurses to the patient, thus the patient will be psychologically prepared from the beginning of the cancer journey and the palliative care stage. Creating awareness is the major key to survival and improving the quality of life.

The existing literature in the counseling and palliative care of patients with pancreatic cancer shows that there are more discoveries arising for nurses to improve the quality of care with also the growing technology. As a nurse based on evidence-based knowledge summaries, one should always provide unbiased, professional and quality care to a patient as they are always the primary contact to the patients.

7.1 Discussion of findings

Communication greatly impacts the patient's care plan development between the patient and the nurses. Regarding survivorship planning as mentioned by Polakowski (2015), the nurses' role is to empower and support the patient to be active in his/her own care plan, whereby, the patient pin points the side effects and the complications of the chemotherapy or radiation during the treatment and notes them down, and when the patient fills in the questionnaire during the clinical visits, there will be notable differences from the results of both the health questionnaire and the patients notes. This helps to create a better survivorship care plan whereby proper treatment plans are incorporated, and the quality of life is improved as the patient's satisfaction is achieved, by easing the cancer symptoms and reducing the complications during the cancer therapy sessions.

In the nurse perspective, understanding what the patient is experiencing based on their worries based and how to deal with the treatment is important. Some patients are scared of the financial burden that comes along with the treatment, sometimes they may decide not to talk about it since they can have over the counter medicines, and through this they are thinking of how to save on the costs of the nausea and vomiting medicines administered because of their expensiveness. Through this understanding of the patients worries, the counseling helps the patient to understand that with complete workout plan based on

the symptom management workbook. It will help the patient to ease their distress and worries therapeutically. (Hagmann, Cramer, Kestenbaum, Durazo, Downey, Russell, Geluz, Ma & Roeland 2018)

In a theoretical approach, educating the patient with pancreatic cancer and its treatment includes defining various pancreatic cancer terminologies, translating the complex medical concepts and terms used in the treatment plan to a language that the patient with pancreatic cancer can understand. These terms include CT (computed topography), MRI (Magnetic resonance imaging), malignancies, chemotherapy and radiotherapy among others. Listening to the patient is crucial, and taking cues as to what the patient wants to know regarding the disease, the care and the treatment and how the patient conveys information. According to Walker, Colledge, Raltson & Penman (2014), the knowledge and skills of a nurse impacts on the care of the patient in that the nurse's effective decision making prolongs the quality of life in conjunction with balance, comfort and the individual wishes of treatment made by the patient.

Exercise and physical activity help patients manage cancer related fatigue. Some patients don't accept the idea of exercise and physical activity in consideration because of financial reasons. The role of the nurse is to counsel the patient of the simple and low-cost activity kits that they can use for the physical activity. The support from the nurses can be conducted through using simple strategies with support group exercises and counseling them on the various exercise programs that are not complicated, and they can be conducted individually at home. This exercise programs should put into consideration the stress reduction strategies, and energy conservation measures. The nurse should focus on supporting the patient by building knowledge to them and equipping them with commitment strategies for the patient to endure the outcome of the exercise and physical activity. (Huether, Abbott, Cullen, & Gaarde 2016)

Nurses fail to support the patient with pancreatic cancer due to fear of enough knowledge or shying away from discussing about certain topics as sex. According to Kotronolaus, Papadopoulou & Patiraki (2009), some nurses lack education of basic sexual health, some nurses tend to wait for the patient to bring up the topic of advice in sexual matters and other nurses secretly hope that the topic will not be brought up. According to myths; age, palliative care, sexual orientation and treatment induced menopause have interfered with the nurses' understanding of patient needs that cancer patients abandoned their sexual needs. This creates distress and prolong the symptoms of the patient, as the patient is stressed. Ignoring and avoiding the patient's sexual concerns, is insufficient provision of support and counseling. The lack of education of the nurses leads to insufficient basic knowledge of sex, thereby, their hesitation to discuss these demanding sexual matters. The attitudes of nurses who do not want to discuss sexual health and

lack initiative of discussing sexual matters with the patient lead to scarce nurse-patient interaction and a biased selection of the patients they care for.

As mentioned by Wilkes & Allen (2018), maintaining a good nutritional status is important in maintaining the patient's health. Nurses should consider a few things when giving counseling to the patient. Oral hygiene is important before chemotherapy because the chemotherapy regimen induces mucositis, therefore, a patient is advised to use salt and baking soda to rinse the mouth before the chemotherapy treatment. Another point is weight loss, whereby not all patients' with pancreatic cancer lose weight, some patients' tend to be obese and thus may continue to gain weight, therefore, the nurses should support the patient and counsel them on their dietary needs to keep them fit with a weight loss diet and the nurse and the patient should create a weight loss goal plan at least weekly. The nutritional needs increase above normal intake because of the cancer metabolism.

Cachexia is normally irreversible and can lead to death with its progression, therefore, nutritional screening at the first stage of cancer diagnosis should be done to prevent malnutrition and decrease the symptoms related to nutrition. The nurse should monitor the patient as the patient balances the nutritional needs while losing weight and at the same time going through the pancreatic cancer treatment. (Wilkes & Allen 2018) The nurse also counsels the patient regarding the non-pharmacological ways of dealing with cancer cachexia and these are through diet and physical activity. Doing physical exercises helps to break down the fats and the proteins which are caused by the irregular metabolism. As cachexia leads to decreased intake of nutrients, the role of nurse is to counsel the pancreatic cancer patient on what to eat in order to balance their energy that their body requires. (Hagmann et al. 2018)

According to Saunders et al. (2009), the early detection of pancreatic cancer is essential for the quality of life and can improve the chance of survival of the patient with pancreatic cancer. This can be made easier for the patients with pancreatic cancer and also for the general public to know what is cancer, what are the symptoms, how does it affect the health and the general well-being of the patient, and what effective treatments are available. Nurses should be sensitive when communicating about certain topics like the timeline of the survival of the patient. Not everyone would like to know how long they have to live. People have lifetime plans underway and draining their motivation will bring about a negative impact. Nurses should also listen to what the patient has to say, and in any chance they would offer a solution which would lead to improving the quality of life for themselves too.

7.2 Discussion of method

Using content analysis method could be unexpectedly challenging and time consuming for first time researchers. The reason for this is, that the researcher discovers that there is no easy step-by-step analysis to construct their data, thus creating frustration. The researcher could read through all the methodology, but they still lack a grip of what to do with the data acquired, for example, categorizing it to units and themes from raw data. This frustration can be eased by writing down ones' research aim, and questions followed by referring to the research aim during the data analysis in order to stay on track. Discussing and reflecting with other researchers who have the same data analysis method always comes in handy in creating new viewpoints. (Erlingsson & Brysiewicz 2017)

Conducting a literature review has its own up and downs, as a researcher, making important decisions is essential. In the beginning, the researcher came up with two research questions, but ended up with one research question. Finding information as a researcher is challenging because the target is always to collect materials written by Finnish authors based on the experiences of patients in Finland, the availability was scarce, so the researcher had to shift the focus to international materials. Consulting library advisors helped to learn how to incorporate different information search methods to acquire scientific academic information. Keeping time was challenging because the thesis process went over three months overtime to complete the research process. As a researcher, I was able to deliver information based on my goal and purpose with the supervision of my thesis supervisor, I chose to focus on palliative care because the quality of life is very important to patients dealing with cancer because there is no cure and patients want to maximize the time they have with their loved ones.

7.3 Conclusions and recommendations

In conclusion, recommendations from this thesis study for the nurse are staying up to date with the relevant scientific knowledge and skills in nursing care aids in boosting one's knowledge as a nurse and helps to prevent ignorance in matters concerning the health and wellbeing of a patient with pancreatic cancer. This helps to keep one as a nurse up-to-date with ongoing pancreatic cancer matters thus easing the counseling and palliative care of the patient and providing more important information regarding the importance of quality of life and how to improve the quality of life for the patient. Actively participating in training courses offered by the health work place is important in training oneself and getting prepared

in holding discussions with patients without fear and lack of knowledge. Lastly, early nursing care interventions have been associated with successful health benefits, such as preventing treatment delays that occur from severe symptoms in the care of a patient with pancreatic cancer thus boosting the counseling of the patient palliatively.

7.4 Learning Experiences

Writing a literature review with content analysis method was not as easy as I envisioned it would be. I thought completing the process would be fast according to the timetable I had created during the thesis plan making. I had obstacles that came along which were, identifying the method of content analysis that I was going to use and breaking down my findings from the research material articles to themes and categories using codes that I had collected to come up to a concrete conclusion. Another major obstacle I had was, familiarizing myself with qualitative analysis of raw data while still using my previous knowledge of data analysis. What I learnt from these obstacles is that, understanding that the content analysis method takes time because every set of data is always different in one way or another and it needs time to be analyzed. It could take days, weeks or months because a lot of thinking, reflection and reviewing is needed in this analysis method.

The phenomenon that I choose to write about was based on my previous study practices where I encountered patients with pancreatic cancer and there was no cure for it, in the beginning I wanted to conduct a qualitative research method using oral/written interviews because with this kind of research method, a researcher goes deeper into the problem but then the Finnish language barrier was the major setback. As a researcher, taking up this topic was the best decision that I made and it was not difficult for me in the beginning because I had already come up with the topics that I wanted to focus about, paying attention that cancer is a vast topic. Creating a thesis plan is always the best way to start up on the final thesis process. The knowledge that I acquired from this research process is going to help me in future as I would like to be an oncology nurse after graduating and it has increased my desire to carry out more scientific research.

As a nurse, this research has helped me to learn about previous information and knowledge that other researchers have discovered in relation to my topic of interest which is counseling and palliative care for patients with pancreatic cancer. It has given me a deeper understanding and the ability to learn more important things in connection to my research topic, I have also seen the false opinions around this topic

through secondary resources. I have acquired critical thinking and analytical skills, reading and writing skills, research skills, data analysis skills, self-learning skills, planning and scheduling skills, as well as technology skills. As a researcher, I learnt that research greatly impacts on the quality of life. As a future oncology nurse, this learning process will help me in aiding in clinical trials that comprise of new medication and treatments for cancer to improve the patients' health and quality of life.

8 REFERENCES

- Ali S., Osmany M., Khan W. & Mishra D. 2014. Fear of death, depression and coping among cancer patients. *Indian Journal of Health and Wellbeing*. Available. <http://web.a.ebscohost.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=3&sid=188f93f5-30fc-4efa-bce0-851bcac2057a%40sessionmgr4010> Accessed 5.10.2017
- American Cancer Society. Available. <https://www.cancer.org/cancer/pancreatic-cancer.html> Accessed 14.4.2017.
- American Society of Clinical Oncology. Finding Support and Information: Counseling. *Cancer Net*. Available. <http://www.cancer.net/coping-with-cancer/finding-support-and-information/counseling> Accessed 14.4.2017
- Aveyard H. 2010. *Doing A Literature Review in Health and Social Care: A Practical Guide*. Available. <https://ebookcentral.proquest.com/lib/cop-ebooks/reader.action?docID=771406>. Accessed 16.4.2017
- Banks S. 2012. My Mother's Daughter, *Clinical Journal of Oncology Nursing*, December 2012. <http://web.a.ebscohost.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=0&sid=fd222187-a3a8-41d3-b022-6c190d82ab9c%40sessionmgr4007>. Accessed 28.08.2018
- Biedrycki B. & Kimmei S. 2016. Management of Advanced Pancreatic Adenocarcinoma. *The Nurse View*. Available. <https://www.sciencedirect-com.ezproxy.centria.fi/science/article/pii/S074920811830038X> Accessed 07.09.2018. Accessed 17.4.2017
- Broomfield R. 2017. A nurses' guide to ethical considerations and the process for ethical approval of nursing research. *Australian Journal of Advanced Nursing*. Available. <http://web.a.ebscohost.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=0&sid=7e61544d-eb5a-4ea0-9da4-d4b6013d8fe2%40sessionmgr4008>. Accessed 9.2.2019
- Doody O. & Noonan M. 2016. Nursing research ethics, guidance and application in practice. *British Journal of Nursing*. Available. <http://web.a.ebscohost.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=0&sid=c45e1d9d-5d29-4292-b1be-0d0ee01ae131%40sessionmgr4006>. Accessed 9.2.2019
- Cancer Nurses Association 2012. *Palliative Approach to Care and the Role of the Nurse*. Available. https://www.cna-aiic.ca/~media/cna/page-content/pdf-en/the-palliative-approach-to-care-and-the-role-of-the-nurse_e.pdf Accessed 16.4.2017
- Costelloe M. & Nelson L. 2004. The needs of diagnosed cancer patients. *Nursing Standard*. vol. 19. pg. 42-44. Available. <http://web.b.ebscohost.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=9&sid=cfd9ca95-4951-476b-90ef-0b3331e83fbd%40sessionmgr104> Accessed 29.6.2017
- Dabisch I., Dethling J., Dintsios C., Drechsler M., Kalanovic D., Kaskel P., Langer F., Ruof J., Ruppert T., & Wirth D. 2014. Patient relevant endpoints in oncology: current issues in the context of early benefit assessment in Germany. Available. <https://theconomicsreview.biomedcentral.com/articles/10.1186/2191-1991-4-2>. Accessed 20.11.2018
- De Kort S., Pols J., Richel D., Koedoot N. & Willems D. 2010. Understanding Palliative Cancer Chemotherapy: About Shared Decisions and Shared Trajectories. Vol. 18, p.164-174. Available. <https://link.springer.com/article/10.1007%2Fs10728-009-0121-4>. Accessed 17.4. 2017
- Driessen C., Kleine-Bolt K., Vingerhoets A., Mols F., & Vreugdenhil G. 2011. Assessing the impact of chemotherapy-induced peripheral neurotoxicity on the quality of life of cancer patients. Available. <https://link.springer.com/article/10.1007%2Fs00520-011-1336-0>. Accessed 20.11.2018

- Elo S & Kyngäs H. 2008. The qualitative content analysis process. *Journal of Advanced Nursing* April 2008, Vol.62(1), pp.107-115. Accessed 20.12.2018
- Erlingsson C. & Brysiewicz P. 2017. A hands-on guide to doing content analysis. *African Journal of Emergency Medicine*. Vol 7, Issue 3, Pgs. 93-99. Available. <https://www.sciencedirect.com/science/article/pii/S2211419X17300423?via=ihub> Accessed 18.2.2019.
- George SZ & Hirsch AT. Distinguishing patient satisfaction with treatment delivery from treatment effect: A preliminary investigation of patient satisfaction with symptoms after physical therapy treatment of low back pain. *Arch Phys Med Rehab*. 2005; vol. 86 pg. 1338-1344. Accessed 14.10.2017
- Glavin R. 2010. Drug errors: Consequences, mechanisms, and avoidance. *British Journal of Anesthesia*. vol. 105. pp. 76-82. Available. <http://www.sciencedirect.com.ezproxy.centria.fi/science/article/pii/S221413911500013X?via%3Dihub#bb0055> Accessed 10.10.2017
- Glowacki D.2015. Effective Pain Management and Improvements in Patients' Outcomes and Satisfaction. *Critical Care Nurse*. Available. <http://web.b.ebscohost.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=1&sid=bea7ba79-a4a2-426b-b63f-adcf531425bb%40sessionmgr102> Accessed 7.10.2017
- Gooden H. & White K. 2013. Pancreatic Cancer and Supportive Care- Pancreatic exocrine insufficiency negatively impacts on quality of life. *Supportive Care Cancer*. vol. 21. pg. 1835-1841. Available. <http://web.b.ebscohost.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=16&sid=5ebee9d1-a54e-4e82-944b-5cd902f41ad9%40sessionmgr104> Accessed 29.6. 2017
- Grossmann S. & Nesbit S. 2014. Cancer Related Pain. *Abeloff's Clinical Oncology (Fifth Edition)*. pg 608-619. Accessed 15.5.2018
- Gupta D., Markman M., Rodeghier M., & Lis C. Pubmed 2012. The relationship between patient satisfaction with service quality and survival in pancreatic cancer. Available. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3496532/>. Accessed 20.11.2018
- Hagmann C, Cramer A, Kestenbaum A, Durazo C, Downey A, Russell M, Geluz J, Ma J. & Roeland E. Evidence-based palliative care approaches to non-pain physical symptom management in cancer
- Holloway, I. & Wheeler, S. 2013. *Qualitative Research in Nursing Healthcare*. 3rd Edition. Wiley-Blackwell Publishing. Accessed 16.4.2017
- Hedges C. & Williams B. 2015. *Anatomy of Research for Nurses*. Conducting a literature search and review. chapt. 6 pg. 97-110. Available. <https://ebookcentral-proquest-com.ezproxy.centria.fi/lib/cop-ebooks/reader.action?docID=3383945&ppg=126> Accessed 13.10.2018
- Huether K., Abbott L., Cullen L., Cullen L., Gaarde A. 2016. Energy Through Motion: An Evidence-Based Exercise Program to Reduce Cancer-Related Fatigue and Improve Quality of Life. *Clinical Journal of Oncology Nursing*. <http://web.b.ebscohost.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=0&sid=0408bb0a-d024-4108-ae70-013df6c4f2f4%40pdc-v-sessmgr06>. Accessed 07.09.2018
- Iott M., Corsini M. & Miller R. 2008. Evidence-based Guidelines for Adjuvant Therapy of for Resected Adenocarcinoma of the Pancreas. *Clinical Journal of Oncology Nursing*. vol. .12, no. 4. Available. <http://web.a.ebscohost.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=7&sid=c3baf9fe-e888-46d8-8382-e1b6bdb6059c%40sdc-v-sessmgr05> Accessed 30.5.2017

- Jara C., Barco S., Gravalos C., Hoyos S., Hernandez B., Munoz M., Quintanar T., Meana J., Rodriguez C., & Penas R. 2017. SEOM clinical guideline for treatment of cancer pain (2017). Available. <https://link.springer.com/article/10.1007%2Fs12094-017-1791-2>. Accessed 20.11.2018
- Jennings C., Cassel B., Fletcher D., Wang A., Archer K., Skoro N., Yanni L., & Del Fabbro E. 2014. Response to pain management among patients with active cancer, no evidence of disease, or chronic nonmalignant pain in an outpatient palliative care clinic. *Journal of palliative medicine*. vol.17 (9), pp.990-994. Available. <https://centria.finna.fi/ncbi.nlm.nih.gov/pubmed/24945588> Accessed 7.10.2017
- Kotronoulas G., Papadopoulou C. & Patiraki E. 2009. Nurses' knowledge, attitudes, and practices regarding provision of sexual health care in patients with cancer: critical review of the evidence. *Supportive Care in Cancer*. <http://web.b.ebscohost.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=0&sid=bb692535-4abc-4fb7-ab7d-6237185520ff%40sessionmgr103>. Accessed 07.09.2018
- Leppert W., & Buss T. 2012. The Role of Corticosteroids in the Treatment of Pain in Cancer Patients. Available. <https://link.springer.com/article/10.1007%2Fs11916-012-0273-z>. Accessed 20.11.2018
- Mishra S., Scherer R., Snyder C., Geigle P., & Gotay C. 2014. Are Exercise Programs Effective for Improving Health-Related Quality of Life Among Cancer Survivors? A Systematic Review and Meta-Analysis. *Oncology Nursing Forum*. Available. <http://web.a.ebscohost.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=0&sid=f7abc723-a4e8-42c8-9cd0-d0440bad3995%40sessionmgr4010>. Accessed 5.10.2017
- Morgan M. 2009. Cancer survivorship: history, quality-of-life issues, and the evolving multidisciplinary approach to implementation of cancer survivorship care plans. Available. <http://web.a.ebscohost.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=2&sid=49fa645b-72ce-403b-9b21-98cdd5bbe154%40sdc-v-sessmgr01> Accessed 12.12.2018.
- Niederhuber J. 2014. *Abeloff's Clinical Oncology*, an imprint of Elsevier Inc. vol. 5. Available. <http://www.sciencedirect.com.ezproxy.centria.fi/science/book/9781455728657> Accessed 15.4.2017
- Nițipir C., Barbu M., Moțatu P., Filipescu A. & Popescu B. 2017. Palliative care of the patient with metastatic pancreatic cancer. *Original Papers: Paliatia: Journal of Palliative Care*. vol. 10. Available. <http://web.b.ebscohost.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=7&sid=9de1663d-a7e4-4d2d-ae00-1189587680df%40sessionmgr103> Accessed 1.10.2017
- Nadine K., Jordana M., Bettina M., Phyllis B., Margaret C., Kristine S., Graham M. & Scott M. 2012. Living beneath the sword of damocles': perceptions of risk and fears of cancer recurrence amongst Australian melanoma survivors at high or moderate risk of developing new primary disease. *Asia-Pacific Journal of Clinical Oncology*. Vol 8. Pg. 36. Accessed 16.6.2018
- Obeid S. 2016. *Chemotherapy, Radiotherapy: Pancreatic Cancer*. The Joanna Briggs Institute. Available. http://ovidsp.uk.ovid.com.ezproxy.centria.fi/sp-3.24.1b/ovid-web.cgi?&S=CADOPDNNPBHFNADBFNHKMBAGEINAAA00&Link+Set=S.sh.21%7c4%7csl_190 Accessed 14.4.2017
- Oosterveld-Vlug M., Donker G., Atsma F., Brom L., Man Y., Groenewoud S., & Philipsen B. 2017. How do treatment aims in the last phase of life relate to hospitalizations and hospital mortality? A mortality follow-back study of Dutch patients with five types of cancer. Available. <https://link.springer.com/article/10.1007%2Fs00520-017-3889-z>. Accessed 20.11.2018
- Pelzer U., Arnold D., Goevercin M., Stieler J., Doerken B., Riess H. & Oettle H. 2010. Parenteral nutrition support for patients with pancreatic cancer. Results of a phase II study. *BMC Cancer*. Available. <http://web.a.ebscohost.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=0&sid=a7f74fec-5180-4433-b4b9-74c198fe2373%40sessionmgr4007>. Accessed 07.09.2018

- Polakowski T. 2015. Caring for the Continuum of Patients with Pancreatic Cancer: The Importance of Survivorship Care Planning. *Clinical Journal of Oncology Nursing*, February 2015. <http://web.a.ebsco-host.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=0&sid=50ab50a3-b5b4-4e70-9862-5453a63d8894%40sessionmgr4009>. Accessed 28.08.2018
- Reilly C., Bruner D., Mitchell S., Minasian L., Basch E., Dueck A., Cella D., & Reeve B. 2013. A literature synthesis of symptom prevalence and severity in persons receiving active cancer treatment. Available. <https://link.springer.com/article/10.1007%2Fs00520-012-1688-0>. Accessed 20.11.2018
- Riedl D., Gastl R., Gamper E., Arnold C., Dejaco D., Schoellmann F., & Rumpold G. 2018. Cancer patients' wish for psychological support during outpatient radiation therapy. Available. <https://link.springer.com/article/10.1007%2Fs00066-018-1288-0>. Accessed 20.11.2018
- Rosenstein D. 2011. Depression and End of Life Care for Patients with Cancer. Available. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3181973/> Accessed 17.4.2017
- Satin J., Linden W. & Phillips M. Depression as a Predictor of Disease Progression and Mortality in Cancer Patients, 2009. vol.115. p.5349–5361. Available. <http://onlinelibrary.wiley.com/doi/10.1002/cncr.24561/full> Accessed 17.4.2017
- Saunders C., Gooden H., Robotin M., & Mumford J. 2009. As the bell tolls: a foundation study on pancreatic cancer consumer's research priorities. Available. <https://bmcrenotes.biomedcentral.com/articles/10.1186/1756-0500-2-179>. Accessed 20.11.2018
- Shi C., Hruban R. & Klein A. 2009. Familial Pancreatic Cancer. Available. <http://web.b.ebsco-host.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=1&sid=2514d316-0eec-4056-897f-8105133a1f3a%40sessionmgr104> Accessed 15.4.2017
- Simanek R., Henry A., Weixler D., Hammeri-ferrari B., Geissler K., & Watzke H. 2012. Parenteral nutrition for symptom control in a patient with pancreatic cancer and generalized edema – a case report. Available. <https://link.springer.com/content/pdf/10.1007%2Fs12254-012-0342-3.pdf>. Accessed 20.11.2018
- Suzuki H., Asakawa A., Amitani H., Nakamura N., & Inui A. 2013. Cancer cachexia—pathophysiology and management. Available. <https://link.springer.com/article/10.1007%2Fs00535-013-0787-0>. Accessed 20.11.2018
- Taverner T. 2015. Neuropathic pain in people with cancer (part 2): pharmacological and non-pharmacological management. *International Journal of Palliative Nursing*. Available. <http://web.b.ebscohost.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=0&sid=2bd90b4e-1ddf-40cb-87d3-8b2a0c5462c5%40sessionmgr101>. Accessed 9.2.2019
- Terveyskylä 2018. Syöpäkipu. Available. <https://www.terveyskyla.fi/kivunhallintatalo/syopakipu> Accessed 18.2.2019
- Towers R. & Diffley A. 2011. A Nurse-Led Cancer Counseling Service. *Cancer Nursing Practice*. vol. 10(6) p. 14-18. Available. <http://web.b.ebscohost.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=2&sid=9b17ca10-b5df-43b6-b626-5082046752de%40sessionmgr102&hid=102> Accessed 14.4.2017
- Vallow S., Zhang M., Greenberg PE., Reynolds JL., White AG. & Birnbaum HG. 2006. Estimated costs of prescription opioid analgesic abuse in the United States: A Societal Perspective. *Clinical Journal of Pain*. vol. 22. pg. 667-676. Accessed 14.10.2017

- Walker B., Colledge N., Ralston S. & Penman I. 2014. Davidson's Principles and Practice of Medicine 22nd edition p.284. Available. <https://studentconsult.inkling.com/read/davidson-principles-practice-medicine-walker-22th/chapter-12/principles-of-palliative-care> Accessed 17.4.2017
- Wan J., Xu S., Wu Y., Wu B., Liao D., Xu N., & Wang G. 2018. Management and survival analysis of elderly patients with a cancer in the digestive system who refused to receive anticancer treatments. Available. <https://link.springer.com/article/10.1007%2Fs00520-018-4065-9>. Accessed 20.11.2018
- Watson M., Hoy A., Wells J., & Lucas C. 2009. Palliative Care: Oxford Handbook of Palliative Care, Oxford University Press USA - OSO, 2009. ProQuest eBook Central. Available. <http://ebookcentral.proquest.com/lib/cop-ebooks/detail.action?docID=975531>. Accessed 15.10.2018
- Wilkes P., & Allen D. 2018. Nutrition Care: Managing Symptoms from Cancer. The Journal for Nurse Practitioners. Available. <https://www.sciencedirect-com.ezproxy.centria.fi/science/article/pii/S1555415518300485> Accessed 07.09.2018.
- World Health Organization (WHO) 2017. Definition of Palliative Cancer. Available. <http://www.who.int/cancer/palliative/definition/en/> Accessed 15.4.2017
- World Health Organization (WHO) 2019. Palliative Care: WHO's cancer pain ladder for adults. Available. <https://www.who.int/cancer/palliative/painladder/en/> Accessed 18.2.2019
- Zhang J., Dhakal I., Gross M., Lang N., Kadlubar F., Harnack L., & Anderson K. 2010. Physical Activity, Diet, and Pancreatic Cancer. Nutrition & Cancer. Vol. 61 pg. 457-465. Available. <http://web.a.ebsco-host.com.ezproxy.centria.fi/ehost/pdfviewer/pdfviewer?vid=32&sid=90e5090a-1d91-4fb6-a58f-8bcf12ce12df%40sessionmgr4007> Accessed 1.10.2017

9 APPENDICES

TABLE 4. The content analysis process of the study

APPENDIX 1/2

| Author | Title | Purpose and method | Findings | Intervention |
|---|--|---|---|---|
| Hagmann C., Cramer A., Kestenbaum A., Durazo C, Downey A., Rusell M., Geluz J., Ma J., &Roeland E. 2018 | 1 Evidence-based palliative care approaches to non-pain physical symptom management in cancer patients. | To review effective approaches for non-pain symptom management for cancer patients. | The focus was on treatment of nausea and vomiting, constipation, diarrhea, anorexia/cachexia, fatigue, and dyspnea. | Psychosocial education of symptom management. |
| Oosterveld-Vlug M., Donker G., Atsma F., Brom L., Man Y., Grenewoud S., & Philipsen B. 2017 | 2 How do treatment aims in the last phase of life relate to hospitalizations and hospital mortality? A mortality follow-back study of Dutch patients with cancer. | To define and relate the treatment aims, hospitalizations, and hospital mortality for patients who died from pancreatic cancer. | How patients with pancreatic cancer least often had a palliative treatment aim a month before death. | The necessity for early introduction of palliative care to support patients with cancer to stay at the place they prefer as long as possible. |
| Wilkes P., & Allen D. 2018 | 3 Nutrition care: Managing symptoms from cancer. | To anticipate and screen for nutritional issues that patients may face over their cancer course. | Educating and guiding patients about the role of a healthy diet aids to regain health through cancer survivorship. | Specific evidence-based strategies to manage nutritional issues. |
| Reilly C., Bruner D., Mitchell S., Minasian L., | 4 A literature synthesis of symptom | The systematic review of the research literature | A discrete set of symptoms is | Clinical study seeking to evaluate |

| | | | | |
|---|--|--|--|---|
| Basch E., Dueck A., Cella D., & Reeve B. 2013 | prevalence and severity in persons receiving active cancer treatment. | of the prevalence and severity of symptoms in patients undergoing cancer treatment. | common across cancer types. | the impact of treatment on patients should consider including measurement of symptoms. |
| Leppert W., & Buss T. 2012 | 5 The role of corticosteroids in the treatment of pain in cancer patients | To show the role of steroids in pain and management of other symptoms in cancer patients and discuss the practical aspects of steroid use. | Pain is one of the most frequent and most distressing symptoms in the course of cancer. | Cancer pain may be relieved effectively with opioids administered alone or in combination corticosteroids. |
| Kotronoulas G., Papadopoulou C. & Patiraki E. 2009 | 6 Nurses' knowledge, attitudes, and practices regarding provision of sexual health care in patients with cancer. | To gather evidence regarding knowledge, attitudes, and behaviors of nurses towards sexual health issues. | Continuing education activities and availability of education materials to nurses to adequately address sexual concerns while caring for patients with cancer. | Dispelling the myths about sexual health in cancer care. |
| Wan J., Xu S., Wu Y., Wu B., Liao D., Xu N., & Wang G. 2018 | 7 Management and survival analysis of elderly patients with a cancer in the digestive system who refused to receive anti-cancer treatments. | A better consideration of how cancer progression in patients who have not received any anticancer treatments could help treating and making end-of-life decisions. | Cancer patients obviously benefited from prophylactic interventions of organ dysfunction & active nutritional support and anti-infection treatment. | More attention to organ protection as the main element of comprehensive cancer management in cancer patients. |
| Simanek R., Henry A., Weixler D., Hammeri-ferrari B., Geissler K., & Watzke H. 2012 | 8 Parenteral nutrition for symptom control in a patient with pancreatic cancer and generalized | The effect of parenteral nutrition in advanced cancer patients. | Locally advanced pancreatic cancer, inflammatory state and recurrent edema are | Persistent symptom control could be achieved by anti-inflammatory |

| | | | | |
|---|---|--|--|---|
| | edema – a case report | | due to an anorexia-cachexia syndrome. | treatment and supplemental parenteral nutrition until death. |
| Pelzer U., Arnold D., Goevercin M., Stieler J., Doerken B., Riess H. & Oettle H. 2010. | 9 Parenteral nutrition support for patients with pancreatic cancer. Results of a phase II study. | | | |
| Jara C., Barco S., Gravalos C., Hoyos S., Hernandez B., Munoz M., Quintanar T., Meana J., Rodriguez C., & Penas R. 2017 | 10 SEOM clinical guideline for treatment of cancer pain (2017) | To establish recommendations that can be applied by professionals in their clinical practice to optimize cancer pain management. | Despite therapeutic advances and well-accepted treatment guidelines, a percentage of patients with pain are under-treated. | Greater emphasis should be placed on non-opioid analgesics and non-pharmacological therapies due to long term side effects. |

APPENDIX 2/2

| Author | Title | Purpose and Method | Findings | Intervention |
|--|---|---|--|--|
| Banks S. 2012 | 11 My mother's daughter. | To document the physical recovery and coping through a symptom management workbook. | It empowers, motivates, and improves the quality of life for the patients and caregivers. | Addressing patient' individualized care. |
| Riedl D., Gastl R., Gamper E., Arnold C., Dejacó D., Schoellmann F., & Rumpold G. 2018 | 12 Cancer patients' wish for psychological support during outpatient radiation therapy. | To investigate the number of patients with a wish for psycho-oncology, treatment paths, and predictors of the wish for PO among cancer patients at the beginning of radiotherapy. | Low emotional wellbeing and lack of social support were strong predictors for this treatment wish. | Stress screening should be implemented in clinical routine for psychosocial problems. |
| Polakowski T. 2015 | 13 Caring for the continuum of patients with pancreatic cancer: The importance of survivorship care planning. | To outline the use of a survivorship care plan to improve communication between the patient and nurses. | How survivorship care planning would be beneficial for all patients with cancer. | To improve the coordination of care and patient satisfaction. |
| Driessen C., Kleine-Bolt K., Vingelhoets A., Mols F., Vreugdenhil G. 2011 | 14 Assessing the impact of chemotherapy-induced peripheral neurotoxicity on the quality of life of cancer patients | To investigate the impact of chemotherapy-induced neurotoxicity on daily activities and quality of life of cancer patients. | Treatment with chemotherapy reported more complaints of neuropathy and paresthesia, dysesthesias in the upper and lower extremities compared | CINQ could be a useful measure to evaluate patients' suffering from neuropathy symptoms. |

| | | | | |
|--|---|--|--|---|
| | | | to those not treated with chemotherapy. | |
| Suzuki H., Asakawa A., Amintani H., Nakamura N., Inui A. 2013. | 15 Cancer cachexia- pathophysiology and management | To recognize the psychosocial and biomedical impact cachexia can have. | Half of cancer patients show cachexia syndrome, with anorexia and loss of adipose tissue and skeletal muscle mass. | The positive impact of supportive care measures and developing pharmaceutical agents for cachexia. |
| Saunders C., Gooden H., Robotin M., & Mumford J. 2009 | 16 As the bell tolls: a foundation study on pancreatic cancer consumer's research priorities. | To discover the views of people affected by pancreatic cancer with regard to research priorities. | Early detection, clinician communication and public awareness, quality of care and the need for more and improved treatment options. | The primary understanding of the role cancer patients in identifying areas of research that are responsive to their needs and priorities. |
| Dabisch I., Dethling J., Dintios C., Dreschsler M., Kalanovic D., Kaskel P., Langer F., Ruof J., Ruppert T., & Wirth D. 2014 | 17 Patient relevant endpoints in oncology: current issues in the context of early benefit assessment in Germany. | The new developments and therapeutic approaches in oncology in regard to early benefit assessment. | The morbidity endpoints to be considered when addressing the complexity of the situation of the individual patient. | The extensive knowledge and experience when assessing the patient-relevant benefit of innovative medicines in oncology. |
| Gupta D., Markman M., Rodeghier M., & Lisa C. 2012 | 18 The relationship between patient satisfaction with service quality and survival in pancreatic cancer. | Evaluating whether an individual patient's satisfaction with the overall quality of care received might influence outcome. | Patients receiving care from diagnosis, treatment history, and specific treatments demonstrated lower mortality. | The patient satisfaction with health service quality was an independent predictor of survival in pancreatic cancer. |

| | | | | |
|--|--|--|---|--|
| <p>Huether K., Abbott L., Cullen L., Cullen L., Gaarde A. 2016</p> | <p>19 Energy through motion: An evidence-based exercise program to reduce cancer-related fatigue and improve quality of life.</p> | <p>To provide an evidence-based activity program for adult cancer survivors after treatment to reduce fatigue and improve quality of life.</p> | <p>As fatigue levels in the decrease, the quality of life improves.</p> | <p>Evidence-based activity intervention, and evaluation of the practice change and a follow up activity.</p> |
|--|--|--|---|--|