AN INVESTIGATION INTO PAIN IN CANCER PATIENTS

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DECLARATION

I, Rowan Paula Robinson declare that this dissertation**, AN INVESTIGATION INTO PAIN IN CANCER PATIENTS** is my own, unaided work. It is being submitted for the Degree of Master of Science at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.

Signature……

…….Day of……..2020 at ……..……..

ABSTRACT

Introduction

Nurses play an important role in cancer treatment delivery, patient information and symptom management, as well as psychological and supportive care. As nurses spend the greatest portion of time caring for patients, they are ideally placed to routinely assess the patient's pain and response to treatment.

Purpose

The purpose of the study was to provide baseline data that could be used to develop a patient informed pain assessment instrument used by nurses practicing in cancer care settings for South African cancer patients.

Objectives

The first objective of the study was to explore which pain assessment instruments are available to assess cancer pain, their characteristics and comparison against the criteria of an ideal instrument. The second objective was to describe how cancer patients experience and describe their pain and what they consider essential for nurses to know about their pain.

Methods

A sequential multi-method study was conducted in two parts: a scoping review and in-depth interviews were used to gather data.

Findings

None of the nineteen identified instruments met the criteria of an ideal pain assessment instrument, and even the ideal criteria as provided by the African Palliative Care Association (2010) and Farrer (2007), appeared to be incomplete and should be updated. The study provided evidence of the participants' experience of cancer pain and what brings relief from the pain. They described their need for information and communication as well as support and compassionate care. Finally participants described what nurses need to know about their cancer pain experience.

Conclusion

Cancer pain is complex, with physical, emotional and psychosocial factors having a profound influence on the unique and personal experience of cancer pain. The successful management of cancer pain is dependent on thorough assessment, re-assessment,

measurement of pain intensity, interpretation of findings and appropriate treatment of the pain including both pharmacological and non-pharmacological options.

For Charlo

Husband, cheerleader, best friend
And the love of my life

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CHAPTER 1

INTRODUCTION TO THE STUDY

1.1 BACKGROUND

Worldwide, the number of people diagnosed with cancer is increasing and more than half of these newly diagnosed patients are from developing countries (International Agency for Research in Cancer 2012). It is anticipated that by 2020, there will be more than 15 million people newly diagnosed with cancer (Ripamonti, Bandieri & Roila 2011).

Pain is often associated with cancer. It is a presenting symptom at diagnosis in over 50% of cancer patients (Mulvey et al 2014). However it is prevalent in all stages of the disease but appears to worsen with advancing disease (Ripamonti, Bandieri & Roila 2011).

Due to various reasons such as lack of resources, distance to treatment centres and lack of adequate primary prevention and screening programs, many cancer patients living in the developing world present at an advanced stage of their disease. It is not only these patients who experience pain, as a systematic review of the literature confirmed that a high percentage of cancer patients complain of pain, irrespective of the stage of their disease (Eaton et al 2015). Despite a dearth of research on cancer pain in South Africa, it seems as if South African cancer patients have similar experiences. In a study to determine the most common symptoms experienced by patients with advanced cancer, pain was experienced by more than 76% of patients (Maree & Wright 2008).

Pain is also associated with cancer treatments (Brant 2018) but may be unrelated to either the cancer disease or its treatment (Miyashita 2018) and experienced as physical or emotional suffering (Yamanaka 2018). The management of pain in cancer patients is therefore critical but often unrecognised or undertreated (Ripamonti, Bandieri & Roila 2011).

Pain can be described as an unpleasant sensory and emotional experience which can only be described by the person experiencing it (Newton, Hickey & Marrs 2009). Pain is commonly feared by patients (Baek et al 2016) and they can experience more than one type of pain in a short space of time (Ripamonti, Bandieri & Roila 2011).

The treatment of pain has three critical components: pain assessment, pain measurement and pain management (African Palliative Care Association 2010). As a subjective experience, cultural, age and gender-related factors need to be taken into consideration (Brant 2017). Pain should be assessed and routinely re-evaluated by means of a reliable

assessment instrument followed by prompt pharmaceutical and non-pharmaceutical interventions (Eaton et al 2015).

Pain assessment instruments are used as a means of systematically and routinely documenting the patient's experience of pain over time and can serve as a valuable communication tool between the patient and members of the multi-disciplinary health team. It is believed that one of the main reasons for inadequate pain management is the lack of pain assessment (Webber 2014) as both the pharmacological and non-pharmacological management are guided by the patient's subjective pain experience. Accurate pain assessment is also dependent on clinical competency of the healthcare practitioner (Weber et al 2014) and the interpretation of findings. However the inability of staff to adequately assess and document their findings is considered a contributing factor to the sub-optimal treatment of pain in adults (Smith Idell, Grant & Kirk 2007).

Nurses play a crucial role in pain management (Miyashita 2018) as they spend the greatest portion of time caring for patients and develop trust-relationships with them. They are therefore ideally placed to routinely assess the patient's pain and response to treatment, communicate these findings to the multi-disciplinary team and support the patient throughout the various stages of their cancer journey.

Several measurement instruments or standardized scales such as visual analogue scales (VAS), verbal rating scales (VRS) and a numerical rating scale (NRS) are used to provide an indication of pain intensity and response to treatment (Ripamonti, Bandieri & Roila 2011). Pain rating scales are often included in pain assessment instruments (African Palliative Care Association 2010).

There are many barriers to assessing pain which include time constraints and workload experienced by staff working in under-resourced facilities, knowledge deficits with regards the assessment, measurement and management of pain and including the interpretation of data (Eaton et al 2015). Pain measurement instruments that are efficient to administer and that are culturally, socially and spiritually acceptable for both staff and patient need to be developed, specifically for diverse countries such as South Africa, in order to facilitate improved pain management.

1.2 PROBLEM STATEMENT

The research problem pertains to cancer pain, specifically pain assessment and patient experiences of pain. Pain assessment is the cornerstone of successfully managing pain (Newton, Hickey & Marrs 2009) and should be the foundational strategy used by nurses

practicing in cancer care settings (Beck et al 2016). According to the regulations regarding the scope of practice of registered nurses in South Africa (South Africa 2013), nursing is a dynamic process which co-ordinates and ensures continuity of care in patients throughout the healthcare experience.

As already mentioned, nurses spend the majority of time with patients compared to other healthcare professionals and are therefore ideally placed to routinely assess pain experienced by their patients. Unfortunately, this practice does not seem to be adhered to. Maree (2010) in a South African study investigating practices of registered nurses in terms of cancer pain practices found that pain is not assessed. Although nursing knowledge and attitude plays a significant role in cancer pain management, additional resources are also required (Beck et al 2016).

The nursing manager of the oncology wards and clinics at an academic hospital in Gauteng expressed his concern about the way pain is managed as currently there is no pain assessment instrument supported by the Gauteng Department of Health, that could guide pain management. The lack of such instrument results in pain not being assessed resulting in pain not being managed according to the pain needs of the patient.

The African Palliative Care Association (2010) does not recommend a specific pain assessment instrument but recommends that the usability of the document and validity for use in Africa should be considered in the selection of an instrument. However, whether the existing pain assessment instruments would be suitable for assessing the pain of South African cancer patients is questionable, as these instruments have been designed in the developed world and not for Africa with its unique challenges, cultures, languages and cancer patient population.

1.3 RESEARCH QUESTIONS

To address the research problem, the following research questions were formulated:

- What pain assessment instruments are available to assess pain in cancer patients, what are the characteristics of these instruments and how do they compare against the criteria of an ideal instrument?
- How do cancer patients experience and describe their pain and what do they consider essential for nurses to know about their pain?

1.4 PURPOSE AND OBJECTIVES

The purpose of the study was to provide baseline data that could be used to develop a patient informed pain assessment instrument used by nurses practicing in cancer care settings for South African cancer patients. The objectives of the study were to:

- Explore which pain assessment instruments are available to assess cancer pain, explore the characteristics of these instruments and compare them against the criteria of an ideal instrument.
- Describe how cancer patients experience and describe their pain and what they consider essential for nurses to know about their pain.

1.5 RESEARCH DESIGN AND METHODS

To answer the research questions, a sequential multi-method study was conducted. Part 1 of the study consisted of a scoping review and answered the first research question investigating what pain assessment instruments are available to assess pain in cancer patients, what the characteristics of these instruments are and how they compare against the criteria of an ideal pain assessment instrument. Scoping reviews create an inventory of essential components or factors of the research topic by listing types of evidence that are available and identifies gaps where evidence has not been comprehensively reviewed before (Dijkers 2015).

The key words “cancer pain” in combination with “assessment tool” and “assessment instrument” were used to search Pubmed, CINAHL, Web of Science and Scopus. Only studies published in English between 2012 and 2016, in a peer reviewed journal of which full texts were available through the inter-university library system were considered for the review. Data extraction Excel spreadsheets were used to record findings.

Part 2 of the study used a qualitative descriptive design to answer the second question which investigated cancer patients’ pain experiences, how they describe their pain and what they considered essential for nurses to know about their pain. Qualitative description enables the researcher to present the language of the participants as a descriptive summary from the patient’s viewpoint (Sandelowski 2000).

The study was conducted in the medical oncology department of an academic hospital in Gauteng. The target population for this study included adult male and female patients treated for cancer in this hospital. Purposive sampling was used to select the participants.

The researcher approached patients who were waiting for a scheduled appointment at the cancer clinics and those admitted to the ward and invited them to participate in the study.

In-depth and minimally structured interviews were used to gather the data, using an interview guide (Addendum 1). According to Tong et al (2007), in-depth interviews can be used to explore the experiences of participants and by asking open ended questions to further investigate concepts introduced by the participants.

Probing and prompting questions were asked to illicit a deeper understanding of responses. The interviews were audio-taped and field notes were taken by the researcher. The interviews were conducted in English, however, a multi-lingual faculty member was present in the interviews to assist with any language issues.

Qualitative content analysis was used to analyse the data. This is a systematic method of describing and measuring data by reducing the concepts that describe phenomena into categories and themes (Elo et al 2014).

Phenomena that emerged from close scrutiny of the data was manually organized into themes and connections between data were made. The final reporting phase of results includes how connections between the data and results were made (Elo et al 2014) and an overview of results is given.

1.6 CLARIFICATION OF KEY CONCEPTS

The following key concepts that apply to this study are described in Table 1.1:

Table 1.1: Key concepts applied to the study

CONCEPT	DESCRIPTION
Allodynia	A spontaneous response to a stimulus which does not usually cause pain is known as allodynia (Treede et al 2015)
Background pain	Background pain is defined as lasting for longer than 12 hours and usually responds well to analgesia (McMenamin 2011)
Breakthrough pain	Breakthrough or episodic pain is described as a moderate to severe flare of pain that breaks through current analgesia (Caraceni et al 2012)

Cancer	Cancer is a group of diseases that all have one thing in common – abnormal, uncontrolled cell growth beyond normal cell boundaries (World Health Organization 2018)
Cancer care continuum	The delivery of cancer care throughout all phases of the disease from before diagnosis, during treatments, survivorship and to after death and bereavement of significant others (National Cancer Institute 2018)
Cancer survivor	A person is a cancer survivor from diagnosis to death (National Institutes for Health 2018)
Hyperalgesia	Hyperalgesia is an abnormally heightened response to a painful stimulus (Reddi, Curran & Stephens 2013)
Ideal pain assessment instrument	The criteria recommended by The Africa Palliative Care Association (2010) and Farrer (2007) were used to describe an ideal pain assessment instrument
Neuropathic pain	Neuropathic pain is caused by damage to peripheral or central nerves as a consequence of trauma, treatments like chemotherapy, ischaemia or inflammatory processes (Gehdoo 2006; Wood 2008; Reddi, Curran & Stephens 2013)
Nociceptive pain	Noxious stimuli including tissue injury activate nociceptor nerve fibres which transmit messages to the central nervous system, which are interpreted as nociceptive pain (Hladnik, Bicanic & Petanjek 2015)
Palliation	An approach to care that improves quality of life and alleviates suffering, for both patients and their families who are faced with a life-threatening or life-limiting disease (World Health Organization 2018)
Survivorship	Having no signs of cancer after completing treatment (American Society of Clinical Oncology 2018)

1.7 CHAPTER DIVISION

This dissertation consists of the following six chapters:

Chapter 1: Introduction to the study

Chapter 2: Literature review

Chapter 3: Research design and methods

Chapter 4: Part 1: Scoping review results

Chapter 5: Part 2: Describing cancer pain: findings

Chapter 6: Discussion, justification, limitations and recommendations

1.8 SUMMARY

Chapter 1 has provided an introduction to this study. In Chapter 2 a literature review provides a summary of important issues relating to cancer.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

Chapter 1 presented an orientation to the study however this chapter will give an overview of cancer in terms of its incidence, prevention and screening, treatment, supportive care and the impact of pain throughout the course of the disease.

2.2 THE INCIDENCE OF CANCER

Cancer refers to a group of chronic diseases that are characterised by abnormal and uncontrolled cell growth (Kalyanaraman 2017). There are more than 100 different types of cancer, each named after the tissue from where it originates (National Institutes for Health 2018). It remains a leading cause of death in developed and developing countries (Torre et al 2015) with the incidence of cancer increasing due to increased age and growth of populations. The International Agency for Research on Cancer (IARC) provides a database called GLOBOCAN, recording the incidence and mortality from more than 180 different countries, on various types of cancer. These results give an overview of the cancer burden in the world.

Worldwide the incidence of cancer is rising. It is estimated that there were 18.1 million people diagnosed with cancer in 2018, with 9.6 million attributable deaths across all ages and both sexes (IARC 2018). It is the second leading cause of death globally (WHO 2018) and thought to be responsible for one out of eight deaths (World Cancer Research Fund/American Institute for Cancer Research 2018). Approximately 22% of men and 18% of women will develop cancer during their lifetime with a predicted mortality rate of 13% and 9% respectively. In 2012 it was estimated that there were 32.6 million people living with cancer worldwide, 5 years after being diagnosed. In the latest GLOBOCAN statistics released in September 2018, this 5-year prevalence has risen to 43.8 million people living with cancer (Figure 2.1).

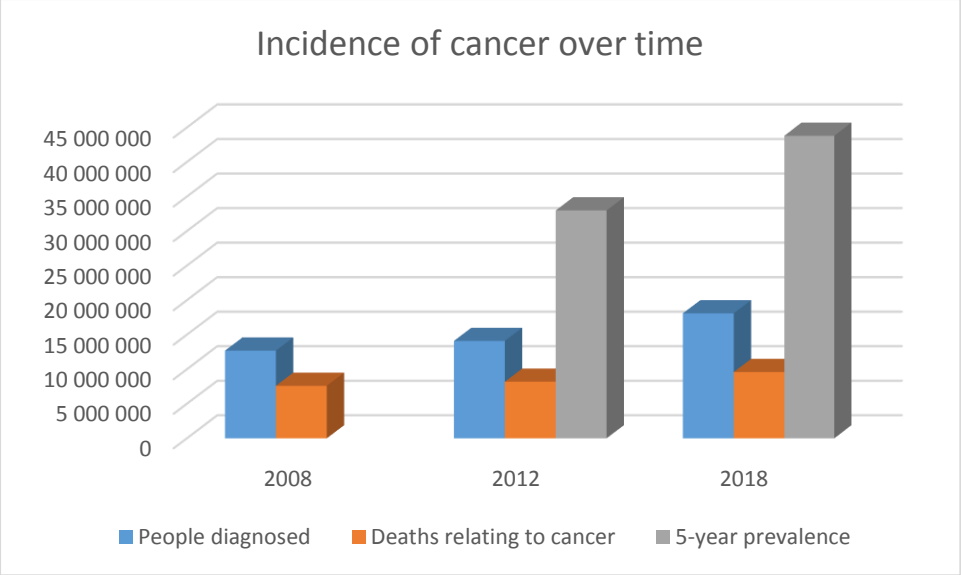


Figure 2.1: Comparison of cancer incidence over time (Source: GLOBOCAN 2008, 2012, 2018)

In 2018 the most frequently diagnosed cancer was lung cancer (11,6%) and female breast cancer (11,6%), followed by colorectal (10,2%) and prostate cancer (7,1%). Figure 2.2 gives a comparison of the most frequently diagnosed cancers over time.

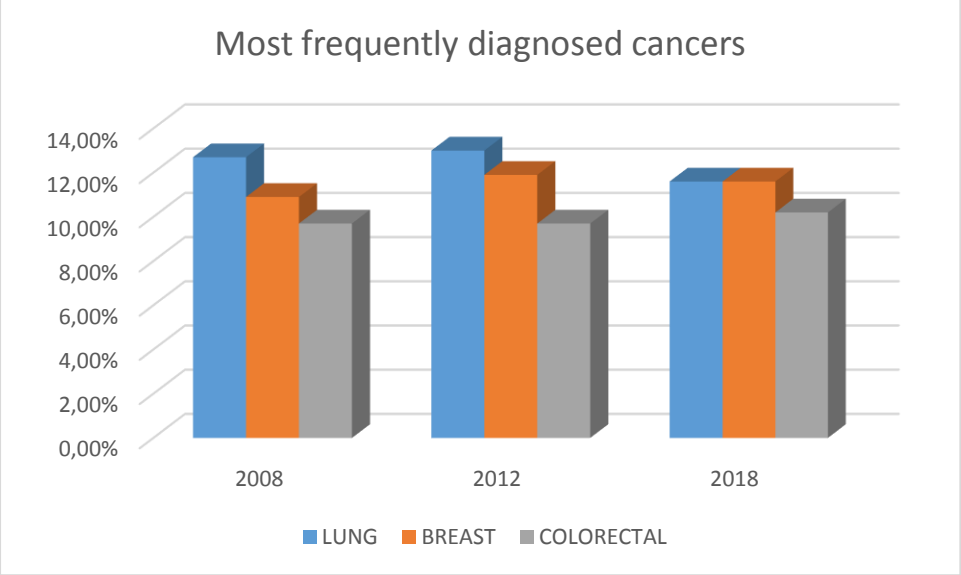


Figure 2.2: Comparison of the most frequently diagnosed cancers over time (Source: GLOBOCAN 2008, 2012, 2018)

The incidence of cancer varies between different countries, but especially between developed and developing countries (Kanavos 2006). This discrepancy may be attributed to a number of factors including limited epidemiological data, paucity of cancer advocacy and

research, limited access to screening and treatment opportunities and additional challenges of fragmented healthcare systems (Maree, Herbert & Huiskamp 2016). Interestingly many of the risk factors for cancer have been linked to social and economic development of a country (Ghoncheh & Salehiniya 2016). The Human Development Index (HDI) is a classification system of social and economic development, comparing countries with high/very high levels of human development to countries with low or medium levels of human development. Indices such as life expectancy, education and standards of living are compared (Roser 2018), profiling the socio-economic status of a country. A high prevalence of cancer is seen in countries with a high HDI, thought to be related to lifestyle choices, but higher mortality rates are seen in countries described as having a low/medium HDI, possibly as a result of some of the challenges described above. In developing countries, the incidence of cancer is about half than that from developed countries and this statistic appears to be confirmed for most of Africa.

Just over a million people in Africa were diagnosed with cancer in 2018. Countries from Northern, Eastern, Central and Western Africa had an average incidence of 13% for both men and women developing cancer (IARC 2018). Interestingly, the incidence of cancer in Southern Africa (22%) was more representative of a statistic from a developed country. There were reports of 114 582 people from Southern Africa being diagnosed with cancer in 2018.

The National Cancer Registry (NCR) of South Africa gathers information from public and private pathology laboratories in the country and analyses information based on IARC methodologies (NCR 2014). The annual incidence of cancer in South Africa is collated and categorised according to age, gender and population group (National Institute for Communicable Diseases 2017). In their most recent report, there were 75 000 people diagnosed with cancer in South Africa in 2014. According to GLOBOCAN 2018, this number has risen to 107 500 in 2018. Excluding basal and squamous cell carcinomas of the skin, the most prevalent cancers were prostate cancer in men and breast cancer in women (Figure 2.3). According to the Cancer Association of South Africa (CANSA®) South Africans have a 25% chance of being affected by cancer – either through personal diagnosis or diagnosis of a family member or friend (The Cancer Association of South Africa 2018). There is a 21% lifetime risk of developing cancer for both South African men and women with a 12% risk of dying from the disease by the age of 75 years (IARC 2018).

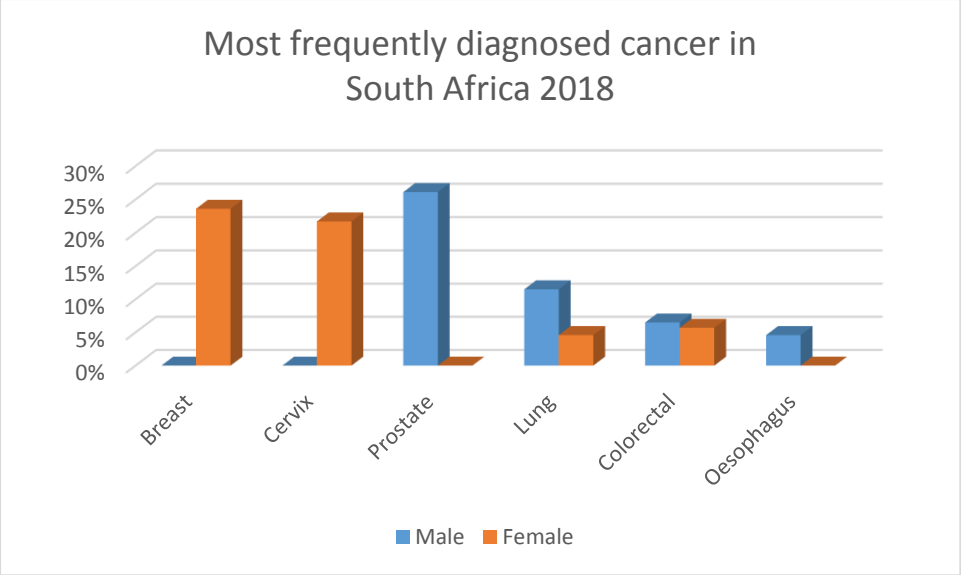


Figure 2.3: The most frequently diagnosed cancers in South Africa 2018 (Source: GLOBOCAN 2018)

2.3 CAUSES OF CANCER

There is no single cause of cancer, but rather many factors known to contribute towards the development of the disease (University of Rochester Medical Center 2018). The transformation of normal cells into malignant cells is a multi-stage process that takes place over time and as a result, the risk of developing cancer increases with age (Baskar & Itahana 2017).

Risk factors known to increase the likelihood of developing cancer include external and internal factors.

2.3.1 External or environmental factors

Approximately 75% of all cancers originate from epithelial tissue (Howard & Chady 2012) which is most exposed to external factors from the environment. Examples of environmental predisposing factors include exposure to tobacco, chemicals such as insecticides and benzene, alcohol, radiation for example ultraviolet and ionizing radiation, biological agents such as viruses, bacteria and parasites (WHO 2018). Dietary influences such as a high fat diet may also be a contributing factor.

2.3.2 Internal factors

It is estimated that 5-10% of all cancers are inherited (Anand et al 2008). This hereditary cancer syndrome is characterised by multiple members of the same blood line, through multiple generations, being diagnosed with the same type of cancer.

Other internal factors include hormones which drive cell proliferation and increase the risk of DNA replication error (Henderson & Feigelson 2000). Examples of cancers driven by hormones include breast, ovary, endometrium, testis and prostate cancers.

Lastly, the immune system plays a vital role in cancer surveillance (Ribatti 2017). When the immune system is overwhelmed for example by chronic disease, or suppressed by medication it may not respond to the presence of abnormal DNA mutations and cancerous cells may grow undetected.

2.4 PREVENTION AND EARLY DETECTION OF CANCER

Cancer places a heavy personal burden on both the patient and family, but also increasingly on communities and governments around the world (World Cancer Research Fund/American Institute for Cancer Research 2018). The incidence of cancer increases with an aging population and an increasing number of people living with and surviving cancer and as such, the costs associated with treating this disease will negatively impact on most global economies (Baskar & Itahana 2017) International strategies have been introduced in an attempt to improve health and lower the incidence of many preventable non-communicable diseases including cancer, and implement strategies to detect these diseases earlier when they are more easily treated (WHO 2007).

Cancer is mostly a preventable and treatable chronic disease and many new cancers could be prevented by promoting and adopting healthy lifestyle choices that could reduce known risk factors (World Cancer Research Fund/American Institute for Cancer Research 2018). Risk factors include alcohol and tobacco use, unhealthy diets, obesity and sedentary lifestyles (Istituto Superiore di Sanita 2014).

Strategies for prevention of cancer could be considered at three levels: primary prevention through behavioural and medical interventions, secondary prevention through early screening and detection initiatives and finally tertiary prevention as a strategy to diagnose and treat the cancer as early as possible with the intent of keeping the disease in remission for as long as possible (Greene 2015).

2.4.1 Primary prevention

Cancer is a global problem but there is a difference in prevalence of certain cancers such as breast, colon and prostate cancers, which are associated with a type of lifestyle more common in developed countries (Kanavos 2006). Cancers more common in developing countries have been linked to infectious diseases such as gastric, liver and cervix cancers. However as lifestyles around the world become more westernised, this prevalence may be changing as can be seen in South Africa where the most common cancers as previously mentioned, are prostate and breast cancer.

Therefore, primary preventative measures including educational programmes promoting the adoption of healthy lifestyle behaviours within the general population, including healthy well-balanced diets, strategies to reduce the excessive use of tobacco and alcohol and the promotion of increased physical activity, could prevent the onset and reduce the incidence of cancer (Smith, Dunn & Greenwald 2011). An example of a simple primary prevention programme could include encouraging the use of sunscreen to prevent skin cancer.

Primary preventative strategies linked to cancers associated with infectious diseases may also include medical interventions such as vaccination programmes against viruses known to cause cancer such as Human Papilloma Virus (HPV), responsible for causing approximately 99% of cervix cancers (Black & Richmond 2018). Vaccination programmes are an attractive option in Sub Saharan Africa where incidence rates for cervical cancer are extremely high. South Africa introduced an HPV vaccination programme in 2014 for girls aged between 9-15 years. It is predicted that this intervention could reduce the incidence of cervical cancer in South Africa by 70-80% (Denny & Kuhn 2017).

2.4.2 Secondary prevention

Secondary prevention of cancer is concerned with detecting the disease in its earliest stages before symptoms appear and when the disease is potentially curable. Examples of screening interventions are shown in Table 2.1

Table 2.1: Examples of screening techniques for early detection of cancer

Cancer site	Population	Technique
Breast	Women age 20+	Breast self-examination Clinical breast examination Mammography
Cervix	Sexually active women	Cytology (Papanicolaou or PAP test)
Colorectal	Men and women age 50+	Fecal occult blood test Stool DNA test Flexible sigmoidoscopy Colonoscopy
Prostate	Men age 50+	Digital rectal examination

(Source: American Cancer Society 2015)

Socio-economic factors impact heavily on screening procedures (Krombein & de Villiers 2006). Access to appropriate health education and healthcare facilities remains a challenge for the majority of South Africans who have lower income levels and limited resources causing delays in early detection and treatment opportunities. These delays contribute significantly to added complications such as disease progression and other suffering (Buccimazza 2015). Other contributory factors for delays in seeking treatment include lack of social and financial support, fear and seeking traditional treatments in preference to western medicine (Brinton et al 2017).

In an attempt to improve accessibility for South Africans living in predominantly remote areas, mobile health clinics have been used to provide basic screening to individuals including education on how to perform self-breast or testis examinations, Prostate Surface Antigen (PSA) finger-prick blood tests to detect abnormalities of the prostate and PAP smears to detect cervical abnormalities (The Cancer Association of South Africa 2017).

2.4.3 Tertiary prevention

Tertiary prevention of cancer refers to the reduction in morbidity and mortality of cancer, through early diagnosis and appropriate treatment strategies (Smith, Dunn & Greenwald

2011). An early diagnosis and treatment intervention is associated with improved patient outcomes (Neal et al 2015). Delays in commencing treatment such as getting appointments or scheduling treatments may be as a result of system delays, which were noted to be longer in South Africa compared to the international norm (Buccimazza 2015).

The diagnosis of cancer involves various tests and procedures to confirm the presence of the disease, the specific type of cancer involved and how far the disease has progressed (Stanford Healthcare 2018). Investigations may include blood tests, biopsies and imaging procedures.

Appropriate cancer treatment is determined by the type of tumour and extent of disease (Gress et al 2017). At diagnosis, a sample of the tumour is graded to assess the degree of differentiation or how mutated the cells are by comparison to the tissue of origin. This assessment gives an indication of how aggressive tumour activity is (Vogel 2011). The stage of the tumour is also assessed to determine the extent of the disease and possible prognosis.

2.5 CANCER TREATMENT GOALS

With an increasing incidence of cancer diagnosis and cancer survivorship in Southern Africa, an increasing number of people require treatment and ongoing care (Baskar & Itahana 2017). There are a number of factors that influence treatment decisions. Depending on disease related factors such as stage, grade and position of the tumour, the following goals of treatment may be considered, that would guide treatment choices:

2.5.1. Cure

The goal of treatment is to achieve a long-term cure and complete remission (CR) of the disease (Neugut & Prigerson 2017).

2.5.2 Control or prolongation of life

Where cure is not a realistic or achievable option, the goal may be to prolong or extend life by slowing the progression of the disease (Kvale 2017) by bringing it under control.

2.5.3 Palliation

Where cure and control are not achievable, the aim would be to improve quality of life by minimising discomfort (Khan & Sheikh 2005; Hui & Bruera 2013). This could be done by controlling pain and other symptoms associated with the physical, social, emotional and spiritual domains of the patient.

2.6 CANCER TREATMENT OPTIONS

Treatment options for cancer typically include surgery, radiation therapy, chemotherapy and immunotherapy (Baskar & Itahana 2017; Iwai et al 2017). Surgery and radiation therapy are localised treatments and chemotherapy and immunotherapy are systemic treatment options. Treatment may be given as monotherapy or in combination with two or more treatment modalities being used.

2.6.1 Surgery

Surgery has several applications throughout the cancer-care continuum, as indicated in the Table 2.2 below.

Table 2.2: Application of surgical interventions throughout the cancer-care continuum

Prevention and early detection	The early removal of pre-cancerous lesions may prevent the tumours from developing into invasive cancers e.g. the surgical excision of non-cancerous polyps from the colon
Diagnosis	Surgical techniques are used to obtain tissue samples for diagnosis e.g. incisional biopsy
Staging and grading of cancer	The pathologic examination of tissue samples which have been surgically removed will provide information on staging, grading and histologic cell-type of the cancer
Treatment	Early stage solid tumours can be excised with wide margins to ensure a good outcome, however some advanced and invasive tumours involving critical structures would require risk to benefit considerations
Reconstruction	Surgical reconstruction may be necessary to improve function and cosmetic appearance after extensive surgery, for example facial reconstruction post head and neck surgery
Insertion of supportive devices	There are various devices that can be surgically implanted to assist with the safe delivery of treatments such as central venous access devices and reservoirs.

(Source: Gillespie 2011)

It is common to experience some pain after surgery (American Society of Clinical Oncology 2018) as a side effect of this treatment. Other side effects could include inflammation, bruising and bleeding, potential infection and fatigue.

2.6.2 Radiotherapy

It is estimated that over half of cancer patients will receive radiation treatment at some point (Citrin 2017). This localised treatment uses high energy particles which interfere with a cell's

ability to undergo mitosis, resulting in cell death. The goal of radiation therapy or radiotherapy is to minimise damage to healthy tissue in the surrounding treatment field, while having a maximum effect on malignant cells (Prasanna et al 2012).

Radiation can be delivered in two ways: either externally delivered from outside the body, or internally making use of temporary or permanently placed radioactive implants (Baskar et al 2012). External beam radiation can be delivered in a single dose, but more frequently the total dose of radiation is delivered in fractions over the course of a few weeks (Koushik, Harish & Avinash 2013). Internal radiation or brachytherapy allows for a higher dose of radiation to be delivered to a smaller field (American Cancer Society 2018).

The side effects of radiation treatment are varied and typically relate to the area that was treated (Howard & Chady 2012). Side effects which often include skin reactions, gastro-intestinal disturbances, pain and fatigue can be acute or chronic in onset.

2.6.3 Chemotherapy

Chemotherapy refers to a group of chemical substances that can be used as a systemic treatment for cancer. Chemotherapy drugs have varied mechanisms of action, but many target the process of cell division (Wilkes & Barton-Burke 2008). These cytotoxic agents can be administered via many routes e.g. orally, intravenously and can be given as a single agent or in combination with other treatments (Payne & Miles 2008).

Due to the significant toxicity of many of these drugs, chemotherapy is often administered in cycles, allowing time for healthy tissue to recover between treatments (Brophy et al 2010). The most common side-effects of chemotherapy include bone marrow suppression, gastro-intestinal disturbances, fatigue and headaches (Aslam et al 2014).

2.6.4 Immunotherapy

Evidence suggests that our immune systems play an important role in cancer surveillance. Immunotherapy is a treatment that uses the immune system to fight infection, cancer and other diseases (Kuroki et al 2012). This treatment acts on the immune system in a variety of ways by changing the immune response so that malignant cells are injured, killed or prevented from dividing. Examples of immunotherapy treatments include cytokines such as interferon, monoclonal antibodies such as rituximab and vaccines e.g. HPV and Hepatitis B vaccines (Ventola 2017).

The side-effect profile of immunotherapy is mostly due to an immune response and can include hypersensitivity reactions, gastro-intestinal disturbances and organ toxicities (Dine et al 2017).

2.7 PALLIATION AND SUPPORTIVE CARE

Palliative care is described by the WHO as being an approach to care that improves quality of life and alleviates suffering, for both patients and their families who are faced with a life-threatening or life-limiting disease. Physical, psychosocial and spiritual problems are identified and treated as early as possible through focussed assessment (WHO 2018).

The word palliate is actually derived from the Latin word *palliatus* meaning cloaked or covered. The aim of palliative care is to cloak the patient and their families in care by minimising pain and other distressing symptoms from the point of diagnosis to after death during bereavement. Unfortunately the term palliative care is often thought to mean terminal care, when all other treatment options have been exhausted. One of the barriers to referral for early palliative care is from some oncologists who are concerned that this misunderstood term may cause the patient to lose hope and therefore referral to this level of care is often delayed until the last few weeks of the patient's life (Bruera & Hui 2010; Klastersky et al 2015) and therefore it has been suggested that the term supportive care be used in preference to early palliative care (Bruera & Hui 2010).

The need for supportive care was introduced early in 1960 with the realisation that the side effects of chemotherapy, that was needed to treat acute leukaemia, had to be managed in order to continue with cytotoxic treatment. A common side effect of these treatments includes myelosuppression leading to thrombocytopaenia and bleeding, leucopaenia with associated infections and anaemia causing patient fatigue (Klastersky et al 2015). Treatment such as a blood product transfusion could be administered which supported the patient's recovery and allowed for the continued administration of the toxic medication needed to treat the cancer.

The Multinational Association of Supportive Care in Cancer (MASCC) is an organisation that was founded in 1990 with the objective of providing education and research for multidisciplinary professionals involved in supportive care in cancer. MASCC describes supportive care as the prevention and management of adverse effects of cancer and its treatment, including physical and psychological support throughout the cancer care continuum (Multinational Association of Supportive Care in Cancer 2018). Supportive care has become associated with improved quality of life (Rosenbaum et al 2004; Scotte 2012) and therefore early referral for appropriate management of symptoms can result in improved patient satisfaction and a reduction in distress for both patient and family members.

The researcher suggests that there is room for both terminologies, but in differing contexts (Figure 2.4). Supportive and palliative care should start at diagnosis as the patient and family may be overwhelmed with information and fearful of their future. Palliative care is commonly associated with end of life care and a patient who is informed that they will receive palliative care might assume that the goal of their treatment had changed. If supportive care was emphasised at diagnosis and introduced by the combined nomenclature Supportive/Palliative Care Team, the transitions that may be needed as goals and treatment options change could be more easily navigated together with the team of familiar experts when palliative care becomes more relevant.

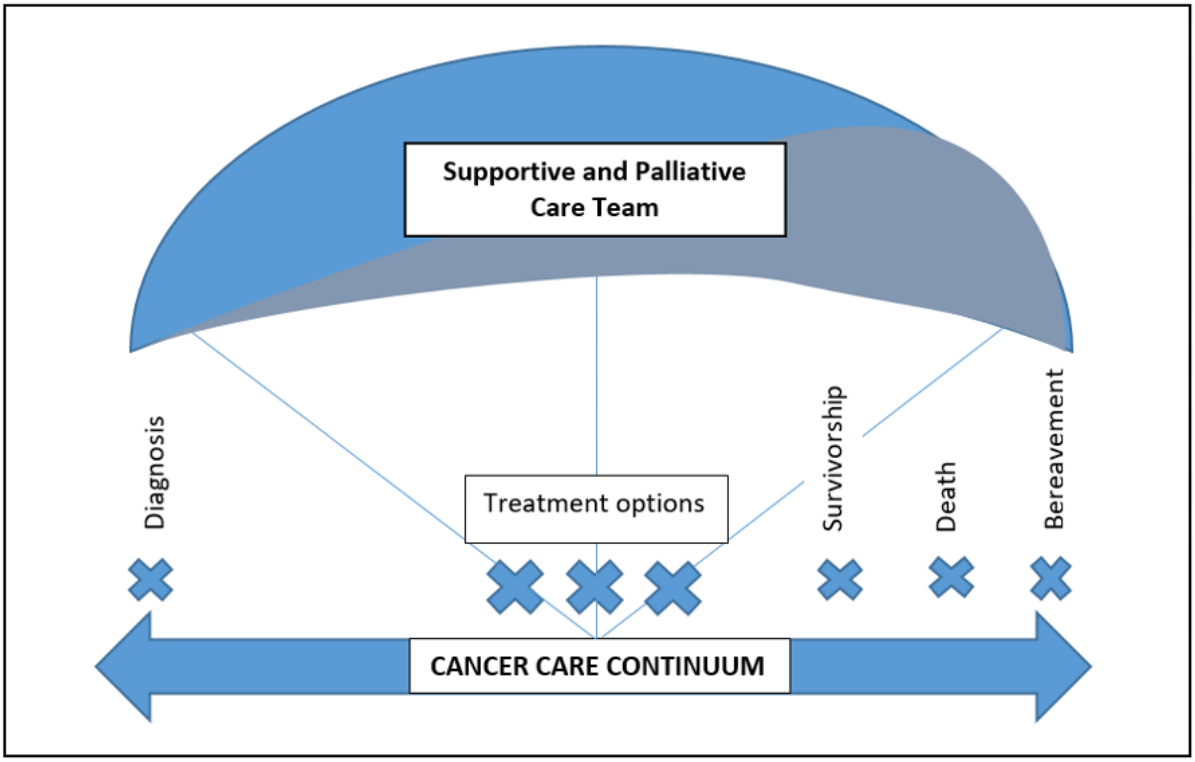


Figure 2.4. Supportive and palliative care in context

2.8 SUPPORTIVE/PALLIATIVE MODELS OF CARE

Medical oncologists Eduardo Bruera and David Hui described three typical models of care for patients with advanced cancer, shown in Figure 2.5 below.

The first model of care was a solo approach whereby the treating oncologist took full responsibility for all aspects of patient care, including the management of the cancer as well as the supportive/palliative care issues. Where this one-stop approach may be convenient

for the patient, the oncologist would need additional specialist training and may experience increased time constraints ultimately leading to burnout.

The second approach would be to delegate all supportive care issues to other specialists in their field. While inter-disciplinary care may be improved, the concern raised was that additional costs of this splintered approach may quickly become prohibitive and communication between disciplines could be fragmented.

Bruera and Hui (2010) recommended an integrated approach between the primary oncologist, who would focus on the management of cancer and the surrounding supportive/palliative care team that would focus on quality of life issues. Using this collaborative approach, patients and their families would have the benefit of remaining close to their treating oncologist whilst being cared for by a single team.

As Bruera and Hui's model was developed in USA it is questionable whether a similar model could be implemented in South Africa. Although there are isolated areas of excellence within the palliative care system in South Africa, a recent survey confirmed that only 18% of patients requiring palliative care actually receive such care (Gwyther et al 2018).

Very similar to the integrated approach mentioned above, the researcher believes that a cohesive and specialised multi-disciplinary team, guided by the treating oncologist or haematologist at specialist hospital-based care level, can provide appropriate treatment, education and support to the patient and family throughout their cancer experience by extension of services from hospital to home-based care.

Each member of the specialised multi-disciplinary team has a contribution to make in supporting the patient and their family. The team member who has already undergone specialised training in their specific field continues to update and share their knowledge with members of the team as well as the patient and family members, and is confident to refer to other healthcare professionals if an identified problem is beyond their scope of practice.

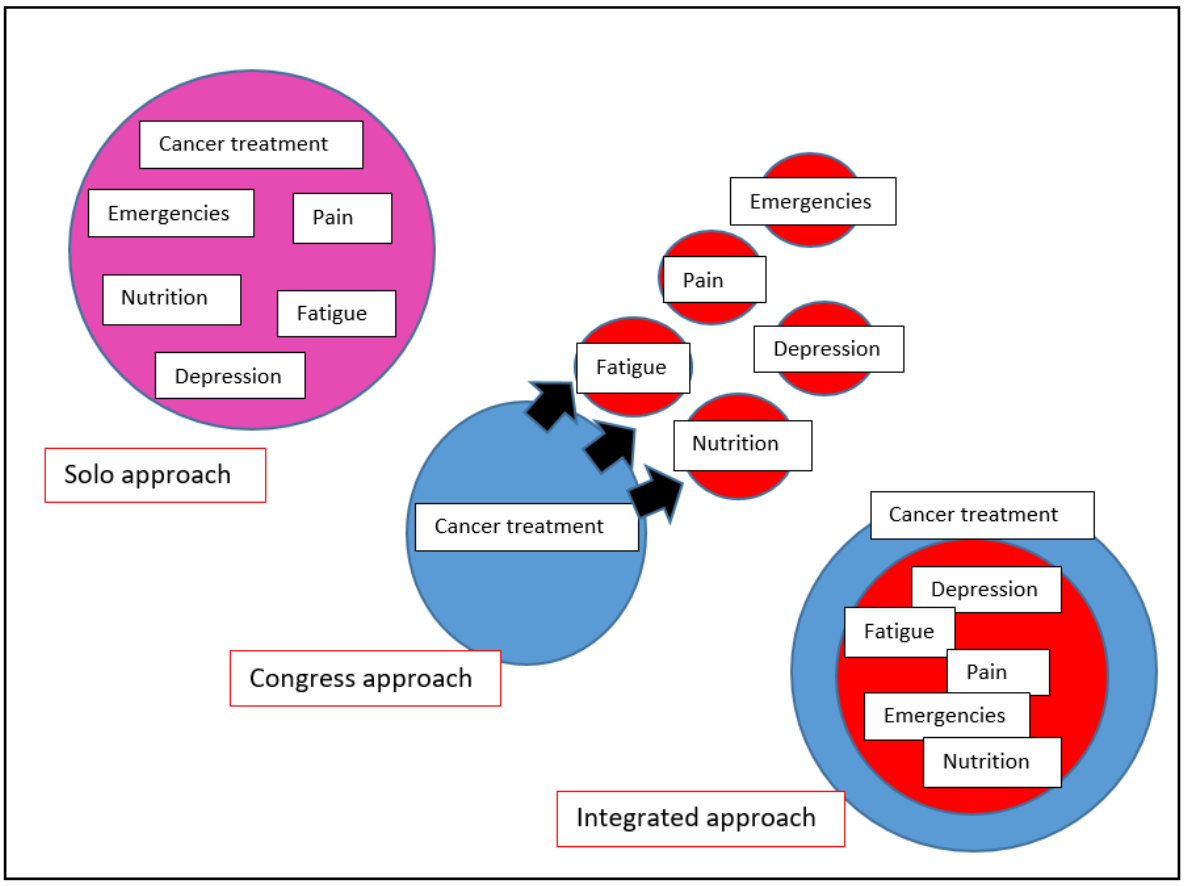


Figure 2.5. Conceptual models for palliative and supportive care in oncology. Source: Bruera & Hui (2010)

Supportive and palliative care use a pharmacological and non-pharmacological approach in order to alleviate suffering. Pain is a common side-effect of cancer treatments, but it is also associated with the disease processes and other unrelated factors (Miyashita 2018). It is often the most feared aspect of the cancer diagnosis (Goodwin, Bruera & Stockler 2014) but it is also an ongoing problem experienced by cancer survivors (Glare et al 2014) and therefore needs to be explored in more detail.

2.9 PAIN

Pain is a subjective sensory and emotional experience in response to actual or perceived injury. It serves a critical protective function as it alerts us to something that is wrong (African Palliative Care Association 2010; International Association for the Study of Pain 2018). The perception of pain varies between individuals as it is also influenced by psychological factors such as past experiences, expectations and fear. By way of example, an identical pain

stimulus can be experienced differently by the same patient, under different conditions (Zeppetella & Ribeiro 2002).

Dependent on the duration of pain, it can be described as being either acute or chronic.

2.9.1 Acute Pain

Acute pain is transient and described as lasting less than six months in duration. It warns us of danger and it causes the fight or flight response consistent with sympathetic nervous system activation, seen as pupil dilation, tachycardia and increased sweating. Acute pain can also draw attention to an injury or illness telling us that something is wrong (Wood 2008).

2.9.2 Chronic pain

Pain that lasts for longer than 3-6 months is regarded as chronic pain (Treede et al 2015). Chronic pain is described as a disease state (Ponte 2012) and is caused by damage to nerves. Nerve damage may be as a result of the tumour pressing against the nerve or chemicals released by the tumour, or due to damage caused by the cancer treatment (Cancer Research UK 2018). Chronic pain is usually persistent and may result in lethargy, sleep disturbances and even personality changes (Twycross 2003).

2.10 TYPES OF PAIN

According to the nursing pioneer of pain management, Margo McCaffery described pain as being what the patient says it is (Pasero 2018) and it is therefore essential to understand both the type of pain and its physiology, in order to better assess and manage the patient's pain experience. There are a number of ways of classifying pain, but for the purposes of this study, it will be described as being either nociceptive or neuropathic pain.

2.10.1 Nociceptive pain

The nervous system has a mechanism of detecting harmful or noxious stimuli, which activates a reflex response in order to protect against current or further injury (Arcourt et al 2017). Examples of noxious stimuli include mechanical stimuli such as pressure, inflammation or tumour growth, or thermal stimuli like extreme temperatures and chemical stimuli from neurotransmitters or toxic substances (Wood 2008). The sensory process that is triggered in response to these harmful stimuli is called nociception, after the Latin word *nocere*, meaning to hurt. The resulting pain that is experienced refers to that individual person's perception of that process.

Once noxious stimuli are detected, chemical mediators like prostaglandin and potassium are released from the damaged cells which are transformed into an electrical signal which in turn can then be conducted to the rest of the central nervous system (Dubin & Patapoutian 2010).

Nociceptors are unspecialized nerve endings of nerve fibres, found throughout the body that can transform mechanical forces, extreme temperatures or chemical stimuli into nerve impulses, which the brain interprets as pain. There are two main types of nerve fibres that conduct impulses away from pain receptors, namely A-delta fibres and C-fibres. A comparison of the two nerve fibres is summarised in Table 2.3 below.

Table 2.3: Comparison of nociceptor nerve fibres

	A-δ (delta) fibres	**C-fibres**
Diameter	Large diameter	Small diameter
Myelination	Lightly myelinated	Unmyelinated
Conduction speed	Fast (2.5-15m/sec)	Slow (less than 2.5m/sec)
Pain sensation	Fast, localised and interpreted as a sudden sharp pain, bringing about the initial reflex response to acute pain	Slow, dull, burning, long lasting
Activation	Activated by stimuli that penetrate, pinch or burn the skin	Activated by stimuli such as a pinch or prick, extreme hot or cold and chemical stimuli especially when applied to the skin

(Source: Bove & Swenson 2007; Hladnik et al 2015)

Stimulation of the nociceptor fibres will result in nociceptive pain. The two sub-types of nociceptive pain are somatic pain and visceral pain.

Somatic pain occurs when the nociceptors located in the skin, connective tissue, bone tissue, muscle and joints are activated causing pain that is often described as throbbing,

burning or crushing. It can be constant or intermittent and is well localized (McMenamin 2011).

Visceral pain occurs when the nociceptors located in the viscera of the internal organs are activated. Visceral pain is not well localized, has a gradual onset and is experienced as a deep, dull or cramping pain. Visceral pain can be caused by distention, inflammation or ischaemia of the organs (Carver & Foley 2003) and is also associated with autonomic responses such as sweating, nausea, vomiting and changes in blood pressure and pulse rates (Sikandar & Dickenson 2012).

The visceral organs are mostly enervated by C-fibres. Pain information is carried to a common area on the spinal cord where somatic nerve fibres converge and the brain misinterprets information received to localise pain in a different area to that of the visceral organ. This pain is called referred pain (Reddi, Curran & Stephens 2013).

There are two main ascending pathways that are responsible for carrying the nociceptive signals from the body to higher centres of the brain called the spinothalmic and spinoreticular tracts, responsible for the localisation of pain and aspects of emotional pain respectively (Reddi, Curran & Stephens 2013).

2.10.2 Neuropathic pain

Neuropathic pain is caused by damage to the peripheral or central nerves as a consequence of trauma, cancer treatments like chemotherapy, ischaemia or inflammatory processes (Gehdoo 2006; Wood 2008; Reddi, Curran & Stephens 2013). It has different characteristics to nociceptive pain as it may occur spontaneously in response to a stimulus which does not usually cause pain, a phenomenon known as allodynia (Treede et al 2015). A person may experience pain from a light touch or caress for example.

Neuropathic pain may also be experienced as a heightened response to painful stimuli, such as the pain from a finger prick experienced as being far more painful than one would expect. This abnormal processing of pain is called hyperalgesia (Reddi, Curran & Stephens 2013).

Terms used to describe neuropathic pain may include a hot or cold sensation, with descriptions including burning, shooting, pins and needles or crawling ants (Chetty et al 2012). Neuropathic pain is usually less responsive to opioid treatment alone (McMenamin 2011).

2.11 PAIN MODULATION

The modulation or regulation of pain involves changing pain signals from the central nervous system, via complex pathways called the descending modulatory pain pathways (DMPP). These descending pathways can alter ascending pain signals sent from the body to the brain. Analgesia and anaesthesia are examples of modulating agents that can decrease or inhibit transmission of pain impulses (Wood 2008; Kirkpatrick et al 2015).

There are various mechanisms in the body that appear to modulate or down regulate pain such as synaptic inhibition, the opioid system and descending inhibition.

2.11.1 Synaptic inhibition

In 1965 Melzack and Wall suggested the “Gate Control Theory” which proposes that transmission of information across a nerve synapse can be blocked at the spinal cord level when an inhibitory nerve is activated with a non-noxious stimulus. This could explain why rubbing an injured area makes the pain feel better (Patel 2010).

2.11.2 The opioid system

The midbrain and medulla of the brain contain a number of opioid receptors and endogenous opioids (e.g. endorphins and enkephalins) which help regulate the pain experience (Al-Hasani & Bruchas 2011).

2.11.3 Descending inhibition

Nociceptive information can be regulated by descending pathways from centres in the brain using the neurotransmitters serotonin and norepinephrine (Patel 2010).

2.12 PAIN PATHWAYS

There are four processes in the pain pathway summarise the physiology of pain. They are transduction, transmission, modulation and perception as described in Table 2.4.

Table 2.4 Pain pathways leading to the perception of pain

4. Perception of pain

The experience and interpretation of pain is subjective and affected by a number of factors such as mood and past experiences. There are various areas in the brain like the thalamus and cortex which appear to play an important role in pain perception.

3. Modulation of pain

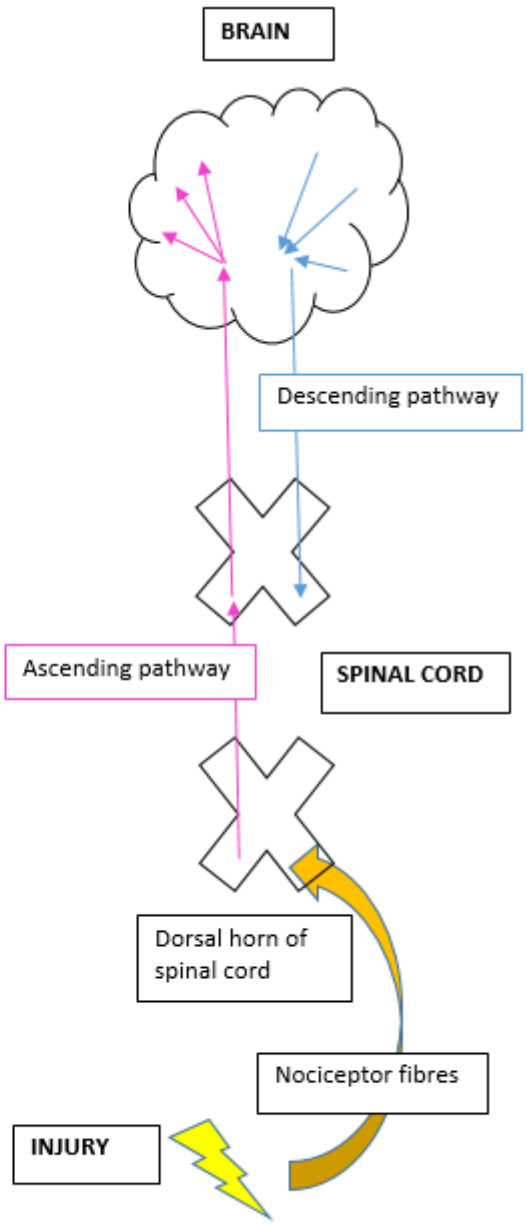
The transmission of pain is changed or inhibited in the spinal cord via the descending modulatory pain pathways which can lead to either an increase or decrease in pain transmission.

2. Transmission of pain

The pain impulse is transmitted to the dorsal horn of the spinal cord and on to the brain stem via the ascending spinothalamic pathway.

1. Transduction of pain

Noxious stimuli are detected by the nociceptor nerve endings of nerve fibres and this stimulation is translated into pain impulses



(Source: Wood 2008; Reddi, Curran & Stephens 2013)

2.13 CANCER PAIN

Pain is experienced by more than half of patients diagnosed with cancer (Pujol & Monti 2007; South African Cancer Pain Working Group 2015). It has been estimated that 30% of

patients will experience pain at diagnosis (Burton, Chai & Smith 2014) with the incidence of cancer pain increasing with advancing disease (Gehdoo 2006; Pujol & Monti 2007; Ripamonti, Bandieri & Roila 2011). Cancer survivors also experience pain which interferes with their quality of life (Fallon et al 2018), making this multifaceted problem one of the priorities of care.

There are many possible causes of cancer pain as depicted in Table 2.5 below.

Table 2.5. Causes of pain in cancer patients.

Disease related pain (most common)	**Iatrogenic pain**	**Comorbidity related pain**	**Other pain**
Tumour involvement of bone	Medical procedures such as blood sampling, tissue biopsy, wound dressing, lumbar puncture, follow up procedures	Diabetic neuropathy Fibromyalgia Acute thrombosis pain Osteoarthritis Vasomotor headache	Emotional pain possibly caused for example by fear, altered body image, isolation, depression, anger
Extension into soft tissues or visceral involvement	Surgical interventions including post-surgical related pain like chronic scar pain, post amputation phantom pain		Spiritual pain and questioning belief systems and the meaning of life
Nerve compression or injury	Radiotherapy causing both acute and chronic pain for example from skin reactions		Social pain caused by loss of social position, altered role in the family, concerns for loved ones
Raised intracranial pressure	Immunotherapy and hypersensitivity reactions causing pain like a headache		Financial pain relating to cost of treatments, absence from work or learning, loss of income

(Source: Twycross, R. 2003; Gehdoo 2006; Pujol & Monti 2007; South African Cancer Pain Working Group 2015)

2.14 MECHANISMS OF CANCER PAIN

Cancer pain is a complex problem and it is important to understand the neurological mechanisms responsible for causing the pain. The experience of cancer pain varies depending on the type of cancer involved, its location and where it has spread to (Schmidt et al 2010). For example, a patient with a carcinoma originating in the lung may not experience any pain whereas a patient with carcinoma in the oral cavity would most likely experience pain as a presenting symptom.

Cancer pain is often thought to be as a result of an inflammatory process. This unsubstantiated claim is refuted by clinical studies indicating that anti-inflammatory medication appears to have limited efficacy in treating cancer pain. The intensity of cancer pain appears to be greater than pain caused by inflammation. One possible explanation for this could be that cells from the tumour are known to recruit neurons, lymphocytes and other cells into the cancer microenvironment which secrete pain modulating substances, which in turn activate nerve fibres within that region (Schmidt 2014).

There is compelling evidence to suggest that cancer cells as well as immune cells in the vicinity of the tumour secrete chemicals such as serotonin, prostaglandins and cytokines that interact with receptors on nerve terminals causing activation of the nerve fibres (Reddi, Curran & Stephens 2013; Schmidt 2014).

2.15 TYPES OF CANCER PAIN

Many cancer patients will experience different types of pain, possibly even simultaneously (McMenamin 2011). In addition to nociceptive and/or neuropathic pain, cancer pain can also be experienced as total pain.

If pain is described as both a sensory and emotional experience, a multidimensional approach should be considered which includes physical, psychological, social, financial and spiritual aspects of suffering (Twycross 2003; Brant 2017). This holistic approach refers to the concept of total pain.

2.15.1 Physical pain

Additional physical symptoms can occur as a result of pain such as fatigue, nausea, loss of appetite, altered mobility and sleep disturbances (Twycross 2003).

2.15.2 Psychological pain

Psychological pain can include emotional distress, fear, uncertainty, anger and hopelessness. Depression is commonly experienced by patients in pain (Brant 2017) which can have a profound influence on their quality of life.

2.16.3 Social pain

Pain can lead to a change in social behaviour including withdrawal from activities, feelings of abandonment and altered interactions with family, friends and communities.

Cultural beliefs can influence how we respond to pain, express that pain and interpret its meaning in our lives (Peacock & Patel 2008).

2.15.4 Financial pain

There is a financial implication that goes with a cancer diagnosis. Treatments are often expensive. Patients with cancer may need to be off work for extended periods of time and they may not be financially compensated during this period. Treatment centres may be far away from home and additional transport costs may be incurred by the patient and visitors. Analgesia may be too expensive.

2.15.5 Spiritual pain

Spiritual and religious beliefs may influence the experience of pain (Brant 2017). Patients may feel that their pain is a test from God, or a punishment to endure. Patients may search for the meaning of life and their continued purpose.

2.16 CLINICAL MANIFESTATION OF CANCER PAIN

Cancer patients often report that their pain changes during the day (Caraceni et al 2012). There are two clinical manifestations of chronic cancer pain, identified as being background or episodic pain.

Background pain usually lasts for longer than 12 hours a day (McMenamin 2011) and is often managed with regular administration of analgesia.

Breakthrough pain is defined as a flare of moderate to intense pain that breaks through the analgesia regimen (Caraceni et al 2012). This type of pain is often treated using short-acting medications.

2.17 MANAGEMENT OF CANCER PAIN

Worldwide the appropriate management of cancer pain remains challenging despite numerous guidelines and availability of treatments (Gehdoo 2006; Eaton et al 2015; Fallon et al 2018). It is estimated that between 30% – 60% of all cancer patients do not receive adequate treatments for their pain (Miyashita 2018; Fallon et al 2018). According to Brant (2017), there appears to be three reasons for inadequate management of pain: lack of knowledge about pain, lack of assessment by healthcare professionals and lack of supportive care services. The barriers to the management of cancer pain are highlighted in Table 2.6.

Table 2.6: Barriers to cancer management

Barriers to the treatment of cancer pain	
Patient related factors	Fear of medication like morphine as it is seen as a drug given at the end of life Fear of addiction or dependence Failure to report the pain Compliance and adherence issues Stoicism Belief that cancer pain is inevitable and part of the disease process
Healthcare professional related factors	Lack of pain assessment and re-assessment Lack of knowledge about cancer pain Inconsistent pain management practices Fear of addiction Time constraints and workload Inadequate documentation leading to poor communication within the multi-disciplinary team
Systems	Available support systems for referral not known Availability of treatment options

(Source: Gehdoo 2006; Smith Idell, Grant & Kirk 2007; Eaton et al 2015; Brant 2017)

According to the African Palliative Care Association (2010), the management of pain has three critical components: pain assessment, pain measurement and pain treatment. Each of these pillars of pain management will be discussed in more detail below.

2.18 CANCER PAIN ASSESSMENT

Initial and ongoing assessment of a cancer patient's pain is a critical step to adequately managing their pain and optimal management depends on exploring each domain of the total pain experience (Brant 2017). Pain should be assessed and routinely re-evaluated by means of a reliable assessment instrument followed by prompt pharmaceutical and non-pharmaceutical interventions (Eaton et al 2015).

Pain assessment instruments are used as a means of systematically and routinely documenting the patient's experience of pain over time and can serve as a valuable communication tool between the patient and members of the multi-disciplinary health team. The initial assessment should include a detailed patient history including details about the intensity and type of pain, a thorough physical examination, a psychosocial assessment and appropriate investigations to determine the cause of the pain (Gehdoo 2006).

Accurate pain assessment is also dependent on clinical competency of the healthcare practitioner (Webber, Davies & Cowie 2016) and the interpretation of findings. However the inability of staff to adequately assess and document their findings is considered a contributing factor to the sub-optimal treatment of pain in adults (Smith Idell, Grant & Kirk 2007).

Nurses are pivotal in the management of pain (Miyashita 2018) due to time spent with the patient and the trust relationship that develops with them. They are therefore ideally placed to routinely assess and re-assess the patient's pain and response to treatment, communicate these findings to the multi-disciplinary team and support the patient throughout the various stages of their cancer journey.

2.19 CANCER PAIN MEASUREMENT

Several measurement instruments or standardized scales such as visual analogue scales (VAS), verbal rating scales (VRS) and a numerical rating scale (NRS) are used to provide an indication of pain intensity and response to treatment (Ripamonti, Bandieri & Roila 2011). Pain rating scales, which are often included in pain assessment instruments (African

Palliative Care Association 2010), are reliable if the patient understands the scale and is able to answer basic questions relating to the intensity of their pain (Gehdoo 2006).

2.19.1 Uni-dimensional scales

Uni-dimensional scales are used to measure pain intensity, at a single point in time. Pain intensity is the most commonly measured dimension of cancer pain (Gauthier et al 2014).

2.19.2 Multi-dimensional scales

Cancer pain is multi-faceted and the measurement of pain intensity alone would not include other important domains of pain which would give a more comprehensive picture of the patient's pain experience (Burton, Chai & Smith 2014; Gauthier et al 2014). A single-item measurement does not provide a full assessment of the patient's pain and therefore multi-dimensional scales are used.

2.19.3 Analgesia scales

Alleviating pain is an important goal of cancer treatment and the adequacy of analgesia relief can be assessed using analgesia scales (Chung et al 2014). Cancer treatments can improve levels of pain by affecting disease progression, however increasing levels of analgesia may hide disease progression. Analgesia scales are a method of capturing specific medications used as well as changes in dosing and frequency.

2.20 CANCER PAIN TREATMENT

The concept of total pain reminds us that we need to treat cancer pain holistically. Both pharmaceutical and non-pharmaceutical interventions are therefore necessary (African Palliative Care Association 2010). The aims of treatment are to bring relief to the distressing symptom as quickly as possible and to prevent its reoccurrence by treating the underlying cause.

There are several guidelines for the treatment of cancer pain using medication. The World Health Organization (WHO) recommends that analgesia be given orally if possible and as appropriate, as this is easier for the patient and family to manage from home. Medication should be given regularly and at fixed intervals to ensure continued relief and by the ladder following a 3 step approach (Figure 2.6). In addition to this sequential ladder, WHO recommends that medication is individualized to meet the needs of that specific patient, with

attention to the detail like writing out the treatment schedules in full so that they can be easily understood.

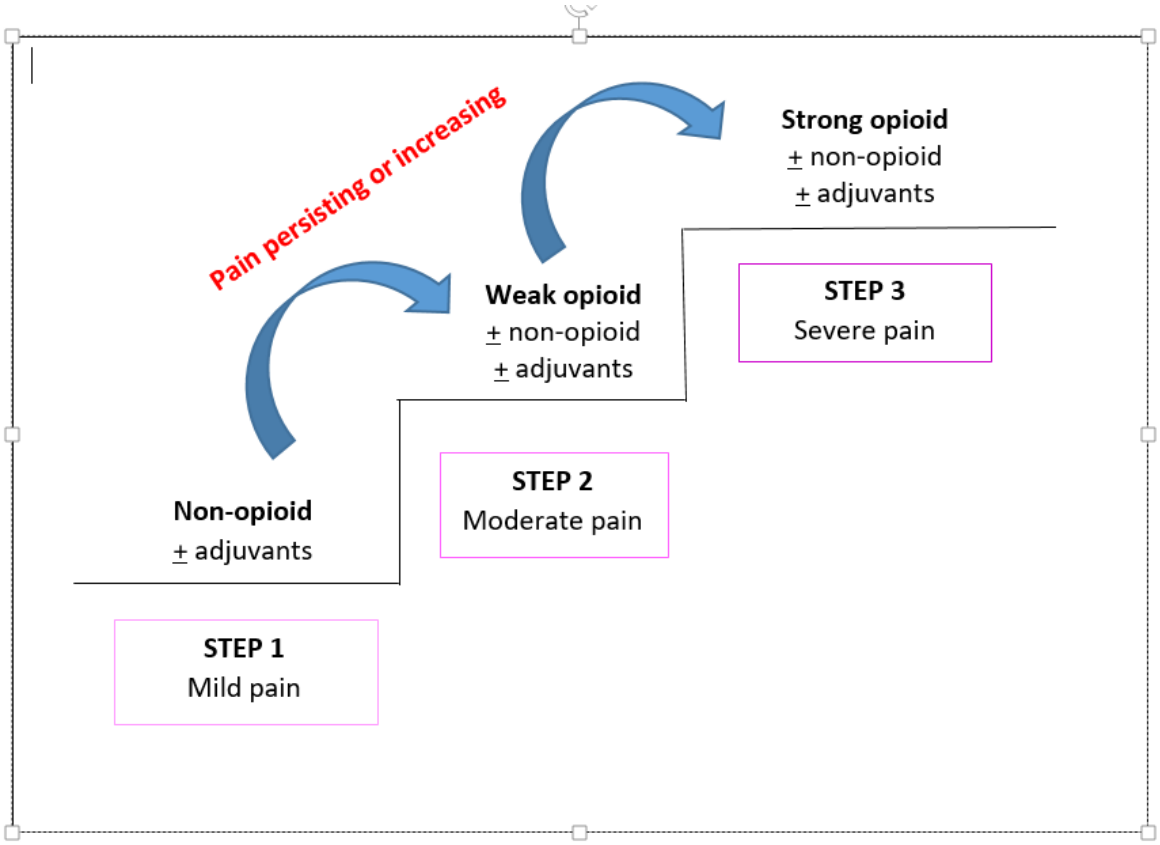


Figure 2.6 The WHO analgesic ladder (Source: World Health Organization 1996)

In a review of non-pharmacologic interventions in the management of cancer pain, Goodwin, Bruera & Stockler (2014) state that there are a number of approaches that can be implemented, including modulation of nociception such as thermal therapy, therapeutic physical therapy, manual lymph drainage and rehabilitative approaches like massage and exercise. Psychological and behavioural therapies could include hypnosis, relaxation therapy with guided imagery and coping skills training (Goodwin, Bruera & Stockler 2014).

2.21 SUMMARY

This chapter presented the incidence of cancer, its causes, prevention, goals of treatment and treatment options. Supportive and palliative care were discussed, with a focus on cancer pain. In Chapter 3 the methods and design for this study will be described.

CHAPTER 3

RESEARCH METHODS AND DESIGN

3.1 INTRODUCTION

In Chapter 2 the literature focussing on cancer in terms of its incidence, causes, prevention, treatment and supportive care with specific reference to pain, was presented. In this chapter, the research methods and design will be described.

3.2 METHODS

This was a sequential multi-method study conducted in two parts. Part 1 of the study was a scoping review and Part 2 of the study used a qualitative descriptive design.

Sequential multi-method studies use qualitative and quantitative methods in a single study to gather results or analyse data (Byrne 2007; Cameron 2009; Mafuba & Gates 2012). Each method is planned to answer a specific research question on its own, but the combined approach helps build capacity and provides a deeper understanding of the studied phenomena (Mafuba & Gates 2012).

Sequential multi-method studies can be implemented using either exploratory or explanatory approaches, depending on the sequence of method selected (Creswell 2014). In this sequential explanatory study, quantitative data were first collected in Part 1 of the study to provide context and then qualitative data were collected in Part 2 of the study to build on the understanding of the quantitative results (Sandelowski 2000; Creswell 2014).

3.3 PART 1: SCOPING REVIEW

As already mentioned, Part 1 of the study was a scoping review. A scoping review creates an inventory of essential components or factors of the research topic by listing types of evidence that are available and identifies gaps where evidence has not been comprehensively reviewed before (Dijkers 2015).

The five step methodological framework described by Arksey and O'Malley (2005) guided the review.

Step 1: Formulate the research question

The following research question was formulated in order to guide the direction of subsequent steps of the study:

- What pain assessment instruments are available to assess pain in cancer patients, what are the characteristics of these instruments and how do they compare against criteria of an ideal pain assessment instrument?

Step 2: Identify the relevant studies.

In this step, decisions were made in terms of the sources of information that should be accessed, the key words to be used in the search as well as the inclusion and exclusion criteria. The key words “cancer pain AND assessment tool” and “cancer pain AND assessment instrument” were used to search the data bases Pubmed; CINAHL; Web of Science and Scopus.

To be considered for inclusion, the work had to assess cancer pain in adults using a pain assessment instrument, written in English, published between 1 January 2012 and 31 December 2016 with full text available through the inter-university library system. Review articles, opinion papers, discussion papers, letters to the editor, editorials, case reports and grey literature were excluded as the researcher wished to capture published research output.

Step 3: Study selection.

Once the list of publications were obtained from the data bases, the titles of the articles were first reviewed to exclude duplicates. Thereafter the titles were once again reviewed to ensure that the work focused on cancer pain in adults; abstracts were used where the title was not clear. Full texts were obtained and reviewed to ensure that the work met the inclusion criteria. The articles were first reviewed by the researcher followed by the supervisor.

One hundred and ninety nine (199) articles were reviewed for inclusion. The titles of these articles were reviewed and a further 60 articles could be excluded due to duplication.

The titles of the remaining 139 articles were again reviewed to ensure that the content of the articles focussed on cancer pain in adults. The abstract of the article was referred to when additional clarity was required. One hundred and fifteen (115) articles were excluded that did not meet the inclusion criteria. Full texts were requested for the remaining 24 articles of which three (3) articles were not available on the inter-university library system.

The remaining 21 articles were eligible for inclusion in the scoping review. Figure 3.1 summarises the search and selection process used.

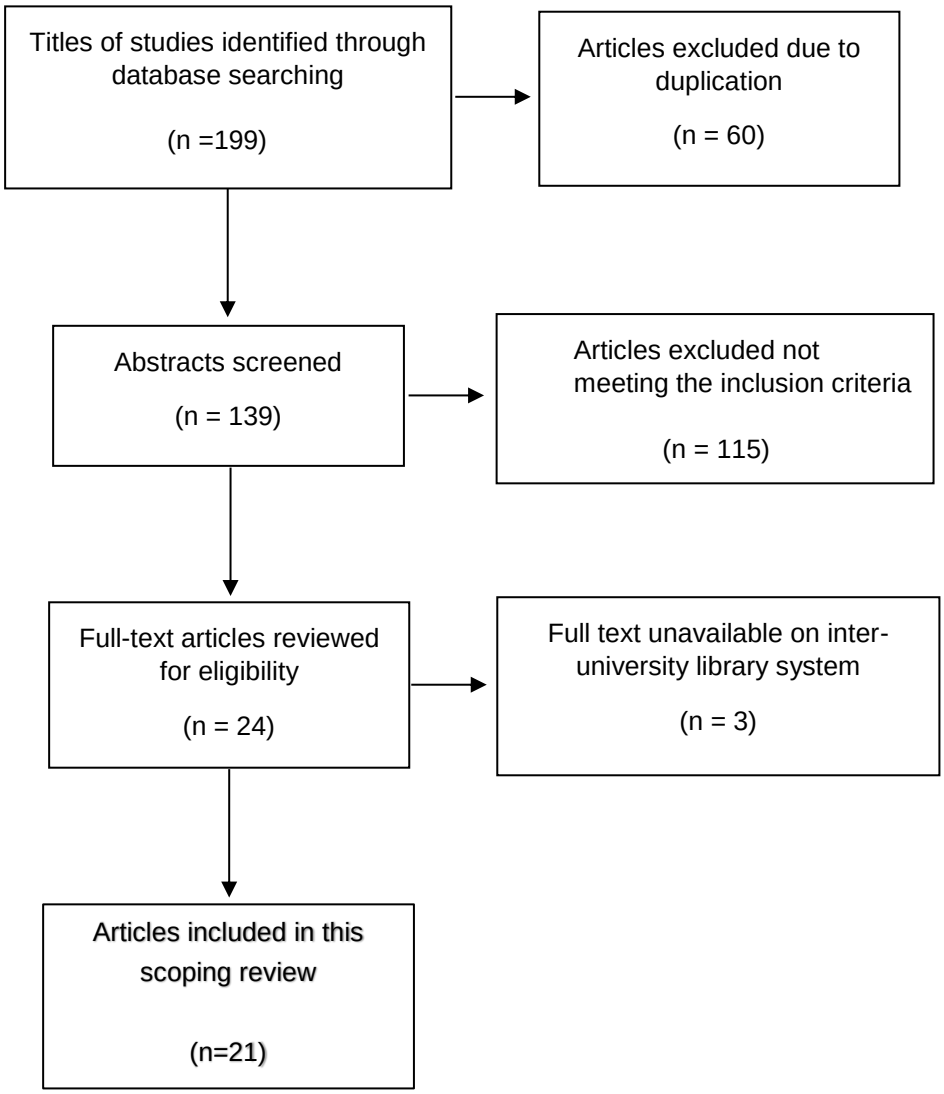


Figure 3.1 Flow Diagram of the Search and Selection Process for the Included Studies (Source: Adapted from Moher et al 2009)

Step 4: Recording pertinent information.

In this step, important information obtained from the selected studies is charted or recorded. The recording of data includes a process of sifting through the data and sorting it according to key identified themes. It is important to determine what information should be considered important and how comparisons between different sources of information can be compared.

Data extraction sheets were developed which enabled the researcher to extract important facts from each selected study and to record this information for later comparison and comment.

The first data sheet (Addendum 2) summarized the selected articles as follows:

- Geographical origin of article
- Name of article, author and year of publication
- Aims and objectives
- Study design, population, setting, sampling method and sample size
- Data collection method and data collection instrument
- Key findings and recommendations

The second data extraction sheet (Addendum 3) developed was guided by the Africa Palliative Care Association (2010) (Addendum 4) and Farrer (2007) who recommended that an ideal pain assessment instrument measuring chronic or cancer pain should also include:

- A body chart to pinpoint the exact location/s of the pain
- A way of measuring the severity of the pain
- Factors influencing the severity of the pain
- Whether the pain is worse at night
- Patient descriptor of the pain

Using this second data sheet, the researcher was able to record the following characteristics of identified pain assessment instruments for comparative purposes:

- Name of instrument and type of instrument (uni-dimensional, multi-dimensional or analgesic scale) and its abbreviation
- Method of administration including number of questions asked
- Whether a body chart and a method of rating the pain severity were included in the instrument
- Type of cancer pain assessed
- Aggravating/relieving factors

- Patient's description of pain
- Current pain medication used
- Interpretation of findings

Step 5: Reporting results.

This step involves analysing, summarising and reporting the results (Arksey & O'Malley 2005). The results of the scoping review are discussed in detail in Chapter 4.

3.3.1 Data analysis

The data analysis involved quantitative frequency analysis and comparison of identified cancer pain assessment instruments in order to identify possible gaps in literature (Kastner et al 2012).

Frequency analysis refers to the number of times an event occurred and analyses this information through measures of central tendency and dispersion (Research Optimus 2018). Central tendency is a measure that describes the norm or average position within the data set and dispersion describes the variability within that data set. According to Reitz (2018), a data set is a grouping of similar information arranged in a systematic way, often for research purposes. The first data sheet focussed on the numerical analysis of geographical distribution of the studies and the range of identified assessment tools.

A second data sheet focussed on the comparison of identified instruments. The following criteria were used:

- The usability of the assessment instrument with reference to how it is administered, how many questions are asked and whether there is clear instruction for interpretation
- The appropriateness of the assessment instrument for use in specific types of cancer pain
- The quality of the assessment instrument as compared to the ideal instrument described previously

3.3.2 Rigor

Rigor is the assessment of the trustworthiness of the data, by examining the reliability and validity of the research (Anderson 2010). The aim of establishing rigor is to ensure that findings of a study are credible from the standpoint of the researcher, participants as well as those who read the study and that potential researcher bias does not go undetected (Arksey & O'Malley 2005; Creswell 2014).

In Part 1 of this study, the researcher and supervisor independently reviewed the full text articles for inclusion through regular consultation and discussion. Had there been any discrepancies, a third person, experienced in reviews, would have been consulted for discussion in order to ensure trustworthiness of the data selection; this was however not necessary.

3.4 PART 2: DESCRIBING CANCER PAIN

Part 2 of the study answered the second research question. The researcher used a qualitative descriptive design to get a deeper understanding of cancer pain, as described by the selected patients who participated in the study.

3.4.1 Research design

According to Sandelowski (2000) the aim of qualitative descriptive studies is to give a complete account of events as they occur and is the method of choice when a deeper understanding of phenomena is required. Qualitative description studies describe the experiences of groups or individuals (Lambert & Lambert 2012) providing valuable information from the patient's viewpoint. However, the researcher interprets these descriptions through her own perception or understanding of the describer (Sandelowski 2000). A qualitative descriptive design was selected by the researcher in order to gain a deeper understanding of the patient's experiences which could influence different aspects of nursing care (Sanjari et al 2014).

3.4.2 Research setting

The setting for the study was in the medical oncology wards and clinic of an academic hospital in the Gauteng Province of South Africa. The hospital has 1088 beds and offers both inpatient and outpatient speciality services (Joburg Directory n.d.) and provides research and training opportunities for doctors, nurses and other allied health professionals.

The hospital forms part of the public healthcare system and receives referrals from hospitals in its catchment areas from within the province but it is also a referral centre for specialist services needed by neighbouring provinces (Gauteng Provincial Government 2018). One of the named specialist services of the hospital includes haematology and oncology. These services are offered free of cost to certain categories of patients for example pensioners, people with disabilities and for those who can prove unemployment. All other patients are charged an admission or consultation fee (Travelground 2018).

The hospital offers both medical and radiation oncology services in order to treat patients with cancer. The radiation unit which treats about 3500 patients per year is the largest in the country (SA Government News Agency 2014). Oncology and haematology patients receive their treatments and consultations as outpatients or as inpatients admitted to one of the speciality haematology or oncology wards.

3.4.3 Population, sampling and recruitment

In descriptive studies it is common to define the population and then include characteristics of the sample of this population who participated in the study. The research population includes all individuals with common defining characteristics (Alvi 2016). The population for this study consisted of all patients diagnosed with cancer treated at the specific hospital. The target population, referring to the entire population in which the researcher would like to generalise the study results (Polit & Beck 2017), consisted of all patients receiving treatment and care at the medical oncology department.

As mentioned previously, quantitative descriptive studies require a level of interpretation. In sampling, the researcher pre-selects certain variables using purposeful or non-random sampling techniques (Sandelowski 2000). A purposive sample is selected based on certain characteristics of the population and according to the objective of the study (Palys 2008; Palinkas et al 2015). Examples of sampling using this technique could include volunteers who agree to participate in the study who have knowledge and experience in the phenomenon of interest. It is noted that by selecting this sampling technique not all individuals had an equal chance of being included in the study.

Individuals in this study were purposefully chosen with specific characteristics to add maximum information and to produce the greatest variation with the sample (Anderson 2010; Etikan et al 2016). The researcher selected participants based on a personal judgement on who would provide the most information, based on her knowledge and experience of the population (Polit & Beck 2017). The risk identified in using this sampling technique is that of researcher bias in determining who could provide valuable information. Therefore maximum variation sampling was used by selecting candidates across a broad spectrum relating to the study topic, in an attempt to gather information from as broad and varied opinion as possible.

Participants were recruited until data saturation occurred and there was no new knowledge being obtained by including more participants. Data saturation occurs when there is enough information and depth of data to replicate the study and the identification of new codes and themes is not needed (Fusch & Ness 2015). The researcher had a sense that data saturation occurred after eighteen (n=18) interviews based on what was heard in the

interviews. To test this assumption, data were collected in two additional interviews to confirm that there were no new themes emerging (Saunders et al 2018).

The researcher approached the patients waiting for a scheduled appointment at the medical oncology clinic and those admitted to the oncology ward and invited them to participate in the study. Information was provided to each potential participant in the form of an information document (Addendum 5) which was discussed and read out aloud. Twenty two patients were recruited and 20 patients participated. Of the two patients who did not participate, one patient was called to see the doctor and did not return and the second patient admitted that she only wanted to participate if it meant that she would see a doctor sooner. Patients who were still willing to participate in the study gave their written consent (Addendum 6).

3.4.4 Data gathering

In-depth and minimally-structured individual interviews (Sandelowski 2000) were used to gather the data, using an interview guide (Addendum 1). Demographic data were gathered at the start of the interview and recorded on an interview guide. The information elicited from the patient, recorded data about the participant's age, gender, diagnosis, date of diagnosis and treatment received. Additional information recording the participant's home language was included.

In-depth interviews can be used to describe the experiences of participants and by asking open ended questions to further investigate concepts introduced by the participants (Tong, Sainsbury & Craig 2007; Merriam & Tisdell 2016). According to Polit and Beck (2017) an effective way of finding out about a person's experiences and feelings, is to ask them directly. However, a limitation of this data gathering method includes the novice researcher's lack of experience. The researcher was careful not to steer the participant's response in any particular direction.

Three broad questions were asked of each participant, with probing and prompting questions added to elicit a deeper understanding of responses for example, "Please help me understand your last comment?"

Some participants requested that the questions be clarified or rephrased in their own language so that they understood the question. The following questions were asked:

- Please tell me what is it like for you to live with pain?
- Please tell me how the pain feels?
- What would you like nurses to know about your pain?

The interviews were mostly conducted in English. However, a multi-lingual faculty member was present in the interviews to assist with any language issues, enabling participants to express themselves in their language of choice when they could not express themselves clearly in English. An added advantage was that this faculty member was also a mental health nurse specialist, so that if the participants became emotionally distressed during the interview, the interview could be stopped and the participant assisted or referred for assistance as appropriate. Two patients became emotional towards the end of the interview and both these interviews and recordings were stopped. Both patients declined being referred for assistance, preferring to be assisted by the researcher and faculty member as a trust relationship had been established between participant and researcher.

Completed interview schedules were placed in a sealed envelope, numbered and entered onto an Excel spreadsheet. The audio-tape recordings were given the same number and were transcribed verbatim.

3.4.5 Data analysis

Qualitative content analysis is the analysis method of choice for qualitative descriptive studies as it focusses on summarising data obtained from verbal and visual sources in its purest form without modification (Sandelowski 2000). As qualitative researchers continually re-evaluate their data to accommodate new insights, content analysis is a description of the varying patterns within the phenomenon being studied (Elo et al 2014).

The process of inductive content analysis was used as described by Elo and Kyngas (2008), where categories or themes are derived from emerging data. The process is divided into three steps:

Step one: Preparation

The aim of content analysis is to summarise the main body of text into smaller categories of content. The summary may include phrases, sentences or even paragraphs which may have several meanings. It is therefore essential for the researcher to become completely familiar with the content of the data in order to accurately represent the intended meaning of that data (Sandelowski 2000; Elo & Kyngas 2007; Gale et al 2013).

In this study, an interview guide was used to guide questioning and field notes were recorded on the interview guide, during the individual interview. All interviews were audio-taped with the permission of the participant (Addendum 7) and, as already mentioned, later transcribed verbatim by the researcher. All names were removed from the transcribed notes,

making identification of the patient impossible and assuring confidentiality. Each participant was assigned a pseudonym.

In order for the researcher to become completely familiar with the data, transcribed interviews were re-read several times, whilst re-listening to the audio-taped interview in order to hear the tone and inflection of the participant's voice. Pauses, emotional outbursts and additional sounds were recorded in transcribed material to add depth and additional insights to the participant's experience. After making sense of the data, the next step was to organise this data.

Step 2: Organising data

The process of organising descriptive data includes coding and creating categories or themes (Creswell 2014). Coding was done by underlining interesting words or phrases in the transcribed script. Each script was re-read several times to ensure all interesting content was included and an independent experienced researcher was asked to check the identified words or phrases of interest from each transcript, for completeness to ensure nothing of importance had been left out. Although latent content such as sighs, laughter and tears were recorded and transcribed, this content was not included in the coding. However when interpretation or clarity of a specific phrase or sentence was needed, the latent content was then taken into consideration in forming an opinion.

Underlined words or phrases were then copied and pasted onto an empty Excel spreadsheet or coding sheet, with one concept per line added. Each concept was linked to its original numbered transcription sheet. Common ideas or similar words appearing on the Excel spreadsheet list were re-arranged and grouped by copying and pasting similar topics into new columns.

Individual columns were scrutinised and compared to other columns containing similar ideas so that emerging themes could be grouped together in categories. This process is called abstraction. An example of the abstraction process used is depicted in Figure 3.2. According to Elo et al (2014) a diagram can be a highly effective way of describing the process of abstraction which is often influenced by the researcher's insight and intuition which can be difficult to describe.

Concepts in each category or sub-category were re-checked against their original transcription to ensure that ideas had not been misinterpreted and incorrectly assigned to the wrong column. An independent and experienced researcher checked the emerging themes. Consensus in opinion was achieved after discussion.

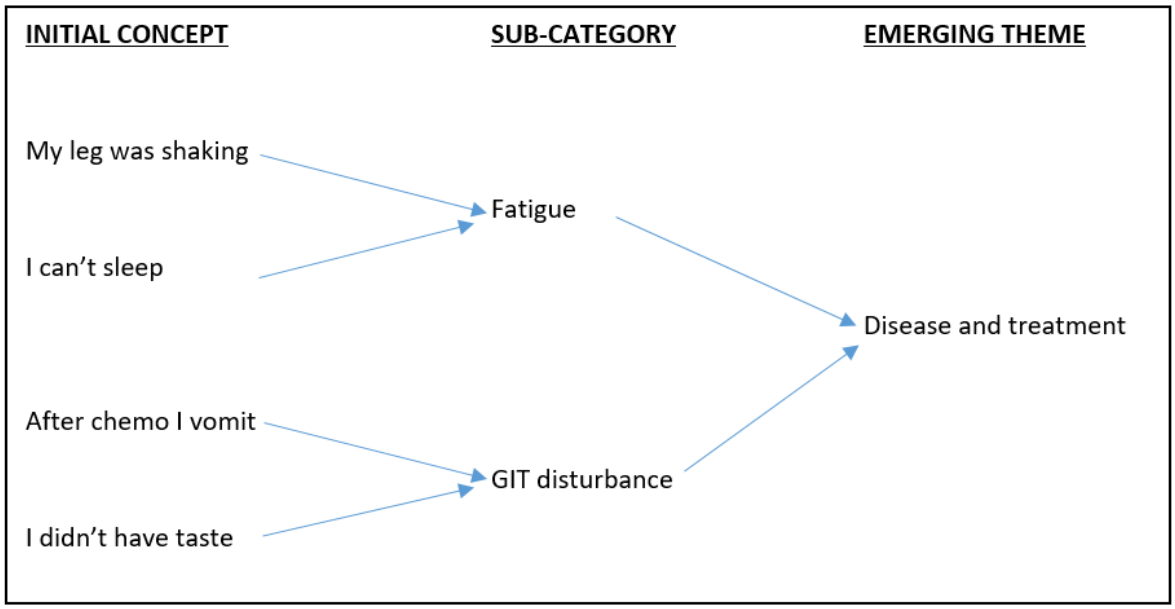


Figure 3.2 An example of the abstraction process
(Source: Elo & Kyngas 2008).

Step 3: Reporting

The final reporting phase of results includes how connections between the data and results were made (Elo et al, 2014). Results should be reported in a systematic and logical way that can easily be understood by the reader and include sufficient detail highlighting both strengths and limitations encountered in the study (Anderson 2010). The analysis and interpretation of results are reported and discussed in Chapters 5 of this dissertation.

3.4.6 Trustworthiness

Trustworthiness is defined as the ability to be relied on and deserving of confidence (Collins English Dictionary 2012). According to Lincoln and Guba in Elo et al (2014), trustworthiness in qualitative studies can be assessed in five different ways using the following criteria: credibility, dependability, conformability, transferability and authenticity.

Credibility:

Credibility is a key component of qualitative studies ensuring a true picture of the data is represented. As per recommendations made by Shenton (2004) to promote confidence in the accuracy of reported data, the following strategies were applied throughout this study:

- Well established research methods were used in the form of in-depth, semi-structured interviews. A second experienced faculty member and researcher was on hand to assist

with any language issues, enabling participants to express their viewpoints in a language of their choice.

- The researcher was introduced to the participants as an experienced oncology nurse who is familiar with the ward and clinic settings. This introduction assisted in building trust relationships between researcher and participant and assured of her familiarity within the participating organisation, so that it was easier for participants to discuss sensitive information.
- In order to encourage honesty from the participants who were contributing data, each person was reminded of their right to withdraw from the study at any point and without giving any reason to do so, without fear of reprisal. Participants wanted to share their stories and they were encouraged to be frank from the start and that their personal information would be kept in the strictest confidence.
- Open ended questions were asked of the participants and their answers were probed to check that the information had been correctly understood and interpreted. At times questions had to be rephrased for greater clarity when it became evident that the participant had not fully understood the question.
- Frequent debriefing sessions were held between the researcher and her supervisor. During discussions the researcher could learn from the insights and experience of her mentor and alternative approaches could be debated.
- The credibility of the researcher is important in qualitative studies as this is the person who is primarily involved with the data collection and analysis. The researcher is an oncology nurse specialist with more than fifteen years' experience in the clinical setting.

Dependability:

Dependability ensures that data is stable and consistent over time (Elo et al 2014; Anney 2014; Shenton 2004). Lincoln and Guba in Elo et al (2014) stress the co-dependent relationship between credibility and dependability, stating that the one assures the other, however in order to directly address the criterion of dependability, each process within the study should be reported in detail. Dependability can be confirmed using an audit trail, stepwise replication where more than two researchers evaluate the data separately, repeating coding strategies and steps of analysis and comparing results (Anney 2014). The following strategies were followed to ensure dependability in this study:

- Careful documentation of all processes followed throughout the study are detailed in Chapter 3 of the dissertation, with findings reported and discussed in Chapter 5
- Individual interviews were audio-taped and transcribed verbatim.

- Identical processes were repeated in each interview with a second faculty member assisting with language issues
- Coding and abstraction were repeated through multiple observations by the researcher and then reviewed by a supervisor to discuss findings and compare results

3.4.7 Confirmability

The criterion of confirmability ensures that the findings that emerge from the study are from the participants' perspectives and not influenced by the researcher's presumptions or biases (Shenton 2004; Anney 2014). The researcher's objectivity and processes undertaken during the course of the study which ultimately led to the recommendations and conclusions in the study need to be audited and scrutinized. The criterion of confirmability was confirmed through audit trails and reflexivity.

- The audit trail described in the section above describes the processes that the researcher followed to ensure that the interpretations of data represent information from the participant and not opinion of the researcher. A supervisor verified that the trail of evidence followed a systematic procedure for analysis so that the risk of interpretation bias was minimized.
- Reflexivity refers to the ways in which the researcher could have influenced the gathering of data through prior assumptions and experience (Mays & Pope 2000). Reflexivity including an assessment of the researchers own perceptions and personal influences which could have shaped the study, were therefore reviewed. Personal and professional knowledge regarding cancer pain may have influenced the direction of probing questions however the findings reported in Chapters 5 are a description of data collected from the participants.

3.4.8 Transferability

Transferability ensures that sufficient detail is included in the study to enable application or extrapolation to another situation or group (Anney 2014; Shenton 2004). The transferability criterion was met by providing thick description, reaching data saturation and through purposive sampling techniques.

- Thick descriptive data refers to an extensive set of details relating to methodology, analysis and interpretation of results, which is described in Chapters 3, 5 and 6 of this research report. According to Shenton (2204) thick descriptive data allows the reader to have a thorough understanding of the phenomena being studied and enables them to compare information in other settings

- Data saturation was achieved after eighteen interviews indicating that there was enough in-depth data to replicate the study
- Purposive sampling techniques helped the researcher focus on participants who could provide information about their experiences of cancer pain, which helped to answer the research question

3.4.9 Authenticity and integrity

This last criterion refers to the extent that the researcher is able to capture a range of realities as experienced by the participants (Elo & Kyngas 2007; Anney 2014). The experience of the participants emerges in the identified themes and the patient's own words and phrases are used to record their reality and heighten the reader's sensitivity to that reality.

3.5 ETHICAL CONSIDERATIONS

The guiding principles for ethical conduct described by Polit and Beck (2010) from the *Belmont Report* were applied to this study. The *Belmont Report* described three broad principles: beneficence, respect for human dignity and justice. To ensure that the study was conducted in an ethical manner, these three principles were applied:

3.5.1 Beneficence

The principle of beneficence refers to the need to minimise harm and maximise benefits. In order to ensure this ethical consideration was observed, the following was done:

- The initial study proposal was presented at the Department of Nursing for peer review and to the Assessors Committee of the School of Therapeutic Services for permission to conduct the study.
- Formal written ethical clearance was obtained from the University of Witwatersrand Human Research Ethics Committee (Clearance Certificate No: M170495) to conduct the study (Addendum 8).
- Permission to conduct the study was obtained from the Nursing Director and Chief Executive Officer of the hospital (Addendum 9).
- Protection from discomfort and harm was provided. When there were signs of discomfort or distress during data gathering, the researcher offered to stop the interview, inform the Unit Manager and reschedule the interview. Ms. Huiskamp, an experienced Mental Health Nurse had agreed to counsel the participant as necessary.

- One patient became short of breath during the interview and the researcher tried to stop the interview. The participant stated that he was used to the feeling and insisted on continuing the talk. The interview was paused and restarted when the patient was more comfortable. The participant became quite emotional at the end of the interview and the audio-tape was stopped immediately and the patient was comforted by the researcher. The participant did not want to have any additional counselling.

3.5.2 Respect for human dignity

Respect for human dignity includes the right to self-determination and full disclosure of all information. This principle was adhered to as follows:

- Human dignity was respected. Participants were made aware of their right to freely withdraw from the study if they wished to without influencing the level of their care.
- An information document was given to the potential participants (Addendum 5) and then informed consent was obtained from those invited and willing to participate (Addendum 6). Further consent before audio taping the patient interviews was also obtained (Addendum 7).
- The participants were able to communicate in the language that was most comfortable for them when they could not express themselves adequately in English.

3.5.3 Justice

Justice refers to the participant's right to fair treatment and privacy. This was ensured as follows:

- Interviews were conducted in a private room in the medical ward.
- Pseudonyms were used instead of participant's names to ensure anonymity.
- Confidentiality was ensured by not divulging the information obtained and only using this information for the intended purpose.
- Once the interviews had been transcribed they have been transferred to a flash drive and deleted from the computer. All data sheets and the flash disk will be sealed in an envelope and placed in a safe in the Department of Nursing Education for a period of three years after the report has been published where after it will be destroyed.

Data gathering only started once consent had been obtained from the Ethics Committee.

3.6 SUMMARY

In Chapter 3 the research strategy, methods and design of the two parts of the study were described. In Chapter 4, the findings of the scoping review will be discussed.

CHAPTER 4

PART 1: SCOPING REVIEW RESULTS

4.1 INTRODUCTION

The results of the scoping review conducted in Part 1 of the study are presented in this chapter, in an attempt to answer the first research question: what pain assessment instruments are available to assess pain in cancer patients, what are the characteristics of these instruments and how do they compare against the criteria of an ideal instrument?

4.2 IDENTIFICATION OF RELEVANT STUDIES

The characteristics of the identified studies are depicted in Table 4.1

Table 4.1: Characteristics of the identified articles

CHARACTERISTICS OF THE ARTICLES (n=21)															
No	**Country of origin**	**Year**	**Name of article**	**Author**	**Aims and objectives**	**Design**	**Population**	**Setting**	**Sampling method**	**Sample size**	**Data collection method**	**Data collection instrument**	**Key findings**	**Recommendations**	**Comments**
1	**South Korea, Asia**	2012	The effectiveness of a self-reporting bedside pain assessment tool for oncology inpatients	Kim et al	To evaluate the effectiveness of bedside self-assessment of pain intensity for inpatients using a self-reporting pain board	Observational prospective study	Adult patients with cancer pain due to disease or its treatment, able to understand Korean	Study was conducted at the Oncology Department of Chungbuk National University Hospital	Consecutive eligible patients	50 patients	Patients and medical staff completed questionnaires and medical records were reviewed	SRB-PAT PMI VRS NRS BPI-sf	Self-reporting bedside pain assessment tool provides a reliable and effective means of assessing pain in oncology inpatients and increase patient and staff communication of pain	The self-reporting board was not seen as effective for patients with poor performance status or impaired cognitive functions, particularly those undergoing palliative care	
2	**South Korea, Asia**	2015	A satisfaction survey on cancer pain management using a self-reporting pain assessment tool	Lim et al	To evaluate pt satisfaction with pain control therapy using a self-reporting assessment tool, explore its usefulness and evaluate pt perception of pain management	Not stated	Adult patients with cancer related pain able to understand the South Korean language, hospitalized for more than 5 days	The study was conducted in 29 different south Korean hospitals	Not stated	587 patients	Patients were asked to record their average pain score day 1-5 and complete a self-reporting pain board and cancer pain knowledge questionnaire	NRS	The use of a self-reporting pain assessment tool as a communication instrument provides an effective foundation for evaluating pain intensity in cancer pain management	Continued patient education regarding cancer pain is needed to eliminate misconceptions	
3	**Taiwan, Asia**	2017	Evaluation of pain intensity assessment tools among elderly patients with cancer in Taiwan	Chang et al	To evaluate the reliability, validity and no-response rate of pain scales among elderly pts with cancer pain awa pt preference for the scales	Cross-sectional correlational design	Elderly patients with cancer related pain, able to communicate in Mandarin or Taiwanese	Participants were enrolled at a cancer-based teaching hospital in southern Taiwan.	Convenience sampling	73 patients	Patient interview	NRS VDS FPS Mental status questionnaire Demographic data sheet	All 4 scales were reliable and valid for assessing cancer pain among elderly pts	Future studies are needed in which the interval between test and retest is shortened	Mental status questionnaire and demographic data sheets do not assess cancer pain and are therefore excluded
4	**Germany**	2013	Quality of life and symptom evaluation in daily oncology practice: a survey of 150 patients with advanced gastrointestinal tumours receiving palliative chemotherapy	Schulthei s et al	To assess the QoL of pts with advanced gastrointestinal tumours receiving palliative chemotherapy using assessment tools with an emphasis on pain and depression	Prospective cross-sectional study	Adult patients with incurable metastatic gastrointestinal tumours undergoing palliative chemtherapy and proficient in German	Patients treated in an outpatient department of the interdisziplinares TumorZentrum Mannheim at the University of Heidelberg, Germany	All patients meetng the inclusion criteria were asked to participate	150 patients	Data were collected over an 8-month period. Patients were asked to complete 3 questionnaires	VAS EORTC QLQC-30 BDI	The analysis indicates the need for better symptom control regarding the examples pain and depression	A regular computer and/or internet-based assessment and evaluation of QoL is a method needing further investigation	BDI does not assess cancer pain and is therefore excluded

CHARACTERISTICS OF THE ARTICLES (n=21)															
No	**Country of origin**	**Year**	**Name of article**	**Author**	**Aims and objectives**	**Design**	**Population**	**Setting**	**Sampling method**	**Sample size**	**Data collection method**	**Data collection instrument**	**Key findings**	**Recommendations**	**Comments**
5	**Italy, Europe**	2013	The effects of low doses of pregabalin on morphine analgesia in advanced cancer patients	Mercadante et al	To evaluate the opioid response in pts receiving morphine and pregabalin, in comparison to patients receiving morphine only	A multicenter prospective randomized controlled study	Patients with advanced cancer	Not stated	Not stated	60 patients	Data were collected at the start and then at weekly intervals for 4 weeks	BPI NRS	The use of low doses of pregabalin added to morphine therapy in advanced cancer pts does not seem to provide advantageious analgesic effect	Further studies with appropriate design should explore whether pregabalin could exert an analgesic effect in patients with specific pain conditions such as neuropathic pain or with using a different dosing schedule	
6	**Italy, Europe**	2014	Comparisons of patient and physician assessment of pain-related domains in cancer pain classification	Brunelli et al	To compare physician clinical assessment with pt-rated evaluations in the classification of cancer pain patients into groups with different pain levels, acording to the presence of breakthough pain, neuropathic pain and psychological distress	Cross sectional observational international survey	Adult cancer patients with metastatic or locally advanced disease	Survey carried out in 17 palliative care or oncology centers in Norway, UK, Austria, Germany, Switzerland, Italy, Canada and Australia from Oct 2008 to Dec 2009	Not stated	1051 patients	Assessments conducted on the same day by healthcare professionals and by patients	NRS BPI ECS-CP ABPAT PD-Q	Pts self-assessment of subjective symptoms should be integrated in future cancer pain classification systems with more objective clinician assessments can improve the classification of cancer pain	Further studies on cancer pain classification are needed using longitudinal study designs, standardized assessment tools and training to assess stable pain control	
7	**Italy, Europe**	2015	Alberta breakthrough pain assessment tool: a validation multicentre study in ancer patients with breakthrough pain	Sperlinga et al	To assess the ABPAT acceptability and efficacy as a tool for the characterization of BTP	Multi-centre, cross-sectional observational study	Cancer patients with locally advanced or metastatic disease with breakthrough pain on analgesia	Seven oncology or palliative care centres in the Piedmont Region in Northern Italy	Not stated	249 patients	Questionnaire was administered to enrolled patients	ABPAT NRS	92,8% of pts stated that questions were easily understandable, 87% stated that the tool allowed to explain extensively the BTP problem	ABPAT is a complex and time-consuming tool and cannot be considered the ideal tool to BTP assessment in the routine clinical practice	
8	**Norway, Europe**	2012	Interviews with patients with advanced cancer - another step towards an international cancer pain classification system	Knudsen et al	To investigate how pts ranked the relevance of several previously identified pain domains, to investigate pts perception of thepain experience and to disclose additional relevant pain domains for cancer pain classification	Mixed method approach	Pts with advanced cancer experiencing pain and receiving opioid treatment	Study conducted at the Department of Oncology, Trondheim University Hospital, Norway and at the Division of Oncology, Medical university of Graz, Austria	Purposeful sampling	33 patients	1. Patients were asked to identify previous pain domains by using NRS 2. Semi-structured interviews were conducted	NRS ESAS	Previously identified pain domains were confirmed to be relevant to the pts, however the ranking differed from the experts' ranking. Sleep disturbances may be added as a domain in a future classification system	A mixed method approach should be considered in the development process of a new cancer pain classification system.	

CHARACTERISTICS OF THE ARTICLES (n=21)															
No	Country of origin	Year	Name of article	Author	Aims and objectives	Design	Population	Setting	Sampling method	Sample size	Data collection method	Data collection instrument	Key findings	Recommendations	Comments
9	Norway, Europe	2013	The Edmonton Classification system for cancer pain: comparison of pain classification features and pain intensity across diverse palliative care settings in eight countries	Nekolaichuk et al	To describe the prevalence of ECS-CP pain classification features in a diverse international sample of advanced cancer patients and to demonstrate the variability of pain intensity at presentation	Multi-centre, cross-sectional study	Pts with advanced cancer	The study was conducted in inpatient and outpatient units, hospices and general oncology and medical wards from 17 centers within Norway, UK, Austria, Germany, Switzerland, Italy, Canada and Australia.	Adult patients with incurable metastatic cancer or locally advanced disease	1051 patients	Data collection was performed by touch-sensitive computers and consisted of two sets of questionnaires completed by clinicians and patients.	ECS-CP ESAS Karnofsky Performance Status Mini-Mental State Examination	The ECS-CP is a clinically relevant systematic framework which is able to detect differences in salient pain classification features across diverse settings and countries	Further validation studies including additional predictor variables, inter-rater assessments, improved definitions for variables and refinement of outcome measures are needed	Karnofsky Performance Status and Mini-Mental State Examination are not cancer pain assessment tools are are therefore excluded
10	Norway, Europe	2014	A cross-sectional study on prevalence of pain and breakthrough pain among an unselected group of outpatients in a teritary cancer clinic	Raj et al	To investigate the prevalence of pain to guide further screening, classification and treatment of pain	Descriptive cross sectional study	Adult patients with cancer having not had a surgical procedure in the last 24 hours	General oncology outpatient department in a university hospital in Trondheim, Norway.	Unselected cohort of cancer outpatients	305 patients	Patients completed two assessment questionnaires	BPI ABPAT NRS	All pts are candidates to be screened for pain and if present, a more detailed pain diagnosis should be established	Follow up assessments should be included with a method to identify patients with neuropathic pain,psychological distress and sleep disturbances	
11	Norway, Europe	2016	Characteristics of breakthrough cancer pain and its influence on quality of life in an international cohort of patients with cancer	Hjermstad et al	To examine the feasibility of using computers for registration of medical and patient-reported data and to examine the prevalence and characteristics of BTP and to investigate the relationship btwn BTP and QoL	Observational cross-sectional multicentre study	Adult patients with incurable metastatic/locally advanced cancer	Patients from 17 cancer care units including university clinics, regional hospitals a local hospital and one hopsice in Norway, England, Astria, Germany, Switzerland, Italy, Canada and Australia participated	Convenience sampling	978 patients	Touch sensitive computers were used to capture data from health personnel and the patient	EORTC QLQ-C30 V3.0,22 ABPAT	BTP is highly prevalent with prolonged episodes despite analgesics and has a pervasive impact on QoL	There is a need for health care professional, patient and carer education to improve pain management and thereby improve quality of life	
12	Norway, Europe	2016	Is it possible to detect an improvement in cancer pain management? A comparison of two Norwegian cross-sectional studies conducted 5 years apart	Thronaes et al	To compare the prevalence and characteristics of pain and breakthrough pain between 2008 and 2014 samples	Cross-sectional correlational design	Adult cancer patients able to read and write Norwegian, admitted to the hospitals or attending the cancer clinics on two pre-defined days	The study was conducted at a university hospital and a local hospital in mid-Norway	Not stated	258 patients	Questionnaires were distributed	BPI ABPAT	Prevalence of CP in 2008 was 55% and 53% in 2014. No improvement in pain control was observed, despite enhanced educational programmes	Improved cancer management is needed, despite existing guidelines, available treatments and educational efforts. Further studies are needed	

CHARACTERISTICS OF THE ARTICLES (n=21)															
No	Country of origin	Year	Name of article	Author	Aims and objectives	Design	Population	Setting	Sampling method	Sample size	Data collection method	Data collection instrument	Key findings	Recommendations	Comments
13	Spain, Europe	2013	Cancer-related neuropathic pain in out-patient oncology clinics: a European survey	Garzon-Rodriquez et al	To estimate the prevalence of cancer-related neuropathic pain in pts with chronic pain and to evaluate to usefulness of the painDETECT screening tool	An observational, non-interventional, cross-sectional, multi-centre study	Adult patients with cancer experiencing chronic pain	The study was conducted between 23 August 2010 and 22 July 2011 in outpatient oncology clinics in Denmark, Germany, Greece, Spain and the UK	Elligible patients attending the outpatient clinics were recruited consecutively	951 patients	Data were collected from 63 physicians from 49 sites in one consultation only	PD-Q BPI-sf EuroQoL Health Questionnaire The Sheehan Disability Scale	A wide range of cancer patients experience cancer related neuropathic pain	Neuropathic pain needs to be identified in order to be managed appropriately. Screening tools like PD-Q may be beneficial	EuroQoL Health Questionnaire and the Sheehan Disability Scale are not cancer pain assessment tools and therefore are not included
14	Jordan, Middle East	2012	Revision and validation of a medication assessment tool for chronic cancer pain management	Salmany et al	To review, modify and test the original MAT-CP in a comprehensive cancer center in Jordan	A cross sectional survey	Records of adult cancer patients	The study was conducted at the King Hussein Cancer Center in Amman, Jordan	Not stated	71 patient records	Information was collected using a special form designed for this purpose	MAT-CP	The tool can be routinely used to assess and compare the quality of pain management in different institutions	Further research is warranted to refine the current tool to link appropriate prescribing to pain relief and quality of life factors	
15	Canada, North America	2011	Optimizing pain relief in a specialized outpatient palliative radiotherapy clinic: contributions of a clinical pharmacist	Gagnon et al	To describe the contribution of the clinical pharmacist (CP) to an outpatient palliative RT clinic	Retrospective analysis of prospective data	Records of adult cancer patients treated at the care centre	Study was conducted at the Cross Cancer Institute, Edmonton, Alberta, Canada between 1 January 2007 and 31 December 2008	Not stated	114 patients	An Excel database was used to prospectively collect anonymized demographic information, disease characteristics, treatment outcomes and types of supportive care recommendations.	ESAS ECS-CP	The CP plays a key role in holistic patient assessment and optimization of pharmacologic therapy, contributing to improved symptom control of pts receiving palliative RT	Additional training opportunities to expand the role and expertise of the clinical pharmacist are recommended	
16	Canada, North America	2014	Validation of the short-form McGill pain questionnaire -2 in younger and older people with cancer pain	Gauthier et al	To evaluate age differences in the validity, reliability and use of the SF-MPQ-2 people with advanced cancer and pain	Prospective observational study	Adult patients with metastatic or inoperable advanced cancer with sufficient profficiency in English	Patients attending outpatient clinics at a comprehensive cancer centre and those receiving hhome palliative care in Toronto, Ontario and Canada between May 2006 and August 2012	Not stated	397 patients	Questionnaires were distributed	SF-MPQ-2 NRS BPI PMI WHO-AL	The SF-MPQ-2 is valid for use in older and younger people with advanced cancer and pain	Age-related patterns in the correlates of neuropathic and nonneuropathic sensory and affective pain qualitites should be evaluated to identify age or life-stage specific profiles, important to different pain qualities	

CHARACTERISTICS OF THE ARTICLES (n=21)															
No	Country of origin	Year	Name of article	Author	Aims and objectives	Design	Population	Setting	Sampling method	Sample size	Data collection method	Data collection instrument	Key findings	Recommendations	Comments
17	Canada, North America	2016	Classification of painful bone metastases as mild, moderate, or severe using both EORTC QLQ-C15-PAL and EORTC QLQ-BM22	McDonald et al	To determine the optimal cut points for pain intensity based on assessing impact on QOL, and the correlation between pain severity and survival	Secondary analysis of data	Patients with bone metastases previously enrolled on a double-blind, randomized, phase III trial	Analysis of data from a trial that investigated the use of dexamethasone in the prophylaxis of pain flare in patients who received radiation therapy for bone metastases	Not stated	298 patients	Data from trial was analysed	QLQ-BM22 QLQ-C15-PAL BPI	Pain can be classified as mild, moderate and severe but cut points should be chosen based on type of measurement tool i.e. fuctional interference or QoL assessment	Pain severity may correlate with survival but further studies are needed	The relationship between pain and functional interference is not the same as that between pain and disruption in QoL
18	USA, North America	2012	Measurement of affective and activity pain interference using the brief pain inventory (BPI): cancer and leukemia group B	Atkinson et al	To evaluate the full 11-item version of the BPI in a sample of patients enrolled in a multi-institutional Phase III clinical trial	Retrospective review	Adult patients diagnosed with metastatic castrate-resistant prostate cancer, enrolled in a Phase III Cancer and Leukemia trial	Patients enrolled in a multi-institutional Phase III Cancer and Leukemia Group B trial,between Feb 1996 and July 1998.	Not stated	184 patients	A one-factor model was compared against two- and three-factor models that were developed, based on the design of the instrument	BPI	BPI can be used to quantify the degree to which pain seperately interferes with affective and activity aspects of a pts everyday life	Further studies to determine whetheR BPI could be further reduced from 11 questions to 3 in order to determine whether a single item can capture the full spectrum of information	Limitations include a single disease type in an all-male sample
19	USA, North America	2015	The routine use of the Edmonton Classifiction system for cancer pain in an outpatient supportive care center	Arthur et al	To assess the utility of the ECS-CP as a tool for predicting pain-related outcomes in patients seen in the outpatient supportive care center at a comprehensive cancer centre	Not stated	Adult cancer patients with a documented ECS-CP assessment at the initial consultation	Outpatient supportive care clinic in a comprehensvie cancer center	Not stated	100 patient records	Electronic charts of 100 patients were retrospectively screened between Feb 2008 and march 2010	ECS-CP ESAS	ECP-CP is a simple and feasible cancer pian assessment tool that can be used in routine clinical practice	Further studies are needed on a larger sample size and that takes into account factors such as age and genetic composition and includes the patient's input	Standardized management plan is followed at this centre with various assessments routinely done
20	United Kingdom	2014	Development and validation of the breakthrough pain assessment tool (BAT) in cancer patients	Webber et al	To develop and validate a breakthrough pain assessment tool for use in the clinical setting	Multi-method study incl. literarure review, Delphi process with experts and semi-structured interviews with pts	In- and out-patients with breakthrough cancer pain	The study was conducted at a hospital in Sutton, a cancer centre in Guildford and at a hospice in Hastingwood in the UK	Convenience sampling	1. 14 experts in the Delphi 2. 10 pts with breakthroug h pain assessing readability 3. 100 patients testing instrument	Questionnaires were distributed	BAT BPI NRS	Evidence provided for the validity and reliability of the BAT for use in the clinical setting	Additional studies are required to assess psychometric properties of BAT	

CHARACTERISTICS OF THE ARTICLES (n=21)															
No	**Country of origin**	**Year**	**Name of article**	**Author**	**Aims and objectives**	**Design**	**Population**	**Setting**	**Sampling method**	**Sample size**	**Data collection method**	**Data collection instrument**	**Key findings**	**Recommendations**	**Comments**
21	**United Kingdom**	2016	Disparities between clinician and patient perception of breakthrough pain control	Webber et al	To establish whether pts and clinicians independently agree on adequacy of breakthrough pain control, management strategy and impression of change over time	Prospective observational study	Adult patients with cancer related pain identified by an expert as being BTcP, on analgesia	In- and out-patients were recruited from a tertiary cancer center, a district general hospital and a hospice in the UK	Not stated	100 pts	Patient completed a questionnaire and a clinician conductetd a clinical assessment. Both were repeated a week later	BAT	There are significant differences in global impressions of BTcP but differences become less as therapeutic relationship evolves. Decisions based on clinical perceptions	Effectivetherapeutic relationships can overcome initial differing opinions	

4.3 ORIGIN OF THE ARTICLES

The largest percentage of articles (48%; n=10) originated from Europe, followed by North America (24%; n=5), Asia (14%; n=3), United Kingdom (9.5%; n=2) and Middle East (4.5%; n=1). None of the articles originated from Africa. Five studies (24%; n=5) were international studies conducted in various countries as a collaborative effort within Australia, Europe, North America and the United Kingdom. Eight studies (38%; n=8) were conducted in multiple centres within one country whilst another eight studies (38%; n=8) were conducted in a single centre. Table 4.2 summarizes the origin of the work.

Table 4.2 Country of origin of articles (n=21)

Continent	Country	n	%
Asia	South Korea	2	10%
	Taiwan	1	5%
Europe	Germany	1	5%
	Italy	3	14%
	Norway	5	23%
	Spain	1	5%
Middle East	Jordan	1	5%
North America	Canada	3	14%
	USA	2	10%
United Kingdom	England	2	10%

4.4 DESIGN AND METHODS USED IN ARTICLES

Most of the studies used a quantitative design (81%; n=17) with some of these studies reporting that cross sectional observation (29%; n=5) was used. However, in addition to these five studies, one study (6%; n=1) referred only to a “cross section” and one study (6%;

n=1) referred to “cross section descriptive” design used. An observational prospective design was used in three studies (18%; n=3). Mixed methods were used in two studies (10%; n=2) which included semi-structured interviews with patients. Two studies did not state what design was used.

4.5 POPULATION

The populations for the studies included patients with histologically confirmed diagnosis of cancer (29%; n=6), inoperable local or metastatic advanced disease (24%; n=5), advanced cancer (14%; n=3), cancer (10%; n=2), advanced gastro-intestinal tumours (5%; n=1) and metastatic castrate-resistant prostate cancer (5%; n=1).

4.6 ELIGIBILITY

Patients had to be older than 18 years (48%; n=10), adult (10%; n=2) or aged 65 or older (5%; n=1). Additional inclusion criteria were the ability to provide written informed consent (33%; n=7), normal cognitive function (24%; n=5) or able to complete the study protocol (5%; n=1). The ability to speak a specific language was stipulated as an inclusion criteria in five studies (24%; n=5). Patients that experienced pain due to cancer (14%; n=3), were treated with opioid medication (14%; n=3), experienced cancer-related chronic pain (9%; n=2), had documented cancer-related breakthrough pain (9%; n=2), were taking regular analgesia (9%; n=2), had no surgical procedures in the previous 24 hours prior to the study (10%; n=2), experienced pain for at least some portion of the 3 days preceding the interview (5%; n=1) or had a worst pain in the last 24 hours $\geq$ 3 (5%; n=1) were included in the studies. Life expectancy of at least 3 months, a performance status between 0-2, and adequate hematologic, renal, hepatic and clotting functions were inclusion criteria in one study each (5%; n=1). Patients that were admitted to medical oncology or hospice units, attended an out-patient oncology unit, admitted to hospital or oncology out-patient departments on pre-defined days or hospitalized for 5 days or more were inclusion criteria in one study each (5%; n=1).

Population and eligibility criteria are summarised in Table 4.3

Table 4.3 Summary of population and eligibility criteria for studies (n=21)

ELIGIBILITY CRITERIA					
Population	**Age**	**Cognitive function**	**Pain**	**Physical ability**	**Accessibility**
Histologically confirmed cancer	>18 years	Able to provide written informed consent	Pts experiencing pain due to cancer	Life expectancy of at least 3 months	Pts admitted to specific oncology treatment facilities on pre-defined days
Inoperable local or metastatic advanced disease	Adults	Normal cognitive function	Pts treated with opioid medication	Performance status between 0-2	Hospitalized for 5 days or more
Advanced cancer	65 years or older	Able to complete the study protocol	Pts experiencing cancer-related chronic pain	Adequate haematologic, renal, hepatic and clotting functions	
Cancer		Specific language restrictions	Pts experiencing documented cancer-related breakthrough pain		
Advanced gastro-intestinal tumours			Pts taking regular analgesia		
Metastatic castrate-resistant prostate cancer			No surgical interventions in preceding 24 hours		
			Experiencing pain in the 3 days preceding interview		
			Worst pain in the last 24 hours $\geq$3		

4.7 SAMPLING

Sampling was primarily convenience (38%; n=8) with two studies using purposive sampling (10%; n=2) and computer-generated randomized sampling (5%; n=1) used in another study. Unfortunately some studies did not specify a sampling method (48%; n=10). Sample sizes varied from 33 patients to 1051 patients.

4.8 DATA COLLECTION METHODS

Just under half of the studies (48%; n=10) had questionnaires completed by both patients and health professionals with three of these studies (30%; n=3) comparing the responses from both groups.

Touch screen computers were used to gather data in two of the studies (10%; n=2). Questionnaires were completed by health professional staff or a researcher in seven studies (33%; n=7) and self-administered by the patient in four studies (19%; n=4).

Five studies reviewed data retrospectively. Three of these studies (60%; n=3) reviewed documentation and charts that recorded specific information of adult patients treated for pain in cancer care centres within a specified timeframe. Information was collected using data capture sheets specifically designed for that purpose. Secondary analysis of data from phase III clinical trials were analysed in two studies (40%; n=2).

Semi-structured interviews with patients were conducted in two mixed method studies (10%; n=2) and a Delphi process was conducted in one study (5%; n=1).

4.9 FOCUS OF THE ARTICLES

Just under half of the articles (48%; n=10) focussed on the usefulness or usability of the cancer pain assessment instrument being studied. Two of these studies (20%; n=2) evaluated a bedside self-assessment instrument and two studies (20%; n=2) explored sub-scales to confirm or compare cut points to evaluate pain or quality of life. One study (10%; n=1) focussed on the affective/activity interference dichotomy, whilst another article (10%; n=1) focussed on the usefulness of the instrument in predicting pain related outcomes in patients seen in an outpatients supportive care unit. One study (10%; n=1) evaluated the reliability of cancer pain assessment instruments for use in an older population and one

study (10%; n=1) explored age-related patterns in people with cancer pain. One study (10%; n=1) developed and validated an instrument for use in the clinical setting and one study (10%; n=1) described the revision and validation of an instrument.

Features of cancer pain were the focus of seven articles (33%; n=7). Pain domains to enhance pain classification were explored in three articles (43%; n=3) and the prevalence and characteristics of breakthrough pain and neuropathic pain were explored in three articles (43%; n=3) and one article (14%; n=1) respectively.

Patient and health professional perception of cancer pain was the focus in two articles (10%; n=2) and one study (4%; n=1) described the contribution of a clinical pharmacist. One study (4%; n=1) explored the patients response to opioid medication. Table 4.4 summarises the focus of the selected articles.

Table 4.4 Summary of article focus

USEABILITY OF THE ASSESSMENT INSTRUMENT (n=10)	**FEATURES OF CANCER PAIN (n= 7)**	**RESPONSES AND CONTRIBUTION TO PAIN MANAGEMENT (n=4)**
Usefulness of a bedside self-assessment instrument	Domains to enhance pain classification	Patient and health professional perceptions of cancer pain
Sub-scales explored to compare cut points	Prevalence and characteristics of breakthrough pain	Contribution of a clinical pharmacist
Affective/activity interference dichotomy	Neuropathic pain	Patients response to opioid medication
Predicting pain related outcomes in out-patients of a supportive care unit		
Reliability of cancer pain instrument for use in older populations		
Age-related patterns in people with cancer		
Development and validation of instrument for use in a clinical setting		
Revision and validation of instrument		

4.10 CANCER PAIN ASSESSMENT INSTRUMENTS USED

Nineteen cancer pain assessment instruments were identified in the selected articles from the scoping review and these were summarised and presented as Table 4.5. The assessment instruments are presented alphabetically under the following headings: uni-dimensional scales (21%; n=4), multi-dimensional scales (63%; n=12) and analgesia scales (16%; n=3).

Table 4.5: Cancer pain assessment instruments

Cancer Pain Assessment Instruments (n=19)															
	No.	Name of instrument	Abbrev.	Ref. article	Method of administration	No. of ques.	Body chart	Method of rating severity	Type of pain	Aggravating/ relieving factors	Patient's description of pain	Interpretation of findings	Current analgesia	Satisfaction with current analgesia	Comments
Uni-dimensional scales	1	Faces Pain Scale	FPS	3	Pts chose face that best depicts the intensity of their pain	1	No	Metric scale usually 6, 7 or 9 faces	Non-specific	Not asked	Not asked	No interpretation	Not asked	Not asked	Used in older pts, incl pts with mild /mod cognitive impairments
	2	Numeric Rating Scale	NRS	1, 2, 3, 5, 6, 7, 8, 10, 16, 20	Number verbally selected by pt. that reflects intensity of pain	1	No	11-point scale with 0=no pain; 10=worst pain	Non-specific	Not asked	Not asked	No interpretation	Not asked	Not asked	Can be administered telephonically
	3	Visual Analogue Scale	VAS	4	100mm unmarked line with standardized wording on the left and right hand sides	1	No	No pain = 0 Worst pain= 10	Non-specific	Not asked	Not asked	No interpretation	Not asked	Not asked	Can be difficult for pts to understand
	4	Verbal Descriptor Scale or Verbal Rating Scale	VDS / VRS	1, 3	Pt. is asked to chose a set of terms that corresponds with numeric value	1	No	0=no pain; 1-4= mild; 5-7= moderate; 8-9=severe; 10= unbearable	Non-specific	Not asked	Not asked	No interpretation	Not asked	Not asked	Descriptions may not apply to all pts and measurements btwn scales are unequal
Multi-dimensional scales	5	Alberta Breakthrough Pain Assessment Tool	ABPAT	6, 7, 10, 11, 12	Completed by physician or nurse awa patient	18	Yes	Duration, mild, moderate, severe	Breakthrough	Yes	Yes	Yes	Yes	Yes	Validated, initially designed for research setting
	6	Breakthrough pain Assessment Tool	BAT	20, 21	Completed by patient	14	Yes	0-10 scale	Breakthrough	Yes	Not asked	No interpretation	Yes	Yes	Validated for use in UK for English speaking pts
	7	Brief Pain Inventory	BPI	5, 6, 10, 12, 16, 17, 18, 20	Questionnaire completed by pt	32	Yes	0-10 scale	Pain intensity and pain interference	Yes	Options provided	No interpretation	Yes	Yes	Translated and validated in several countries, modified version of WBPI
	8	Brief Pain Inventory - short form	BPI-SF	1, 13	Questionnaire completed by pt	15	Yes	0-10	Pain intensity and pain interference	Not asked	Not asked	No interpretation	Yes	Yes	Uses 24-hour recall of pain

Cancer Pain Assessment Instruments (n=19)

	No.	Name of instrument	Abbrev.	Ref. article	Method of administration	No. of ques.	Body chart	Method of rating severity	Type of pain	Aggravating/ relieving factors	Patient's description of pain	Interpretation of findings	Current analgesia	Satisfaction with current analgesia	Comments
Multi-dimensional scales	9	Edmonton Classification System for Cancer Pain	ECS-CP	6, 9, 15, 19	Questionnaire completed by clinician	5	No	None	Incidental, nociceptive and neuropathic	Not asked	Not asked	Yes	Not asked	Not asked	Patient self-report and pain intensity not included. Psychological distress and addiction included
	10	Edmonton Symptom Assessment System	ESAS	8, 9, 15, 19	Questionnaire completed by pt or caregiver	10	Yes	0-10 scale	Non-specific	Not asked	Not asked	Yes	Not asked	Not asked	Assesses common symptoms in cancer pts incl. pain
	11	EORTC QLQ-BM22	QLQ-BM22	17	Questionnaire completed by pt	22	No	1-4 scale	Bone metastasis	Yes	Not asked	Yes	Not asked	Not asked	Questionnaire developed for cancer patients with bone metastasis
	12	EORTC QLQ-C30	QLQ-C30	4, 11	Questionnaire completed by pt	30	No	1-4 and 1-7 scales	Non-specific	Not asked	Not asked	Yes	Not asked	Not asked	QoL for cancer patients including pain
	13	EORTC QLQ-C15-PAL	QLQ15-PAL	17	Questionnaire completed by pt	15	No	1-4 scale	Non-specific	Not asked	Not asked	Yes	Not asked	Not asked	Questionnaire developed for end of life cancer patients
	14	McGill Pain Questionnaire - short form	SF-MPQ	16	Self administered multi-choice checklist	15	No	None, mild, moderate, severe	Non-specific	Not asked	Options provided	Yes	Not asked	Not asked	Short form may be more appropriate for clinical setting
	15	painDETECT	PD-Q	6, 13	Patient self-administered questionnaire	15	Yes	0-10 scale and graded options	Neuropathic pain	Not asked	Not asked	Yes	Not asked	Not asked	Relating to pain experienced in last 4 weeks
	16	Self-reporting bedside pain assessment tool	SRB-PAT	1	Patient self-administered + clinician questionnaires	7+5	No	0-10 scale	Non-specific	Not asked	Not asked	No interpretation	Yes	Yes	Designed as a survey. Includes barriers to pain management

Cancer Pain Assessment Instruments (n=19)

	No.	Name of instrument	Abbrev.	Ref. article	Method of administration	No. of ques.	Body chart	Method of rating severity	Type of pain	Aggravating/ relieving factors	Patient's description of pain	Interpretation of findings	Current analgesia	Satisfaction with current analgesia	Comments
Analgesia scales	17	Medication Assessment Tool for chronic Cancer Pain	MAT-CP	14	Assessment performed by clinician	36 criteria	No	n/a	Non-specific	n/a	Not asked	No interpretation	Yes	Yes	Measures adherence to WHO guidelines
	18	Pain Management Index	PMI	1, 16	Assessment performed by clinician	2	No	0-10 scale	Non-specific	n/a	Not asked	No interpretation	Yes	Not asked	Measures balance of analgesia and pain intensity
	19	World Health Organisation Analgesic Ladder	WHO-AL	16	Assessment performed by clinician	1	No	n/a	Non-specific	n/a	Not asked	No interpretation	Yes	Not asked	4-pt scale of analgesia use

4.10.1 Uni-dimensional scales

There were four uni-dimensional scales mentioned in the scoping review articles.

The Numeric Rating Scale (NRS) as a uni-dimensional scale was the scale most referred to in the articles (48%; n=10), followed by Verbal Descriptor Scale (VDS) or Verbal Response Scale (VRS) (10%; n=2). The Faces Pain Scale (FPS) and Visual Analogue Scale (VAS) only appeared in the one article each (5%; n=1). This frequency is depicted in Figure 4.1. The researcher notes that the NRS is an integral part of many multi-dimensional scales and therefore is frequently referenced.

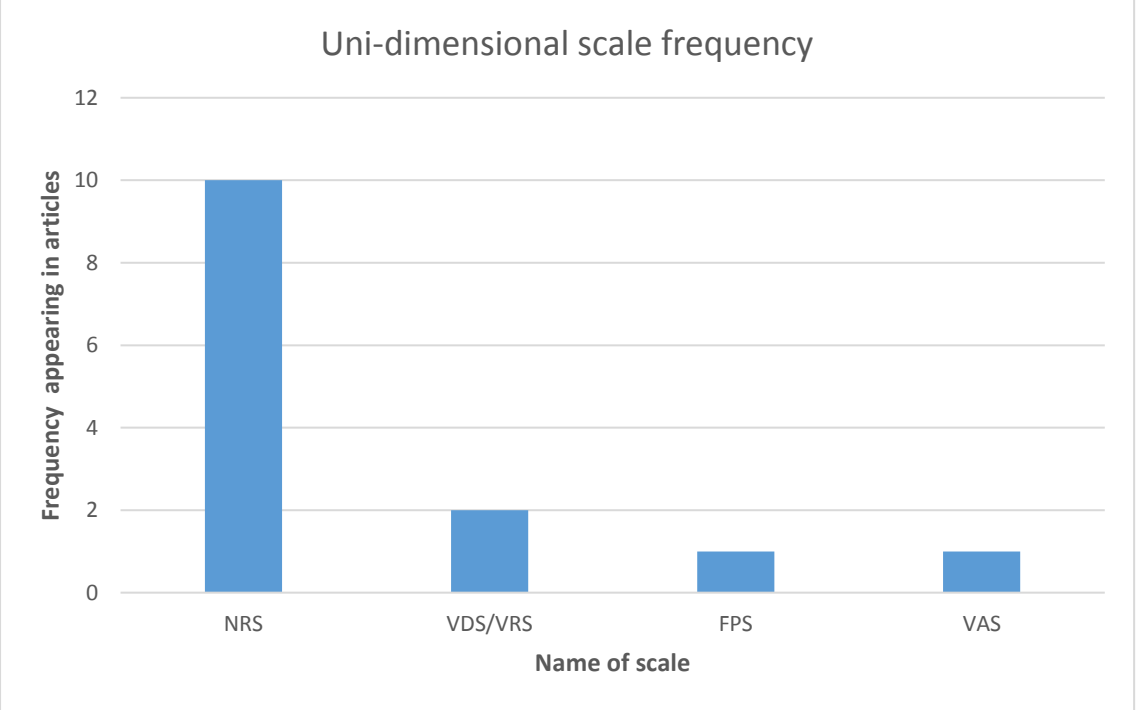


Figure 4.1: Frequency of uni-dimensional scales appearing in selected articles (n=4)

4.10.2 Multi-dimensional scales

Twelve multi-dimensional scales (57%; n=12) were identified. The Brief Pain Inventory (BPI) was the most frequently identified multi-dimensional pain scale as the BPI appeared in eight articles (38%; n=8), with Alberta Breakthrough Pain Assessment Tool (ABPAT) in five articles (24%; n=5). The Edmonton Classification System for Cancer Pain (ECS-CP) and Edmonton Symptom Assessment System (ESAS) appeared in four articles (19%; n=4) respectively. Breakthrough pain Assessment Tool (BAT), Brief Pain Inventory (short form) (BPI-SF), Quality of Life Questionnaire C30 (QLQ-C30) and Pain Detect Questionnaire (PD-

Q) were referenced in two articles (10%; n=2) respectively with the remaining Quality of Life Questionnaire Bone Metastases (QLQ-BM22), Quality of Life Questionnaire Palliation (QLQ15-PAL), Short Form McGill Pain Questionnaire (SF-MPQ) and Self Reporting Bedside Pain Assessment Tool (SRB-PAT) mentioned in only one article each. Figure 4.2 summarises the frequency of multi-dimensional scales in the articles.

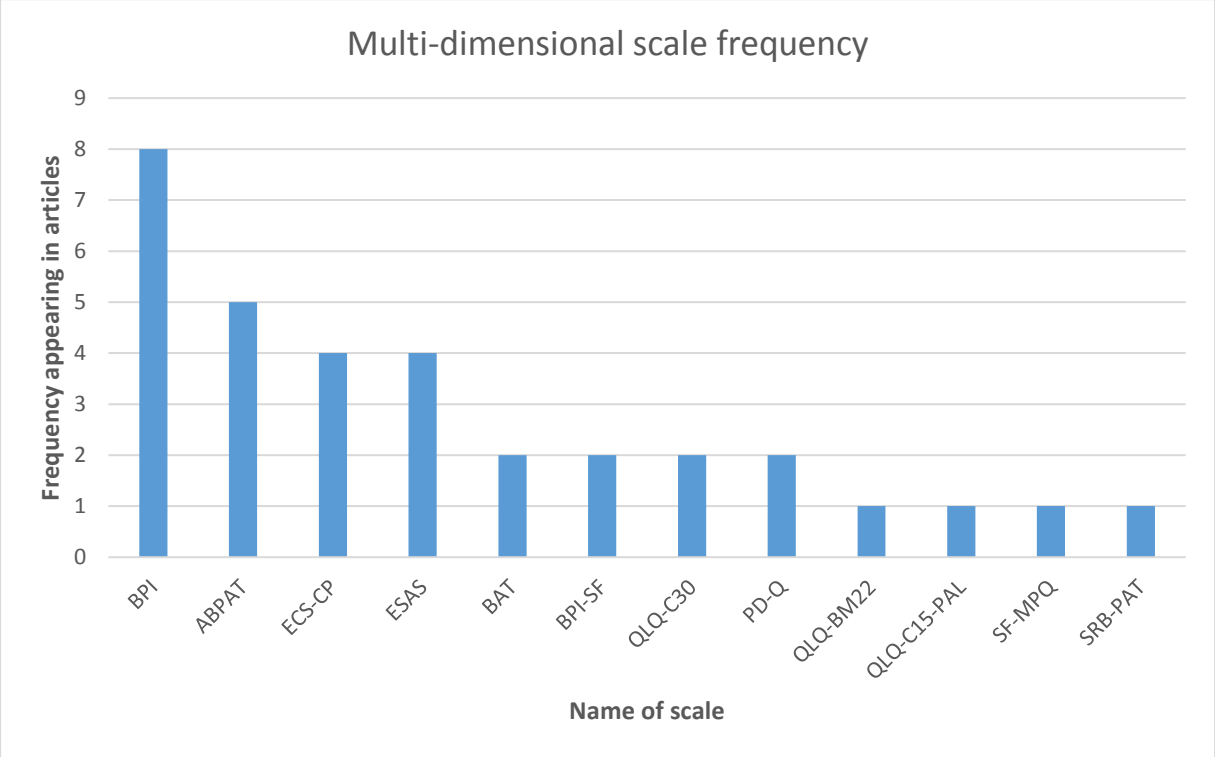


Figure 4.2: Frequency of multi-dimensional scales appearing in selected articles (n=12)

4.10.3 Analgesia scales

Three analgesia scales (14%; n=3) were identified in the scoping review. Categorised under analgesia scales, the Pain Management Index (PMI) was identified in two articles and Medication Assessment Tool for Cancer Pain (MAT-CP) and World Health Organisation Analgesia Ladder (WHO-AL) are mentioned in one article respectively, as depicted in Figure 4.3.

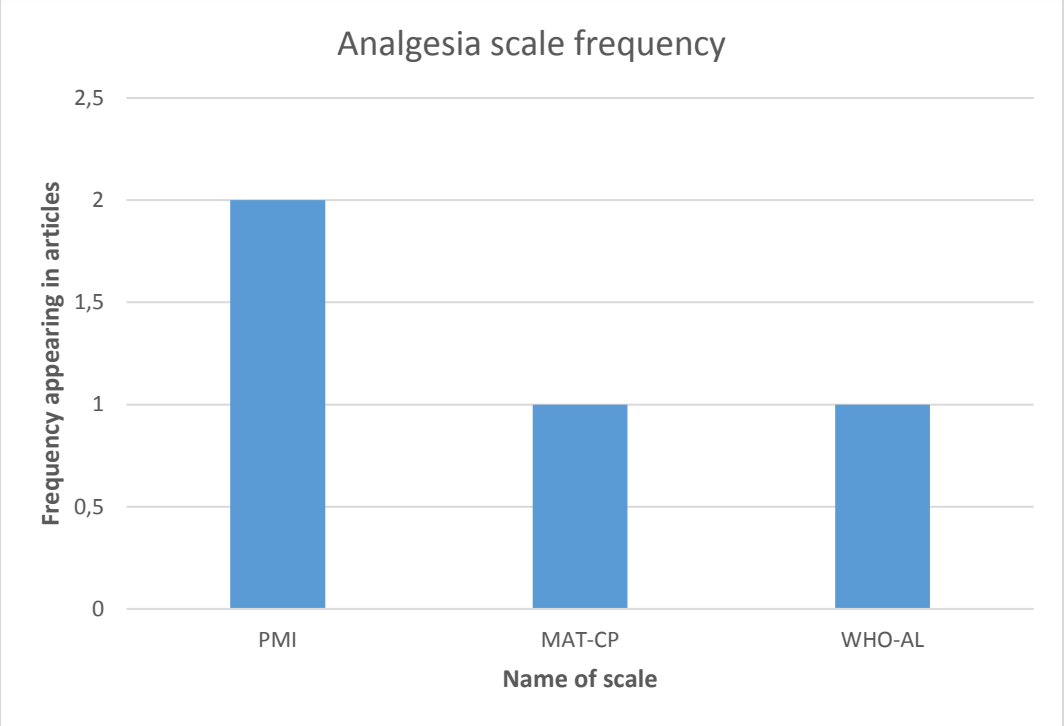


Figure 4.3: Frequency of analgesia scales appearing in selected articles (n=3)

4.11 COMPARISON OF CANCER PAIN ASSESSMENT INSTRUMENTS

The pain assessment instruments were compared under the following headings: the usability of the instruments, the appropriateness of the assessment instruments for use in specific types of cancer pain and comparison between the instruments and the criteria for an ideal pain assessment instrument.

4.11.1 Usability of the instruments

Comparisons were made based on how the instruments are administered, how many questions are asked and whether clear instruction for interpretation is evident.

All of the uni-dimensional instruments (100%; n=4) consist of only one question. The patient is asked to associate their current level of pain against a set point on a scale, represented by a numeric number or a cartoon of a face showing increasing levels of distress. Three of the instruments (75%; n=3) are administered by a health professional and one instrument (25%; n=1) the NRS, can be self-administered by the patient or administered telephonically by a health professional. The interval points described on NRS and VAS are equidistant, but those on FPS and VDS are unequal. All four instruments (100%; n=4) do not contain clear instructions for interpretation.

The number of questions asked in the multi-dimensional assessment instruments range from 5-32 with a mode of 15 questions. In order to assess how time consuming the instruments are to administer, the researcher categorised the instruments in terms of the number of questions asked in each, as being short (1-10 questions), moderate (11-20) and long (21 questions and more). In addition, to assess how complicated the assessment tools are it was found that nine of the instruments (75%; n=9) are completed by patients with the ESAS completed by either the patient or care-giver and can also be administered telephonically. Two instruments are completed by both patient and health professional (17%; n=2) and one instrument is completed only by the health professional (8%; n=1). Five instruments (42%; n=5) ask patients to recall their pain over a 7-day period, three instruments (25%; n=3) refer to a 24-hour recall and one instrument (7%; n=1) enquires about pain experienced during the preceding month. The duration of pain recall is unspecified in three of the instruments (25%; n=3). Eleven instruments (92%; n=11) use Likert-type scales to rate pain severity with nine instruments (75%; n=9) using numeric values and two instruments (17%; n=2) using verbal descriptors. The ECP-CP provides pre-determined and varied options for selection. The majority of instruments (67%; n=8) provide clear instruction for use and interpretation of findings.

All of the analgesia scales (100%; n=3) are administered by a health professional. Only PMI (33%; n=1) rates severity of pain using a numeric value scale against the balance of analgesia, with the remaining two analgesia scales measuring adherence to guidelines and use of analgesia only. The instruments do not provide clear instruction for use or interpretation of findings.

4.11.2 The appropriateness of the assessment instruments for use in specific types of cancer pain

All of the uni-dimensional scales (100%; n=4) measure pain intensity only, unspecific to a cancer pain type, however the multi-dimensional scales can be used to measure various cancer pain domains (Table 4.6). The analgesia scales measure the appropriate use of analgesia only.

Table 4.6: Summary of the multi-dimensional scale measurements of cancer pain domains

PAIN INTENSITY AND INTERFERENCE	CLASSIFICATION OF PAIN	GENERAL SYMPTOM ASSESSMENT INCLUDING PAIN
BPI BPI-SF	Nociceptive or neuropathic pain ECS-CP PD-Q Pain from bone metastasis QLQ-BM22 Breakthrough/ episodic pain ABPAT BAT Unspecified type of cancer pain SF-MPQ SRB-PAT	QLQ-30 QLQ-C15-PAL ESAS

4.11.3 Comparison between the instruments and the criteria for an ideal pain assessment instrument

The assessment instruments were compared to the ideal instrument described previously.

As previously mentioned, all of the uni-dimensional scales measure pain intensity only and the analgesia scales assess the appropriate use of analgesia, making comparison of these instruments against the criteria of an ideal pain assessment instrument impossible.

However, while assessing whether the multi-dimension assessment instruments met all requirements of an ideal pain assessment instrument, it was noted that although eleven instruments (92%; n=11) had been validated and tested for reliability for use in various countries, there was no evidence to support that these instruments had been validated within the South African context. All instruments were age appropriate. Table 4.7 depicts the

comparison of multi-dimensional instruments against the criteria of an ideal pain assessment instrument.

Table 4.7 Comparison of multi-dimensional pain assessment instruments meeting the criteria of an ideal pain assessment instrument

Pain assessment instrument	Validated	Age appropriate	Measures levels of pain	Measures different pain types	Body chart to pinpoint pain	Aggravating / relieving factors	Patient description of pain	Length of instrument *	Scores easily understood	Instructions for
ABPAT	Yes	Yes	Yes	Specific	Yes	Yes	Yes	Moderate	Yes	Yes
BAT	Yes	Yes	Yes	Specific	Yes	Yes	No	Moderate	Yes	No
BPI	Yes	Yes	Yes	General	Yes	Yes	No	Long	Yes	No
BPI-SF	Yes	Yes	Yes	General	Yes	No	No	Moderate	Yes	No
ECS-CP	Yes	Yes	No	Specific	No	No	No	Short	No	Yes
ESAS	Yes	Yes	Yes	General	Yes	No	No	Short	Yes	Yes
QLQ-BM22	Yes	Yes	Yes	Specific	No	Yes	No	Long	Yes	Yes
QLQ-C30	Yes	Yes	Yes	General	No	No	No	Long	Yes	Yes
QLQ15-PAL	Yes	Yes	Yes	General	No	No	No	Moderate	Yes	Yes
SF-MPQ	Yes	Yes	Yes	General	No	No	No	Moderate	Yes	Yes
PD-Q	Yes	Yes	Yes	Specific	Yes	No	No	Moderate	Yes	Yes
SRB-PAT	No	Yes	Yes	General	No	No	No	Moderate	Yes	No

* short (1-10 questions), moderate (11-20 questions) and long (21 questions and more)

4.12 LIMITATIONS OF STUDIES

There were several limitations identified in the studies which included preconceptions about pain, small size of sample population and high rate of drop off as a result of death of patients with advanced disease, cultural, age and language restrictions, including lengthy assessments in time-constrained clinical settings.

4.13 SUMMARY

A scoping review was done in an attempt to explore what pain assessment instruments are available to assess pain in patients with cancer, and to compare the instruments. The results of the scoping review were presented in this chapter. In the next chapter, the patient's cancer pain experience will be described.

CHAPTER 5

PART 2: DESCRIBING CANCER PAIN: FINDINGS

5.1 INTRODUCTION

In an attempt to answer the second research question: how do cancer patients experience and describe their pain and what do they consider essential for nurses to know about their pain, a qualitative descriptive study was conducted in Part 2 of the study. The findings of this phase are presented in this chapter.

5.2 THE PARTICIPANTS

The participants consisted of 20 patients (n=20) who suffered from a variety of cancers. The ages of the participants ranged from 20 to 76 years, with an average age of 52.2 years (SD ± 14.62). The majority of the participants were female (11 of 20). Many of the participants (7 of 20) indicated that Zulu was their home language. The majority of the patients had solid tumours (14 of 20) whilst the rest suffered from one of the haematological malignancies. Two of the participants had developed a second malignancy during their cancer journey. Table 5.1 summarizes the general information of the participants. Pseudonyms have been used to protect the identities of the participants.

Table 5.1: General information about the participants (n=20).

Pseudonym	Age	Gender	Home language	Diagnosis
Peter	37	M	Zulu	Multiple myeloma
Mary	67	F	Northern Sotho	Breast cancer + multiple myeloma
James	76	M	Xhosa	Oesophageal cancer
John	51	M	Afrikaans	Melanoma
Martha	62	F	Zulu	Breast cancer
Magdalene	52	F	Tswana	Breast cancer
Joanna	36	F	Not stated	Colon cancer
Andrew	59	M	Zulu	Multiple myeloma
Susanna	62	F	Not stated	Acute myeloid leukaemia + breast cancer
Salome	73	F	Afrikaans	Breast cancer
Prisca	71	F	Tswana	Breast cancer
Junia	30	F	Southern Sotho	Breast cancer
Julia	51	F	Afrikaans	Breast cancer
Ammia	45	F	Zulu	Breast cancer
Philip	51	M	Zulu	Chronic myeloid leukaemia
Perpetua	45	F	Xhosa	Colon cancer
Bartholomew	47	M	Zulu	Lymphoma
Thaddeus	48	M	Not stated	Multiple myeloma
Thomas	20	M	Zulu	Sarcoma
Mathew	61	M	Ndebele	Lymphoma

The majority of patients had received a combination of surgical and chemotherapy treatments (13 of 20) with two patients receiving surgical, chemotherapy and radiotherapy treatments (2 of 20). Five patients received chemotherapy treatments alone (5 of 20).

5.3 THEMES AND CATEGORIES ARISING FROM THE DATA

Two themes and six categories arose from the data. The themes that were identified are pain as a multi-dimensional experience and the needs of the patient. Table 5.2 summarizes the themes and categories.

Table 5.2: Themes and categories arising from the data

THEME	CATEGORY
Pain as a unique multi-dimensional experience	- The physical experience of cancer and its treatments - The psychosocial burden of having a dread disease - Factors relieving pain
The needs of the patients	- The need for information and communication - The need for compassionate care and support - What nurses need to know about the pain experience

Theme 1: Pain as a unique multi-dimensional experience: "*Cancer pain is a very very complicated pain"*

Category 1: The physical experience of cancer and its treatments

Pain was a major problem for the participants. It was a unique experience with each person experiencing their pain differently. Junia stated: *There is physical pain, there is emotional pain. For me the most painful one for me was emotional one.* Mary had been diagnosed with the same type of cancer as Junia but her experiences were different; she said: *The breast it wasn't sore…it was just that thing that comes sometime because they did the biopsy.*

All the participants could identify the types of pain they experienced and sometimes they experienced different types of pain at the same time; the intensity of the different pains also varied. Joanna explained: *The heavy pain you will see feel like a deep breath here, the sharp pain bites you. Narrow pain like something you can feel it far but it's still coming, something slowly coming. That pain is a different pain.* Andrew added: *Today that pain sometimes it just keep quiet. It's not talking...*

Many participants experienced pain as a presenting symptom that caused them to seek health care prior to their diagnosis of cancer. Initially the participants did not know what the cause of the pain was. Philip stated: *All this time I thought I had got ulcer because the pain was on the stomach*. Bartholomew remembered: *It started with a heavy headache that doesn't go away at night.*

Most of these participants remembered their initial pain as being specific to where the cancer was found and experienced pain in a breast, abdomen, shoulder or legs. Words used to

describe their pain included *tingling, sharp, stabbing, piercing, bursting* and *like lightening* and *something that had been dug from the body*. Two participants recalled experiencing unresolved pain throughout the body which they could not describe; they explained: *Something is wrong in your body* (Peter) and *Right there where the cancer is…* (Joanna).

Some of the participants had an expectation that cancer would cause pain. Mary was adamant: *Everybody who had that breast thing that they've got* [have] *that kind of pain …* [also] …*the pains of myeloma.* James added: *It doesn't matter if at some point there is not treatment, but there would be pain.*

Any new pain caused many of the participants to fear that the cancer had relapsed or spread. Junia confided: *It's just a pain, but because you have cancer, you react.* Susanna shared her experience: *No after being told, you know they* [pains] *come after being told that it's spreading. All along I never had pain.* Peter reflected: *It wasn't just pain, it was the cancer.* Julia confirmed: *It is* caused *by the cancer and that it has spread.* However, not all agreed; some believed that the pain they experienced was a good thing because it meant that they were still alive. Ammia said: *I am glad that the pain is there...since I started feeling the pain when you pinch me I can feel it, so I am going somewhere. It's a pain but I am happy about it.*

Subsequent medical investigations and interventions were also painful. Philip said: *The other pain that I am feeling at the moment right now, is where they took the bone marrow.* Bartholomew added: *The pain I have got is where the catheter* [is]…

Many participants felt that the treatments for cancer made the pain worse. For some participants the surgery they had added to their pain; having had a mastectomy, biopsy or spinal surgery were specifically mentioned. Peter explained: *I think it was affect that of the operations because most of the time it's become hot inside.* Perpetua added*: Obviously after operation you will get more pain* and Thaddeus remembered: *The pain I was having was from the throat…the cut…* However, not all the participants agreed and some experienced less pain after surgery. Joanna said: *since they've done the operation I was feeling good* and Amnia agreed: *I think that the operation was better than that* [chemotherapy].

The participants were divided as to whether chemotherapy made their pain better or worse. Perpetua said: *This chemo thing was not meant for human beings. Maybe it was meant for lions. Even if I survive this cancer, this chemo will kill me.* Magdalene added: *It's the devil. It is the devil alive.* In contrast, some participants experienced that chemotherapy relieved their pain. Peter acknowledged: *Chemo makes the pain better* and Mary noted: *After taking chemo everything was fine*. Junia added: *Though chemo is painful, at least it helps with lots of pains in the body… rather give me the chemo because my pain is not going away.*

The participants were of the opinion that the many side-effects they experienced due to the chemotherapy caused pain. Fatigue, described as being *tired* and *weak* was a major challenge for the participants. The fatigue they experienced was caused by pain, lack of sleep and fear. John explained: *For me it's a constant pain that doesn't go away. It keeps you from sleeping at night time*. Magdalene added: *The pain goes away but you don't really sleep as the mind keeps on working.* Andrew confessed that he was too frightened to close his eyes in case he died in his sleep. He said: *You don't want to close your eyes. You don't know how it is. You think even if I close your eyes, maybe I'm going now.* Fatigue also affected activities of daily living such as dressing, making a bed, going out and even walking. Mary said: *My activity was less and it was too much of a mission to go out;* Mathew added: *I couldn't go to church…* Julia concluded: *My life is just about lying down and pain.*

Gastro-intestinal disturbances added to the participants' pain. Ammia said: *When I get home I vomit: that was the worst pain*… Junia agreed: C*hemo drives you crazy. You become dizzy, you vomit; if you didn't eat at all you become worse.* Suzanna added: *When I eat I will get pains until here…deep to my stomach and then I'll have a running stomach.*

Some of the participants experienced neurological changes as a result of the chemotherapy. These changes included a loss of sensation or a sensation of pins and needles in their feet and an intolerance to temperature changes. Some of the participants experienced pain when they touched something whilst others experienced burning and itching which also caused pain. Joanna said: *Once you touch something silver – the pain! I can't even open the pot because it's silver*. Perpetua added: *Anything that touch my skin it's itchy, it's burny*. Martha described her experience as follows: *I think it's chemo because sometimes I'm getting very cold and the pain! Hey, it's hurting me, sometimes I can't even walk properly.*

Some of the participants also experienced headaches. John said: *The chemo that's causing the problem you know. It's not like a normal headache…it's a constant headache, like a migraine*. Junia agreed: *The headache will be killing me.*

The participants experienced physical changes as a result of receiving chemotherapy which included hair loss and changes to their nails and hormonal changes which shrunk the vagina and caused hot flushes. Junia explained: *Chemo takes away from the person is the physical changes. One the loss of the hair, the hair will fall and the vagina will shrink. It shrinked after the chemo.* Perpetua added: *This thing kills your immune system. You get like your finger prints are vanishing…your feet are peeling. I had like hot flashes.* John said: *I get fever. Cold and hot fevers*. Salome noted that her bones had become brittle as a result of a calcium deficiency and explained: *All the calcium in my body is virtually gone I'm breaking,*

I'm breaking in my sleep. And I've got the most harsh pain in my whole body because it's all over.

The participants agreed that is was important to be informed about the side effects of chemotherapy so that they were prepared for the changes they would undergo. However, even being informed could not prepare them totally. John said: *They did warn me there can be side effects so it could have been worse.* Ammia disagreed: *I knew what was going to happen, but I never expected it to happen the way it happened.*

Category 2: the psycho-social burden of having a dread disease

The participants agreed that the effects of cancer and cancer treatments are not limited to the physical but also influenced their lives as psycho-social beings. The participants experienced emotional pain, heartache, a sore heart and a sore soul. Peter said: *Outside is fine, but inside is not fine.* John added: *It's not just a physical pain, it's a mental pain as well you know. It can bring you into a struggle.* Perpetua shared: *The pain is in your soul; it's not in your body.*

The emotional pain the participants experienced was worse than the physical pain because it was not anticipated. They described the trauma of being diagnosed and treated for a dread disease. Julia explained: *The pain of my thoughts that it is cancer. This is a pain, and then came the heartache.* Susanna agreed: *Sometimes from nowhere I will start crying. Emotional pain is worse than the physical because I didn't expect it.*

For some participants the diagnosis of cancer was synonymous with death and most agreed they feared death. Death was also associated with pain, adding to their fears. Fear of death extended to their families, which added to their suffering. Mary stated: *I hated death, to fear the pain of death.* Prisca described her experience: *I didn't tell everybody because I don't want to be hurt because they would tell me you are going to die.* Mary was adamant: *Everything is frightened of death: even the stones do feel the death because the rain rains on it and the sun suns on it and then it crack.*

Participants shared the trauma of seeing others suffer in the treatment centres. Joanna described her experience: *The pain mixes with your brain and what you were thinking about, what you see.* Perpetua added: *Chemotherapy kills your soul. You see kids taking chemo. I never cried, diagnosed, but when I saw that boy I cried the whole night.*

The participants experienced various losses which included losing their bodies as known to them. Junia described the loss of her breast and her baby: *I woke up and another torture. No*

breast. Only one…two weeks after [starting chemotherapy] *they terminated the baby. Which was one of the serious things even today when I think of that loss it's huge for me…*

Some of the participants found it difficult to cope with their illness. Some participants' pain had become too much to cope with; some felt worthless and unsure about their future role in society, some asked questions about ever being normal again whilst others even had suicidal thoughts. Perpetua explained: *It kills your soul, it does that to you. As a strong person that I am, but I was never suicidal, I was just wishing to go to sleep and never wakes up… It was scary especially for my family as well and my husband. If I was going to be weak for them, they are going to be weak for me.* Mary said: *When I came out of here* [hospital] *I didn't go back there* [to work] *because I was no use to her.*

Some of the participant's relationships had come under pressure after the cancer diagnosis, which had led to communication breakdown, isolation and problems in the marriage. Andrew confided: *Our relationship is not right. We don't talk too much since I came from hospital….she doesn't touch me… when I came back I found them planning a funeral. They were thinking that I am going, so I'm still here. So the relationship between us is not good.* Joanna said: *You feel like nobody wants you because everything changed*. Thomas added: *It has changed my life a lot. It has changed how I am with my friends. I used to talk with my mum and have fun with my mum, but now we just sit…*

Stigma added to the participants' emotional pain. Some participants preferred to isolate themselves from their families or communities in order to stop rumours and subsequent manipulation of truth. Mary described her experiences: *They spread some words around. Look at her – she is sick, she is going to die.* Philip added: *They* [colleagues] *can't keep secrets. They will start to attack me somehow…maybe the others won't have much details about the disease, they thought that maybe if I sit next to them the disease will spread to them.* Andrew was also concerned: *In my street there are about 4 people or 5 dying because of cancer. Some of them say it* [is] *witchcraft.* Thaddeus added: *For us most black people they dangered if they get ill; the sickness that the one with cancer is not completely their own, most of the people think then somebody gave given him muti* [traditional medicine] *or so.* Although several participants experienced the need to isolate themselves from their communities and families, they were also lonely. Being nursed in reversed isolation added to their loneliness. Bartholomew said: *But nobody comes. Nobody comes…they stand outside there…yes, a lot* [lonely]. *A lot. It is my first time to see that I am being isolated.*

The participants who were far from home struggled more than those who were well supported and had family and friends to talk to. Some of the participants had to watch other patients receive visitors and be able to share experiences with their families and friends

whilst they were far from their loved ones, which added to their emotional pain. Junia reflected: *When you sit alone in a corner, then whatever that's eating you inside will kill you.* Joanna said: *My emotional pain what makes things worse for me while I was taking the treatment. My family was far away.* John agreed: *The most difficult thing for me is to be here and not where I belong*. Julia described her experience: *The loneliness – I think that this is the most painful.*

Category 3: factors relieving pain

The participants agreed that the analgesia they took relieved their pain. However, some did not experience relief every time they took the medication. Mary said: *The pain is still going on but the pills numb it.* Some experienced unwanted side-effects that frightened them whilst others refused to take analgesia because they feared the side-effects. Salome explained: *I am on morphine, 60mg in the morning and 60 at night. Sometimes it helps but sometimes it don't.* Perpetua noted*: Morphine, that thing makes you dream like the wildest dream, that you think you are dead doing this other thing it's afterlife.* Perpetua who refused to take analgesia said: *Let what they feed me do what it does, but I am not going to add on it taking these bunch of pills, because all those pills got side effects.*

It was not easy for the participants to take tablets every day. For some, swallowing was not always easy whilst others found the pain medication quite confusing. Ammia confessed: *Taking a pill every single day is something else; it's not easy.* Thaddeus remembered: *I couldn't eat – there was nothing that I could eat and it was difficult to swallow also.* Peter said: *It confuse us when you get a lot of tablets because it's not working the same…They give me different tablets. So when I am there in my house I mix it myself so I know which one is stronger than the other one. I have to take maybe the strong tablets and weak tablets and mix it. When I get a new type of pain tablets here I so test it alone.*

A few participants conserved their pain medication – some saved it for when they experience severe pain, whilst others did not receive enough tables to last for a month and therefore had to take it very sparingly. Mary said: *If I overdo now, then when the worst pain comes, this pill won't be working for me.* Andrew added: *I only get 10 tables per month…*[take them] *when it is too much…I don't want to finish them.* However, having prescribed pain medication did not necessarily control the participants' pain and caused frustration. Julia said: *I always tell the doctors and all they can prescribe is a pain pill…*

Despite sleep disturbances experienced as a result of pain, sleep relieved pain and resulted in less cancer and treatment related side-effects. Peter said the following: *Sometimes I drink another one* [pain pill] *and get asleep. So when I wake up the pain is gone.* Thomas

experienced the following: *During the day it doesn't go completely, but during the night because you sleep it does go completely.* John said: *I sleep a lot. I didn't do anything else you know to help try to fight the headaches.*

With the majority of participants using the words *hot, fire, coal* or *burning* to describe their pain, some of the participants used additional measures to relieve their pain. James said: *Something was burning at the chest...pain tablets generally* [help] *for pain, but when I experience the pain on the chest I usually drinks water and it goes away.* Martha agreed: *I just sit and drink too much water. Sometimes it's cooling down the pains.*

The participants were divided on how they felt this pain could be treated. Perpetua said: *emotional pain – that one needs therapy*. Most of the patients described pills or tablets or medication and did not specify medication given for depression. Thomas stated the following: *The pain that makes you so sad, that one doesn't work so well with tablets*. Martha disagreed: *Since taking those depression tablets, it's better*. In addition to medication, interacting with others relieved emotional pain. Mary explained: *You need someone to talk to* and Perpetua added: *That's how I survived the chemo and the cancer: because I talk about it.* Junia agreed: *I am this person who doesn't have friends. But the people that I talk to on WhatsApp…even on Facebook, the friends that I meet… so the emotional thing, the best way talk about it.* However Joanna cautioned: *When you talk, that things goes out…when the peoples is in pain, sometimes they don't want to talk. They just crying.* Susanna agreed: *I phone my husband so that I must be able to cry.*

Faith and hope for a healthy future helped participants cope with their pain. They hoped that they would be healed and believed that God would intervene and relieve the distressing symptoms they experienced. John explained: *The Lord learned me to give my burdens and pain to him. So that makes it easier for me to carry you know. Not giving up.* Julia said: *I trust God. My life is going to be normal after this and it is so. I have hope. I see light. I see my grandchildren*. Andrew agreed: *Is that thing that one day I'd be healed. That hope.* Julia added: *I trust in God, but He must take the pain away* and Mary stated: *Why does He spare you when you are sick? Because He's still got purpose for you.* James added: … *if you don't have faith, you won't get better.* Perpetua added: *As long as you believe in God, you will pull through*.

In summary, cancer pain was a unique experience and could be caused by the disease, its treatment or the side-effects of that treatment. The participants experienced different pains in different parts of their bodies, sometimes simultaneously. However the participants also experienced emotional pain, caused by fear of death, trauma, losses, stigma and loneliness. Emotional pain was more painful that the physical experience. Factors relieving pain varied

and included analgesia and other medications, sleep, water as well as interaction with others, faith and hope for a healthy future.

Theme 2: The needs of the patient: "*my journey could have been different …"*

Category 1: The need for information and communication

Some of the participants did not know what cancer was and feared that it could spread to their families. Philip said: *I was not knowing since I was born what is leukaemia, so this is the first time I am coming across this…what worries me is that it looks like a dangerous disease. Since it is in the blood, so the blood circulates to all the parts of the body, what worries me that sometimes this disease will be carried to delicate parts of the body like the brain.* Bartholomew admitted: *I didn't know what is cancer…is there anything you can do for cancer which is lymphoma?* Peter said: *I want to know that sick can they affect my family or not?*

The participants also had unmet information needs in terms of the stage of their disease, their treatment and prognosis. Philip explained: *At what stage, you always ask yourself at what stage maybe is the disease going in? Is it at a higher stage or a beginning stage, or in the middle stage?* Bartholomew added: *I haven't been told by the doctor that you are at this stage, at this stage, at this stage. I need to be alive. If I knew this and if there would be a word what they say is for this reason, or for this reason why they isolated me.* Peter said: *I just want to know how many chances am I have to go from now since I now have the cancer? … I have three months now of attending that chemo so it will take how long to be treated?* Peter concluded: *When you get somebody who can help you to answer those questions, you can feel better.*

Some of the participants were misdiagnosed and also received incorrect information about the symptoms they presented with. Magdalene recalled: *It was bleeding from the nipple. The doctors kept giving me medication and said there's no need to run to the clinic because I'm giving you treatment. It will go away.* Junia added: *we get wrong information, we are misled at the very same hospitals that we go to… a lack of information kills*. Philip concurred: *I can be fixed if I get proper counselling from the person who knows most about the disease.* However, this was not the case for all. Martha said: *It was sore and then my sister's daughter, it's a nurse, came there and I asked her there is something which I don't understand under my breast. Then she said she want to try that to take me to the clinic. She said I must go to the clinic it's a cancer.* Prisca shared the following: *I have knowledge*

because I experience with my cousins. So I accept that this is breast cancer and then I went to the clinic.

Communication with their doctors was also a problem as the doctors were perceived as busy and used language that the participants did not necessarily understand. Susanna said: *You don't have anybody that you can talk to. The doctors are so busy and you cannot even ask them anything.* Thaddeus added: *Yes, they gave me medicine, but I don't understand the language of the doctors that gave that medicate me.* Prisca also described the importance of helping the doctor and nurses understand what she was feeling. In her words: *If the pain should come, to talk to tell the doctor, to tell the nurses. Because by talking and helping them understand what you are feeling, that's part of the way of making it better.*

Bad news was not always broken in a therapeutic manner. Susanna said: *You know the way they bring it, it could be a soothing way to me. But the way they brought it, it was a hurting way.* Junia added: *I don't want you to tell me what you think I need to hear, I want you to tell me reality.*

Category 2: the need for compassionate care and support

The participants shared the compassionate and empathetic care that they had received from some of the nursing staff and their families. John said: *they feel with me; they understand my confusion and my pain and try to help…them just coming and asking "how are you feeling", helps me coping with it …even though I know the medicine they are going to give me is not really going to relieve the pain.* Julia agreed: *that touch you get – that's the best.* Family support was particularly important and this was confirmed by Joanna: *Family it's playing an important role*. Johanna said: *When the family they come, now the people they talk, they started to laugh. They laughing even that one that sick also smiles. That smile counts, then to stay like that day and night 24/7. It counts.*

Participants experienced the distress of being away from home, being lonely and frightened and this influenced how they experienced pain. Salome said: *Sometimes just a soft hand, I am praying for you. That would do so much. Somebody that can take me in her arms and say I am praying for you…you people because you there and because are willing to listen, you teach me to just go on.* John added: *To interact with one another. It's very important you know. And if you have it, it helps a lot. There is some nurses we have some conversations with…if they come and ask you with compassion and understanding that cuts open, it's all ok, you can see from experience that they care more than just doing their job.* Julia concluded: *I said to one of the sisters yesterday, your presence makes me forget the pain.*

We chat with each other and it was so nice that moment. I said to her - perhaps that also counts.

Unfortunately not all interactions with nurses were experienced positively. Some nurses did not treat their patients with respect and dignity. John observed: *It's a job and you do it you know. And you want to get it finished because you want to go home. Or get to the next one* [patient]. Junia described her experience: *I will say to her, sister I've got pain, then they say wait a minute and we will attend you. That's how most sisters work: wait, we will attend you…then maybe after 15 to 20 minutes then they go and call the doctor. Cancer patients need to be loved. They don't need you to come and stress them, already they are stressed. The sisters will just shout at you without even thinking… I remember when there was this time where I even cried, then one of them came they said: you know what? You are such a spoiled brat…* Ammia added: *They just tell it's side effects and that they go away with time, there is nothing much I can do because I do have medication.* Mary concluded: *Yes, they know we are getting pain…by looking at you and all that, this lady is sore…but really they don't feel it properly.*

Participants described the care they received from a younger generation of healthcare practitioners. Junia said: *I am doubting their* [younger generation] *skills. I don't think they are trained enough to be dealing with cancer patients pains.* Perpetua added: *So I don't know you doctors you have done psychology and everything, I should think you would understand something like that, but that is how it felt.* Salome said: *Some of them, they don't feel your pain; they say: wait your turn. That's all.*

Having a strong support system guided the patients throughout the cancer journey. This team included family members, trusted friends within the community, colleagues at work and healthcare professionals. Joanna stated: *When the family is together and you share, like they talk to you, they show they love you. That counts a lot.* Susanna agreed: *A big support that I got, it was from my husband, because for all those days, he never missed hospital.* Perpetua described her experiences*: A good support system, it helps a lot.* Thaddeus agreed: *You must have a friend that will be able to understand you and walk with you.*

However, not all the participants had a good support system. Junia said: *If my journey that time had great doctors, the great support system, my journey would have been different because I would not have cried so much, I wouldn't have so many sleepless nights at home.*

The health care system did not meet the needs of the participants. The participants experienced the doctors to be very busy which made it difficult to speak to them. Some expressed their frustration in having to wait for results of scans and blood tests, experiencing delays in treatments. Having to wait in queues after arriving very early at the clinic in the

morning and having to wait for available beds to receive their treatment resulted in pain and frustration. Salome said: *They just said to me there is no space for you. They are not in pain, I am in pain. They don't experience it, I am experiencing it. They see so many sick people.* Junia added: *But they should also think about those patients who are sitting that side. They left their homes at four o'clock in the morning others leaving at three. They come here, the next thing they should wait four, five hours to get whatever that they came here for. You become dizzy, you vomit…*

In addition, seeing other sick patients while waiting for your turn to be seen by the doctor added to the participants' distress. Ammia remembered: *When she was done with chemotherapy, she had finished all her eight sessions. After she had suffered that much she couldn't make it…she was admitted the same day and then the next day she passed on…you know, it is so, sometimes I don't think it is fair. I don't think it is fair.*

Category 3: what nurses need to know about the pain experience

Not all the participants were sure what they would like nurses to know about their pain or how they should tell them. Many participants wanted the nurses to know that they experienced different types of pain and that these different pains could not be treated the same. Most participants experienced physical and emotional pain, however finding the correct words to describe their pain was challenging. Junia said: *The pain that we go through is different…like our bodies are different. And as much as we are different, we handle pain differently.* Andrew explained: *I am going to tell you today that pain sometimes it just keep quiet, it's not talking, I don't know why…that one is badder I think, that's my thought:* [it] *is next to the heart. So that's why I feel bad because when it started, even breathing…you feel that this one is killing me.* Salome added: *God, give me the right words to tell this person that's trying to take away my agony and my pain. Help me to explain it right, because I don't know how to explain it.* Mary explained: *I really don't know to tell you the truth. Because in my language they say "I can't feel the nerve that is in your shoe if I'm not wearing it". The one that's wearing it… if it's got a nail in it you're the one that's feeling it.*

Some of the participants found it difficult to talk about their pain, especially when very distressed. Magdalene said: *When they crying that shows that the pain is too heavy. It's unexplained because they cry, up until that person or patient calm down and explain…I'm feeling pain or maybe I've got a problem one, two, three. It can be at home it can be at work. Plus my sickness, my diseases with that pain or with the stress that you just get it at home or work or wherever.*

The roles of the healthcare practitioners were not always clear, and who would take action based on the information relayed. Peter said: *Sometimes I think the doctor they know better than the nurses, but even the nurses when they are here they learn about what this thing, they learn everything about the cancer. Sometimes the nurses have a knowledge more than the doctors but the doctors have the powers to the nurses.* James added: *So the sister's knowledge if he explains the pain as sharp and hot. The sister would take that information and decide what is best for him, because he is not an expert. The sister is an expert.*

Some participants were specific in what they wanted nurses to know about their pain. John said: *For me it's a constant pain that doesn't go away. It doesn't matter what you do it's all, awake with it, or asleep with it...it's not just a physical pain its mental pain also you know. It can bring you into a struggle.* He added that he wanted nurses to ask him: *How deep is your pain? Is it past the physical pain?* Joanna agreed: *what type of pain, where is the pain…what causes the pain….who is staying with you at home…..who is visiting you on the visiting hours?* Andrew added: *Maybe you can say what kind of pain are you feeling?* Perpetua suggested a more direct approach: *Ask the patient, are you in pain? Yes or no. That's going to be the answer. Do I want painkillers? No thank you. Don't force the patient with the pills because you are going to waste them. And don't force them to drink them in front of you. It's a pain killer – pain won't kill anybody, the disease will.*

The second theme presented the participants' experiences regarding information, compassionate care and support and what they would like nurses to know about their pain. The participants experienced unmet information needs and wanted information about their disease, stage and treatment and participants were specific on how this information should be communicated to them and how they should be treated. In addition, the need for compassionate care and strong support systems were important. Not all participants were clear on what they needed nurses to know about their pain or how they should describe their pain to the nurse, while others felt that nurses should ask questions that prompt information about physical and emotional pain that assessed the patient holistically.

5.4 SUMMARY

This chapter presented the findings of Part 2 of the study. Two themes arose from the data which included the patients' unique and multi-dimensional experience of cancer pain and the needs of the cancer patient.

In the next chapter the findings of Part 1 and Part 2 of the study will be discussed and the justifications, limitations and recommendations for the study will be presented.

CHAPTER 6

DISCUSSION, JUSTIFICATION, LIMITATIONS AND RECOMMENDATIONS

6.1 INTRODUCTION

In chapters 4 and 5 the findings of Part 1 and Part 2 of the study were presented respectively. In this final chapter the findings of both parts will be discussed and the justification, limitations and recommendations of the study will be given.

6.2 DISCUSSION

6.2.1 Part 1: Scoping review

The scoping review provided evidence that the work focusing on cancer pain originated primarily from the developed world and mostly from palliative care research centres. Unfortunately none of the articles in the review originated from Africa. Maree, Herbert & Huiskamp (2016) when reviewing South African cancer nursing research output between 2005 and 2014, found the same trend as none of the articles included in that review focused on pain. According to Beck & Falkson (2001) and Gwyther et al (2018), the management of pain in South Africa remains a challenge that could be aggravated by the lack of research.

With regard to the designs used in the studies, it is hardly surprising to note that the studies were primarily quantitative as pain assessment instruments were investigated. However what was of interest is that some of the studies provided a language restriction as an inclusion criteria. In a multi-lingual country such as South Africa with its 11 official languages (Miaschi 2018) this language restriction would exclude a large part of the South African population from participation in studies.

Just under half of the studies included data collected from questionnaires completed by both patients and healthcare professionals, however just under half of these articles identified a disparity between clinician and patient assessment of pain and the need to bridge this gap was highlighted. Fallon et al (2018) identified the importance of patient involvement or self-assessment in order to better understand their unique perspective of the pain experience, however it could be argued that the incongruence between patient and healthcare practitioner assessment is due to a lack of understanding of the complexity of cancer pain.

An area of focus in many of the articles was the contribution of healthcare practitioners to pain management. Evidence suggests that ongoing educational effort to improve all levels of the health professional's knowledge, including open debate regarding attitudes towards pain and treatment should be encouraged throughout professional practice. One study (Webber, Davie and Cowie 2016) suggested that through improved communication and trust, differences in opinion could easily be overcome. In another study (Webber et al 2014), the need for certain clinical skills in the assessment of pain was identified. A multi-disciplinary approach to assessing, measuring and treating cancer pain was recommended (Glare et al 2014) however inadequate knowledge and attitudes towards pain may hamper optimal care given by many health professionals (Maree 2010; Eaton et al 2015; Beck et al 2016).

Another area of focus in the identified studies was the suitability and usability of the pain assessment instrument under review. The results of the study indicate that an appropriate pain assessment instrument should be selected. Certain factors should be taken into account when selecting an appropriate pain assessment instrument, including the patient's age, level of education and cognitive ability. This is particularly noteworthy in a country such as South Africa where levels of education and literacy are disproportionately distributed across the country (Statistics South Africa 2017). In addition, the instrument should be simple and efficient to administer and able to capture a complete description of the cancer pain, at all stages across the cancer care continuum (Gauthier et al 2014). Effective management of cancer pain is dependent on pain assessment and re-assessment, measurement of pain intensity and treatment of pain (Salmany et al 2012; Gauthier et al 2014; Burton, Chai & Smith 2014). Without systematic assessment of pain using appropriate assessment instruments, pain is often under-reported and inadequately managed (Patrick et al 2015).

A few articles focussed on the features of cancer pain. More than half of patients diagnosed with cancer experience pain (Zeppetella & Ribeiro 2002; Paice 2018) and therefore the need to better understand the complexity of cancer pain was identified. Sperlinga et al (2015) reported that the Alberta Breakthrough Pain Assessment Tool (ABPAT) effectively assessed breakthrough pain, however another study suggested that more work is needed in defining variables associated with breakthrough pain (Hjermstad et al 2016). Standardised metrics could improve the consistency and validity of neuropathic pain assessment (Brunelli et al 2014) and several studies identified the need for a pain classification system that included assessment of neuropathic and breakthrough pain but also identified psychological distress and sleep disturbances as influencing the patient's perception of pain (Knudsen et al 2012; Brunelli et al 2014; Raj et al 2014).

The identified assessment instruments were presented under three categories: uni-dimensional, multi-dimensional and analgesia scales. The most frequently referred to scales were the Numeric Rating Scale (NRS), followed by the Brief Pain Inventory (BPI), Alberta Breakthrough Pain Assessment Tool (ABPAT) and then the Edmonton Classification System for Cancer Pain (ECS-CP) and Edmonton Symptom Assessment System (ESAS).

In order to explore the characteristics of the identified cancer pain instruments, they were compared on their usability, appropriateness for use in specific types of cancer pain and against an ideal instrument.

The uni-dimensional instruments are simple to administer with only one question being asked however there is no clear instruction on how to interpret and apply the finding. Hui & Bruera in Wickham (2017) suggest that patients should be asked what an acceptable level of pain and relief would be for that patient and then on reassessment, adjust analgesia doses accordingly. As seemingly simple as the uni-dimensional instruments are, the FPS with its characterisation of a face depicting an increasing level of distress can be used in patients with mild to moderate cognitive function, however the limited descriptive choices available in the VDS may not apply to all patients. Additionally both instruments could be confusing as measurements between scales are not uniformly incremental. Patients may also have difficulty in understanding the VAS as they are asked to choose a number that relates to their level of pain. The association between these two concepts may not be clear especially to patients with impaired cognition (Burton, Chai & Smith 2014). The popularity of the NRS is evident in the frequency of its inclusion in many of the multi-dimensional assessment instruments (Chang et al 2017) and the apparent ease of administration which can be useful for patients with lower literacy (McDonald et al 2016). While the uni-dimensional assessment instruments measure the intensity of pain, providing a guide to the urgency of the pain experience and response to treatment (Burton, Chai and Smith 2014), they do not provide a clear understanding of that patient's personal pain experience, other than to provide a comparison to the previous measurement of pain intensity. The patient may experience more than one pain in different parts of the body at a time and these pains may differ in onset, duration and type. Although the uni-dimensional assessment instruments could be repeatedly used to measure the intensity of each individual pain, the description of each type of pain would be excluded in the assessment (Bendinger & Plunkett 2016) and therefore the uni-dimensional scales are not appropriate for assessing specific types of cancer pain and fall short of the criteria of an ideal assessment instrument.

The multi-dimensional scales outweigh the uni-dimensional scales as they have a more comprehensive approach to assessing pain including pain intensity, pain type and aggravating or relieving factors and assess the patient's experience of pain over time. The multi-dimensional assessment instruments are made up of several questions and therefore take longer than the uni-dimensional instruments to complete. A lengthy questionnaire may be tiring for the elderly, cognitively impaired or for patients who are in pain to complete, hence a shorter version of the original instrument was designed in two identified instruments for use in the clinical setting (Herr & Garand 2001). Both of these shorter versions provide pre-determined options for the patient to select from when describing their pain. This limitation of choice to describe a patient's unique experience of pain may not provide an accurate or adequate assessment and may not take into account differences in culture, age and gender. It has been mentioned that cancer pain is complex, associated with both physical and psychosocial symptoms (Hui & Bruera 2013; Hudson & Falk 2018) which may be influenced by the patient's comorbid conditions, past experiences, and even race, age and gender as well as expectation, knowledge and state of mind (Davidhizar & Giger 2004; Bedi et al 2009; Glare et al 2014). Of the twelve multi-dimensional pain assessment instruments identified in the articles, only two assessment instruments ask the patient to describe their pain in terms of quality, type, onset or response to treatment, using their own words. The remaining instruments provide pre-determined answers for the patient to select from to describe their physical pain, or do not ask about the patient's description of pain at all. It is also interesting to note that only four assessment instruments pose a question relating to the presence of psychological distress and question symptom severity, however all four assessment instruments limited responses by providing model answer options to select from. According to Li et al (2017) anxiety and depression are common in patients experiencing cancer pain and these psychological symptoms can complicate the management of pain. The multi-dimensional scales can be used to assess specific and general types of cancer pain however the researcher did not find evidence of an assessment instrument that comprehensively assessed total pain.

Half of the multi-dimensional scales enquired about the use of analgesia, and yet Chung et al (2014) state that there are multiple factors that contribute towards the experience of pain including psychological states, social issues and analgesia use. It is noteworthy that only six cancer pain assessment instruments included a question on the patient's satisfaction with current analgesia. The guidelines for selecting the ideal pain assessment instrument did not include this critical consideration. In terms of comparing the multi-dimensional scales it was only the ABPAT, BAT and BPI that met the criteria of an ideal instrument, as specified by The Africa Palliative Care Association and Farrer.

Clearly the analgesia scales that only measure adherence to analgesia guidelines and are administered by a healthcare professional would not fit the profile of an ideal pain assessment instrument. The assessment of the appropriate use of analgesia is a newer dimension that should be included with pain assessment, pain measurement and pain treatment in the overall management of cancer pain (Salmany et al 2012). However the analgesia scales do provide an interesting insight into the use of these pain medications.

Only one instrument in the selected articles included a question relating to addictive behaviour. Opioid medication is commonly prescribed in cancer patients with moderate to severe chronic pain (Portenoy, Mehta & Ahmed 2017; Nelson 2018), however over-treatment or excessive use of these medications especially when used to inappropriately treat co-morbid anxiety or depression can be more harmful than beneficial to the patient (Bruera & Paice 2015). The prevalence of addiction in cancer patients is unknown, however it is noted that some of the risk factors for addiction or substance use disorder such as excessive tobacco and alcohol use are also risk factors for certain cancers (Paice 2018). In her article on opioid analgesics, Wickham (2017) emphasised the importance of understanding the mechanisms of opioid medication and the need for clinicians to anticipate and appropriately manage potential side effects, toxicities and possible abuse. She recommended the routine inclusion of assessment for addictive behaviour, although this was not included as a recommendation in the ideal pain assessment instrument.

None of the assessment instruments reviewed included an assessment of non-pharmacological support to treat pain, although this was also not considered as a criterion in the ideal pain assessment instrument criteria.

6.2.2 Part 2: Describing cancer pain

Of the twenty South Africans who participated in the study, it is interesting to note that nine female participants had been diagnosed with breast cancer. This statistic is in keeping with the high prevalence of breast cancer in this country.

The study provided evidence that the participants experienced pain as unique, multi-dimensional and very complicated. Participants in the study described how their pain changes from day to day and that they can experience different types of pain at varying intensities, in different parts of the body. Participants experienced both physical and emotional components of pain. Physical pain was often the presenting symptom at diagnosis and experienced where the cancer was found. It was interesting to note that the participants

associated pain with their cancer and therefore each new pain brought about the fear that the cancer was spreading.

Physical pain was also experienced as a consequence of cancer investigations and treatments. Whereas bone marrow biopsies and urinary catheters were described as being painful, many participants experienced chemotherapy as being the most painful medical intervention. The side effects of this treatment were also experienced as painful.

However the emotional pain experienced by the participants far outweighed the physical pain experience as patients described their fear of death and loss. It appears that the experience of pain and the patient's ability to cope with that pain is also influenced by the patient's state of mind (Brant 2017) which could be exacerbated by states of loneliness, fear and vulnerability. These painful descriptions cannot be discounted if we consider the concept of total cancer pain encompassing physical, psychological, social, spiritual and cultural domains (Brant 2017).

Participants described the factors that brought about pain relief. The participants gave confusing accounts of the analgesia medication that they had received, sometimes only receiving a few tablets at a time to last for the month while others appeared to hoard their medication. The pharmacological treatment recommendations for cancer pain management are well described in the literature (Ripamonti et al 2012; Mercadante et al 2015; Fallon et al 2018) with several references to the World Health Organization's stepladder approach to pain treatment described in 1986, remaining the gold standard for comparison. While it cannot be said with certainty that the WHO guidelines were followed, it is evident that there are compliancy and adherence issues and that participants did not receive adequate information about their analgesia or their pain control options.

In addition to analgesia, the participants experienced sleep and water as being beneficial for pain relief, as well as interacting with others and keeping faith and hope alive. According to Menefee Pujol & Monti (2007) additional treatments such as focussed relaxation, meditation and music therapy could also be considered. Aaronson et al (2014) suggest that cancer survivors should be encouraged to participate in the planning of their own non-pharmacological pain management strategy, with a focus on improving sleep, social integration and functional capability. This could be achieved through the implementation of individualized educational programmes, with an aim of bringing about pain relief, improving overall well-being and empowering the patient to make informed choices (Yamanaka 2018). Participants observed that emotional pain could be treated with therapy. The significance and impact of physical, psychosocial, spiritual and financial pain of cancer should be included topics when preparing and supporting our patients and their families.

According to Menefee Pujol & Monti (2007), a multi-disciplinary approach which includes the patient's inputs should be considered in order to optimise pain relief through pharmacological as well as non-pharmacological strategies. The researcher is of the opinion that in a culturally diverse country such as South Africa, alternative therapies including inputs from traditional healthcare workers would also be beneficial in the provision of holistic care.

The need for quality information and improved communication was also identified by the participants of the study with several participants emphasising their need for additional information about their disease and its treatment. According to Davidhizar & Giger (2004) and Miyashita (2018), information about the disease of cancer, the various treatment options and anticipated side-effects of these treatments should not only be discussed at a level that the patient can understand, but also discussed in the language of their choice so that subtle variations in translation or interpretation can be avoided. Participants in the study suggested that this information should be given in a therapeutic manner that is not hurried, giving time to explore options and to ensure that concepts are understood. Time appears to be a commodity that is in short supply in this research setting. Participants observed that nursing and medical practitioners did not have the time to answer questions or explain things in an acceptable manner. Although this may be as a result of the large volume of patients seen in that oncology facility it is a concern that participants queried whether the younger generation of healthcare practitioners were properly trained in counselling and assisting patients with cancer.

According to Miyashita (2018), nurses have a profound impact on patient education in cancer pain management. With effective health information, patients would anticipate the possible complexity of cancer pain and understand the importance of communicating both physical and psychological aspects of this pain to the healthcare team so that realistic expectations can be nurtured. It could be argued that this discussion should commence during consent-to-treatment processes undertaken by the doctor but supported by other members of the healthcare team including nurses throughout the cancer care continuum.

Most of the participants experienced a need for compassionate care. Trzeciak & Massarelli (2019) describe compassion as being an emotional response when seeing pain and suffering in others and a genuine desire to assist. Compassionate care appears to have a positive impact on how patients experience their pain. Participants who had received a gentle word or a soft touch were still in pain but appeared to endure their pain better than the participants who had been spoken to harshly or felt that they were not cared for or respected.

Participants that had good support structures and were able to discuss their experiences of both physical and emotional pain with trusted family, friends or healthcare practitioners also appeared to manage their cancer journey more readily. Ongoing education and counselling at all levels and at all stages of the disease are needed for patients and their family members. In order to do this effectively, it appears that healthcare practitioners also need training in cancer pain management, how to use opportunities to educate patients and how to deliver bad news in a simple and more compassionate way. According to Maree (2010), nurses who spend the most time with cancer patients, should study cancer pain and its management to better fulfil their role in patient care.

Participants were divided as to what they wanted nurses to know about their pain. Many participants wanted nurses to understand the complexity of cancer pain and that the experience of cancer pain can vary each day. Participants felt that nurses should assess pain holistically, asking questions that prompt additional information. According to Pathak, Sharma & Jensen (2018), the level of education, including cognitive and functional ability of patients, age and culture were also observed as being limiting factors when assessing pain. Assessment of the cancer patient's pain should therefore also include an assessment of their knowledge of cancer pain and available options to self-manage it (Webber, Davies & Cowie 2016), thereby providing an excellent communication opportunity between clinician and patient and a focus on continued educational support.

Participants in the study mentioned the importance of nursing being more than just a job and that they could tell which nurses had empathy from the way they were spoken to. The participants wanted to feel that they are cared for and that their viewpoint is valued. The need for accurate information that is given at a level and in a manner that is understandable, was emphasised. It was interesting to note that some participants said that even if their cancer and pain could not be successfully treated, it was helpful just to have somebody that was willing to listen to their story. A professional relationship based on care and mutual trust brings about a better understanding of the pain experience (Brant 2018). It is the researcher's opinion that nurses, especially those practicing in busy healthcare settings may appear to be devoid of feeling but this may be a consequence of being faced with overwhelming pain, grief and despair on a daily basis and having to cope with increasing patient numbers. Educational gaps and other barriers to pain management also have an impact on effective pain management (Wickham 2017). It would be interesting to study what coping skills, effective communication and pain management strategies are taught to nursing staff working in these highly-emotive and specialized cancer care settings.

From the findings in this study it is clear that cancer pain is complex and the successful management of cancer pain remains a challenge. Of the nineteen assessment instruments identified, it is suggested that not one met the criteria of an ideal pain assessment instrument, as even the ideal criteria as provided by the African Palliative Care Association (2010) and Farrer (2007), appeared to be incomplete and should be updated. The study provided evidence of the participants experience of cancer pain and what brings relief from the pain. They described their need for information and communication as well as support and compassionate care. Finally participants described what nurses need to know about their cancer pain experience.

6.3 JUSTIFICATION FOR THE STUDY

The purpose of the study was to provide baseline data that could be used to develop a patient informed pain assessment instrument used by nurses practicing in cancer care settings for South African cancer patients.

The first objective of the study was to explore which pain assessment instruments are available to assess cancer pain and to explore the characteristics of these instruments, comparing them against the criteria of an ideal instrument. This was done in Part 1 of the study. The second objective was to describe how cancer patients experience and describe their pain and what they consider essential for nurses to know about their pain. This was done in Part 2 of the study.

The objectives of the study were therefore achieved.

6.4 LIMITATIONS OF THE STUDY

This study consisted of two parts. The scoping review had several inclusion criteria, including a language restriction, articles published within a specific time period, full article availability on the university library system and peer reviewed literature that may have caused certain cancer pain assessment instruments to be excluded from the study. In addition, the qualitative part was based on in-depth interviews with cancer patients receiving treatment at a busy tertiary hospital with limited resources. It should also be noted that the experiences of the patients as described in the qualitative study could be interpreted in more than one way. The researcher was aware of potential bias and was careful to present data in

an authentic manner, however the fact that the participants were aware that the researcher was an experienced oncology nurse may have influenced some of their requests for additional information about their disease and its treatment.

6.5 RECOMMENDATIONS

A patient informed cancer pain assessment instrument should be developed that includes aspects of uni-dimensional, multi-dimensional and analgesia scales in one assessment instrument. Pain intensity must be measured, but total pain should be assessed, including physical, emotional and psycho-social factors contributing to pain. The instrument should be tested in a pilot study.

In addition the researcher recommends additional continuous professional development for cancer care providers on how to manage total cancer pain through appropriate measurement, assessment and reassessment and treatment of pain which includes both pharmacological and non-pharmacological interventions and how to communicate effectively with these vulnerable patients at all stages within the cancer care continuum. The importance of compassionate care and support should be emphasised.

Additional research on cancer pain is needed, especially in diverse countries such as South Africa, to better understand the complexity and influence of culture, language and education on the pain experience and also on the management of that pain. Cancer pain assessment instruments need to be developed that accommodate a diverse range of responses and additional studies should be undertaken to validate these instruments in South Africa and other developing countries.

6.6 CONCLUSION

Cancer pain is complex, with physical, emotional and psychosocial factors having a profound influence on the unique and personal experience of cancer pain. The successful management of cancer pain is dependent on thorough assessment, re-assessment, measurement of pain intensity, interpretation of findings and appropriate treatment of the pain including both pharmacological and non-pharmacological options.

The lack of a cancer pain assessment instrument to guide pain management was identified as a problem at an academic hospital in Gauteng. In order to address this problem, the researcher conducted a scoping review in Part 1 of the study in order to explore what pain

assessment instruments are available. Nineteen cancer pain assessment instruments were identified and the characteristics of these instruments were summarised and compared against the criteria of an ideal pain assessment instrument. However none of the instruments fully met the criteria of the ideal and even the ideal criteria appeared to be incomplete and need updating.

In order to understand how cancer patients experience and describe their pain and what they consider essential for nurses to know about their pain, qualitative descriptive design was used in Part 2 of the study. In-depth interviews were conducted with twenty adult patients receiving treatment at a medical oncology ward, with two themes emerging from the data. Pain as unique and multi-dimensional was identified in the first theme, experienced physically as a consequence of the disease and its treatments, but also from the psychosocial impact of having a dread disease. Participants described the factors that brought pain relief. In the second theme, the participants described their need for information and communication, compassionate care and support and included what they felt was essential for nurses to know about their pain.

6.7 PERSONAL REFLECTIONS

I have learned so much during the course of this study. After twenty years of working with cancer patients, I was horrified to realise how little I knew about cancer pain and its impact on every sphere of the patient's life. I am particularly grateful to the participants who shared their intimate stories of pain with me and allowed me to witness their most vulnerable moments. Their insights were invaluable to me and I will carry their stories close to my heart and throughout the rest of my professional career. I will continue to teach and learn, ensuring that their suffering was not in vain. My patients have often been my best teachers.

In addition to learning more about the study topic, I also learned of the importance of looking at problems from varying angles. When one approach is unsuccessful, try another. I have learned humility – that my opinion is not the only opinion. I have learned patience, perseverance and a determination to constantly challenge my pre-conceived ideas. I thank my supervisor for that.

Finally, I can confirm the validity of my personal mantra: *Everybody has something to learn and everybody has something to teach.*

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ADDENDUM 1: INTERVIEW GUIDE

INTERVIEW GUIDE

Demographical data:

Age:

Gender:

Diagnosis

Date of first diagnosis

Treatment received: SURGICAL / RADIATION / CHEMOTHERAPY

Additional information (from participant)

Home language

Interview questions:

1. Please tell me what is it is like for you to live with pain?
2. Please tell me how the pain feels?
3. What would you like nurses to know about your pain?

ADDENDUM 2: CHARACTERISTICS OF THE ARTICLES

Characteristics of the Articles															
No	Country of origin	Year	Name of article	Author	Aims and objectives	Design	Population	Setting	Sampling method	Sample size	Data collection method	Data collection instrument	Key findings	Recommendations	Comments

ADDENSUM 3: CANCER PAIN ASSESSMENT INSTRUMENTS

Cancer pain assessment instruments														
No.	**Name of instrument**	**Abbrev.**	**Ref. article**	**Method of administration**	**No. of ques.**	**Body chart**	**Method of rating severity**	**Type of pain**	**Aggravating/ relieving factors**	**Patient's description of pain**	**Interpretation of findings**	**Current analgesia**	**Satisfaction with current analgesia**	**Comments**

ADDENDUM 4: GUIDELINES FOR SELECTING A MEASUREMENT TOOL

GUIDELINES FOR SELECTING A MEASUREMENT TOOL

(Africa Palliative Care Association)

1. Must be age appropriate. Must have tested psychometric properties: validity and reliability

2. Must be able to measure different pain levels

3. Must be able to measure the right “type” of pain (e.g. chronic, acute, procedural)

4. Must have the correct format and length – many measurement tools are complicated and time consuming and not recommended in all situations

5. Must be able to produce an easily understandable score

6. Must have clear instruction on application and interpretation

7. Note: many pain measurement tools are available but few are tested and validated for use in Africa. There are no tools designed specifically for use in end-of-life pain measurement

ADDENDUM 5: PATIENT INFORMATION DOCUMENT

INFORMATION DOCUMENT - Patient

Study Title:
AN INVESTIGATION INTO PAIN IN CANCER PATIENTS

Good day!

My name is Rowan Robinson and I am currently registered as a student at the University of the Witwatersrand in the Department of Nursing. I am wanting to learn more about how patients with cancer experience their pain. If nurses have a better understanding about pain, they may be able to understand how to care for patients in a better way. The title of my research study is “An investigation into pain in cancer patients”.

I am inviting you to take part in this study. You will decide whether you want to participate or not. I am asking cancer patients from the oncology wards and the oncology clinics if they would like to take part in this study.

If you agree to talk about your pain to me, I will interview you for about 60 minutes in a private and quiet place in the hospital, so that we are not interrupted and so that you feel safe. If you feel that you want to stop the conversation at any stage and for any reason, or if you should become uncomfortable, I will stop and we can reschedule the talk if you choose to do so. Should you feel emotionally distressed during or after the interview, Ms. Huiskamp, an experienced Mental Health nurse has agreed to counsel you if you feel that this becomes necessary. You may change your mind and decide not to talk to me anymore and you may withdraw from the study at any stage. This will <u>not</u> affect how nurses care for you in the future in any way and you will not lose any benefits to which you are entitled.

I would like to ask your permission to audio-tape the interview, so that I can play back the conversation to myself, making sure that I have understood and heard every word said. If you agree to this tape recording, I will ask you to sign a separate consent form giving me permission to do this. After I have finished the interviews I will type out the words of the conversations. I will remove all names so that nobody can be identified. You would not be able to withdraw from the study at this point because I would not be able to identify your specific conversation.

Once the interviews have been typed out, they will be transferred to a flash drive and deleted from the computer. All data sheets and the flash disk will be sealed in an envelope and placed in a safe in the Department of Nursing Education for a period of three years after the report has been published where after it will be destroyed.

I will do my best to keep all personal information confidential, although I cannot guarantee this. If the law insists, I may have to make personal information known. The Research Ethics Committee may check on the quality of my work and make sure that I have represented information accurately.

Please note that you will not receive any money or goods should you decide to take part in this study. The only benefit may be that the findings from this study may help nurses to better understand the pain experienced by their patients.

If you need extra information about this study please contact me ROWAN ROBINSON. My cell phone number is 082 579 3551.

If you would like more information about the ethical permission of the study or would like to report or complain about how the study was done, please contact Prof Peter Cleaton-Jones. His telephone number is 011 717 2301 during office hours and his e-mail address in Peter.Cleaton-Jones@wits.ac.za

Kind regards and best wishes

Rowan Robinson
1599654@students.wits.ac.za

ADDENDUM 6: PATIENT CONSENT FORM TO PARTICIPATE IN STUDY

CONSENT FORM - Patient

I have been given the information sheet on the research study Title: “AN INVESTIGATION INTO PAIN IN CANCER PATIENTS”

I have read and understood the information sheet. If I agree to participate in the study, I will be interviewed for approximately 60 minutes about my experiences of pain as a patient with cancer.

I understand that it is up to me whether or not I would like to participate in the interview and that there will be no penalty or loss of benefits that I am entitled to if I decide not to participate. I also understand that I may stop participating at any time until the interview has been typed, without any penalty or loss of benefits to which I am otherwise entitled.

I understand that the researcher involved in this study will make every effort to ensure confidentiality and my name will not be used in the study reports. No identifying information will be included when the interview is typed. I have been given the contact details that I may call if I have any questions or concerns about the research.

This study has been explained to me. I have read and understand this consent form. I agree voluntarily to participate in the interview for this study.

_____	_____
Signature of participant	Date
_____	_____
Signature of witness	Date
_____	_____
Signature of investigator	Date

ADDENDUM 7: CONSENT BY PATIENT TO AUDIOTAPE INTERVIEW

CONSENT FORM FOR RECORDING SEMI-STRUCTURED INTERVIEW

I have been given the information document on the research title: "AN INVESTIGATION INTO PAIN IN CANCER PATIENTS". I have read and understood the information document.

I understand that I can decide whether or not the interview should be recorded and that there will be no penalty or loss of benefits that I am entitled if I decide that the interview may not be recorded. I also understand that I may discontinue participation at any time without any penalty loss of benefits to which I am otherwise entitled.

I understand that information from the recording will be typed and that these transcripts will be given a code and my name will not be mentioned. I understand that I can ask the person interviewing me to stop recording, and to stop the interview altogether, at any time.

I consent voluntarily for the researcher to record the interview.

_____ _____

Signature of participant Date

_____ _____

Signature of witness Date

_____ _____

Signature of investigator Date

ADDENDUM 8: HUMAN RESEARCH ETHICS APPROVAL

R14/49 Mrs Rowan Robinson

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M170495

NAME: (Principal Investigator)	Mrs Rowan Robinson
DEPARTMENT:	Nursing Education Charlotte Maxeke Johannesburg Academic Hospital
PROJECT TITLE:	An Investigation towards the Development of a Patient Informed Pain Assessment Instrument for Cancer Nursing
DATE CONSIDERED:	05/05/2017
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof Lize Maree
APPROVED BY:	Professor P. Cleaton-Jones Chairperson, HREC (Medical)
DATE OF APPROVAL:	23/08/2017

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 10004,10th floor, Senate House/3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. in this case, the study was initially review April and will therefore be due in the month of April each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

ADDENDUM 9: LETTER OF PERMISSION GAUTENG DEPARTMENT OF HEALTH

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:
Ms. G. Ngwenya
Office of the Nursing Director
Tell: (011): 488-4558
Fax: (011): 488-3786
16 January 2020

Mrs. Rowan Robinson
Department of Nursing Education
University of Witwatersrand
Faculty of Health Science
NHRD REF: GP_2017RP38_325

Dear. Rowan Robison

RE: **"An investigation towards the development of a patient informed pain assessment instrument Cancer nursing "**

Permission is granted for you to conduct the above recruitment activities as described in your request provided:

1. Charlotte Maxeke Johannesburg Academic hospital will not in anyway incur or inherit costs as a result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.

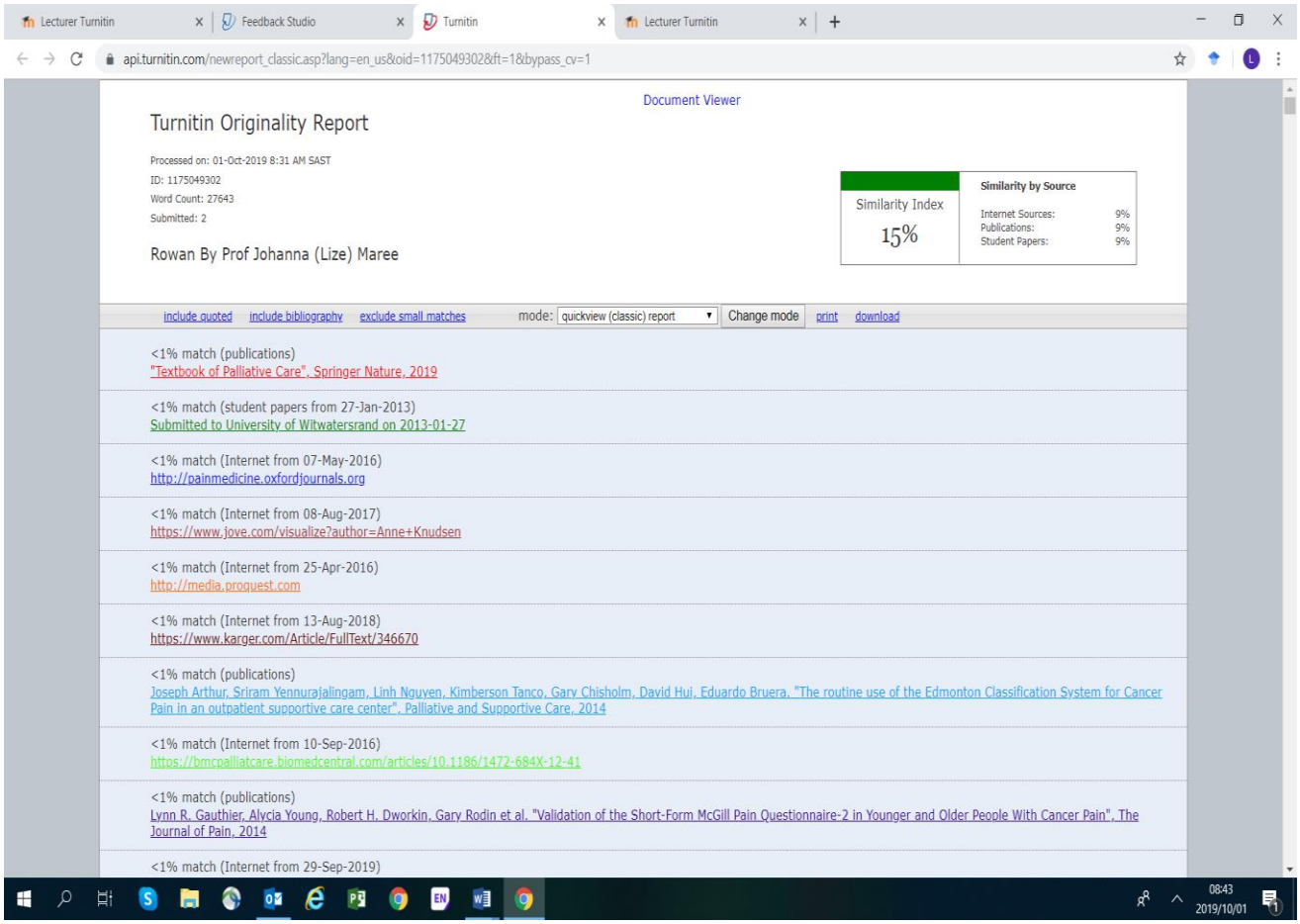
Please liaise with the Head of Department and Unit Manager or Sister in Charge to agree on the dates and time that would suit all parties.

Kindly forward this office with the results of your study on completion of the research.

Supported / not supported
Ms. M.M Pule
Nursing Director
Date: 17/01/2020

Approved / not approved
Ms. G. Bogoshi
Chief Executive Officer
17.01.2020

ADDENDUM 10: TURNITIN REPORT



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Rowan By Prof Johanna (Lize) Maree

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