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Unrelieved cancer pain in Palliative care

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Abstract

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Previous research studies and statistics have shown that despite widespread use of pain alleviation strategies and recommendations, pain is under treated in as many as 50% of patients receiving treatment for the disease report unrelieved pain (Ashley, 2008).

The purpose of this study was to determine the factors contributing to unrelieved cancer pain in palliative care and to establish what can be done by nurses to improve the current pain management situation.

A systematic literature review was carried out through NELLI electronic library. Four electronic databases were used; PUBMED, CINAHL, Taylor & Francis, and SAGE. Following predetermined criteria of English language, full text articles, and articles published from 2005 to 2014; a total of 10 articles were finally identified and analysed for the study.

The findings revealed three main descriptive categories including professional barriers, system barriers and patient barriers. The professional barriers entailed medical staff training and medical personnel attitudes. The system barriers entailed the health care system, laws and regulations as well as government economy whereas as the patient barriers included patient attitudes and the complex psychological milieu of cancer.

Deductions from the findings were made of the nurses’ contribution and role in improving the situation and reducing the occurrences of unrelieved pain among cancer patients in palliative care.

The ethical issues were considered at all times throughout the research process. An observation was made of insufficient knowledge and research on unrelieved cancer pain. Extensive research was recommended in light of this observation.

Key words: unrelieved pain, cancer, palliative care

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1 Introduction

The prevalence and management of pain in cancer patients has been widely studied and documented owing to the high and increasing number of people who suffer from different forms of cancer. According to the World Health Organization cancer statistics of 2012 an estimated 14.1 million people worldwide were diagnosed with cancer annually. There were 32.6 million people living with cancer within 5 years of diagnosis in 2012 (International agency for research on cancer 2012).

Pain has been defined by the International Association for the Study of Pain (IASP) as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in such terms of damage” (American Pain Society 2008).
Studies have shown that Pain, which can be caused by the disease itself or by treatments, is common in people with cancer, approximately 70% to 90% of people with advanced cancer experience pain (Lesage and Portenoy 1999).

Bhavani (2006) mentions that “the prevailing view is that management of both cancer and acute pain is not quite very controversial because a clear relationship between the disease and the patient’s pain can be identified” (Bhavani 2006). And yet evidence demonstrates that pain is undertreated in the palliative care settings, contributing significantly to patient discomfort and suffering at the end of life. “Studies suggest that as many as 30% of newly diagnosed cancer patients, 40% of those undergoing treatment, and 75% of those in the terminal phase of disease have unrelieved pain despite widespread use of pain alleviation strategies and recommendations. One study reported that more than 50% of cancer patients have increased suffering requiring sedation in the last days of life”(Ferrell & Coyle 2006)

“Unrelieved pain impairs health and quality of life of the sufferer and deprives patients and their families’ interaction with possibility of growth and reconciliation before death. It therefore diminishes society’s wellbeing” (Hospice and Palliative Nurses Association 2012).

“The great difficulty of understanding the nature of chronic pain is that chronic pain sufferers often lack objective physical evidence that proves the existence of their pain. There is no “pain-o-meter. “Pain is an entirely subjective experience; pain is simply whatever the patient says it is. Because pain assessment is entirely subjective, it is not as easily quantified as pulse, blood pressure, temperature and respirations, although pain evaluation is now dubbed the “fifth vital sign” (Bhavani 2006).

Dalal& Bruera (2009) state that “chronic pain in cancer patients is a multifaceted complex syndrome involving biological, psychological and social contributors and consequences various factors influence the production, perception and expression of pain including tumours, treatment and individual characteristics e.g. genetic, emotional/cognitive status, sociodemographics and history of addition as well as the type of cancer, the stage of the disease, and the patient's tolerance.” These aspects must be considered in caring for patients with cancer in palliative care if the quality of life is to be improved.

“The most common cancer pain is from tumours that metastasize to the bone. As many as 60 to 80% of cancer patients with bone metastasis experience pain. The second most common cancer pain is caused by tumours infiltrating the nerve and hollow viscous. Tumours near neural structures may cause the most severe pain. The third most common pain associated with cancer occurs as a result of chemotherapy, radiation, or surgery” (Swierzewski, 2015).

Since pain is very frequently emphasized among medical professionals, health care researchers and patients, its management is very vital particularly with metastasized cancer. It is in line with this that the WHO developed the three- step pain ladder where the first step is the use of non-opioids, the second being opioids for mild to moderate pain and finally opioids for moderate to severe pain. The WHO guidelines have been used as a basis for the formulation and constant update of European pain management guidelines first in 2003 then 2007, the current edition with partial updates is that of 2013 which is has an expanded section 3.5 dedicated to palliative care (European Association of Urology, 2013).

The American pain society (2008) however points out that not all people with cancer do experience pain in spite of the attention to drawn to pain.

The purpose of this study is to determine the factors contributing to unrelieved pain among cancer patients in palliative care using a systematic literature review.
This is with the aim of finding ways in which nurses can contribute to improving the current pain management situation.
The guiding research question to this purpose is as follows:
What can be done by nurses to improve the current pain management situation?

2 Definition of key concepts

2.1 Unrelievedpain

Coyle and Layman-Goldstein, (2001) define unrelieved pain as “ a persistent unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in such terms of damage and that this kind of pain normally eludes standard medication and is continuous, leaving the patients in a state of constant discomfort.”

The European pain federation (2012) refers to unrelieved pain as that pain which is chronic or recurrent. It is a major healthcare problem and a disease in its own right even though it is considered a symptom of disease.

According to Coyle and Layman-Goldstein (2001), unrelieved pain exhibits the following characteristics

- persists more than 3 months
- adaptation of autonomic system occurs
- objective signs of pain are not exhibited
- contributes to fatigue, depression, insomnia, general despair, withdrawal and desire for death if poorly managed
- is frequently unrecognized, untreated or under-treated

2.2 Cancer

“It is a class of diseases characterized by out-of-control cell growth. There are over 100 different types of cancer, and each is classified by the type of cell that is initially affected” (Crosta, 2015).

“Cancer harms the body when damaged cells divide uncontrollably to form lumps or masses of tissue called tumours except in the case of leukaemia where cancer prohibits normal blood function by abnormal cell division in the blood stream. Dangerous, or malignant, tumours can grow and interfere with the digestive, nervous, and circulatory systems, and they can release hormones that alter body function.”

“When a tumour successfully spreads to other parts of the body and grows, invading and destroying other healthy tissues, it is said to have metastasized. This process itself is called metastasis, and the result is a serious condition that is very difficult to treat” (Crosta, 2015).

2.3 Palliative care

Palliative care is “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”(WHO, 2002).
World Health Organisation provides the following as the provisions for palliative care

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (WHO 2002).

In Finland, Palliative care is a” continual form of treatment, conducted in a way that is sensitive to the dignity of a patient and significant to the quality of life of patients and their close-ones. The aim is to make death as free of symptoms and free of apprehension as possible, and to ensure that relatives and friends are in a position to cope with the patient’s death” (Cancer society of Finland, 2009).

3 Purpose statement and research questions

The purpose of this study is to determine the factors contributing to unrelieved pain among cancer patients in palliative care.
This is with the aim of finding ways in which nurses can contribute to improving the current pain management situation?

Research question

What factors are contributing to unrelieved pain among cancer patients in palliative care?

4 Methodology

4.1 Literature review

A systematic literature review was used during data collection in this research. This was in a bid to summarize previous studies on unrelieved pain among cancer patients in palliative care in order to answer the research questions. A qualitative approach was used. The methodology implementation included a number of steps in order to convert the research questions into a research, and identify current knowledge with regard to relevant concepts and contexts. These included reference to keywords, literature search from predefined databases, limiting the search by setting a criteria, literature filter by criteria.

A systematic review was used as it seeks to bring together relevant literature in detail for review in order to gain the information and knowledge about a specific topic (Aveyard 2010). Literature reviews have also been traditionally used in health care literature, used widely to sum up previously researched literature focusing on a particular research question. They offer a reliable, transparent, clear and reproducible way of organizing, evaluating, analysing and interpreting existing evidence (Hemingway & Brereton, 2009). Thereby adding value by offering comprehensive search for information.

A systematic search was conducted through predefinition a review protocol to obtain appropriate studies as suggested by Kitchenham (2004) in Procedures for Performing Systematic Reviews in which he stated that a “pre-defined protocol is necessary to minimize possible researcher bias.” A systematic review favours production of reliable findings that can consequently be used to inform decision making as it uses explicit methods with the aim of reducing bias.

4.2 Data sources and search

The starting point for gathering data was an online search. The data was primarily accessed through the Laurea AMK electronic portal (NELLI) on recommendation by the Laurea AMK librarian as a credible source for academic material. The aim of the preliminary search was to identify existing systematic reviews and assess the volume of potentially relevant studies.

The research was carried out by two people. The predefined protocol was jointly decided upon by both researchers. The data search process was done in chronological steps which included planning, searching, assessing and finally writing in order to maintain the systematic approach. Screening of titles and abstracts as well as reviewing potentially eligible full text articles was performed independently by the two reviewers. Cases of disagreement were discussed until a consensus was reached.

The research questions were narrowed down to major key search words namely, unrelieved pain, cancer patients, palliative care. There were no synonyms used as this effort only diverted our focus to areas irrelevant to our study.
An electronic search was performedduring10th December 2014- 29th January 2015infour databases. Taylor and Francis, and SAGE, PUBMED, CINAHL.
Key search terms were separately searched in 2 main filters which included, unrelieved pain AND cancer patients, Unrelieved pain AND palliative care. This produced noticeably fewer and more relevant results.

Literature filter was done by criteria of articles published between years 2005 to 2014, the text had to be written in English and had to be full text (except PubMed where free full English text was used). Contents of titles as well as abstracts was a filter for sources to be included. Sources were selected for review when they met the criteria. The search from all databases produced a total of 236 articles. 219 articles were discarded and 17 were selected for evaluation from which 10 were selected for review.

Table 1illustration of the data search process

DATABASES	SEARCHWORDS	NO OF HITS	RELEVANT	NOT MEETING CRITERIA
Taylor and Francis **Sage Journals**	Unrelieved AND pain AND Cancer patient, palliative AND care	14	1	13
Sage Publications	Unrelieved AND pain AND Cancer AND patient AND palliative AND care	84	6	78
CINAHL	Unrelieved AND Pain ANDcancer ANDpalliative care	2	0	2
PUBMED	Unrelieved AND pain AND Cancer AND palliative care	135	3	132
TOTAL		235	10	225

4.3 Inclusion and exclusion criteria

The data were selected based on the research question and purpose statement with criteria to guide the process. Exclusions are set of predefined criteria used to identify subjects which will not be included or which will have to be withdrawn from a research study after being included, while inclusion criteria are set of predefined characteristics used to identify subjects who will be included in a research study (Salkind 2010).
Higgins and Green (2011) emphasized that the method used for this procedure must be transparent to minimize biases and human errors.

The inclusion criteria was in place to ensure that information is not too generalized in which case information would have been hard to compare and synthesize as pointed out by Centre for Reviews and Dissemination 2009.
To be included, studies had to meet the following criteria;
Studies had to focus on cancer patients from the age of 18 and above. Children fell into a category needing specialized care and treatment and we chose not to focus on them.
The text had to be written in English language. This was set as such since it is the language both researchers could read and interpret well; using other language might have caused misinterpretation of information. The studies also had to be published between 2005 and 2014, this was to ensure that information is current.
The study resources and articles had to be Full text in order to ensure that the relevant information was analysed in its complete form.

Figure1. Below is an illustration of the processes of data selection.

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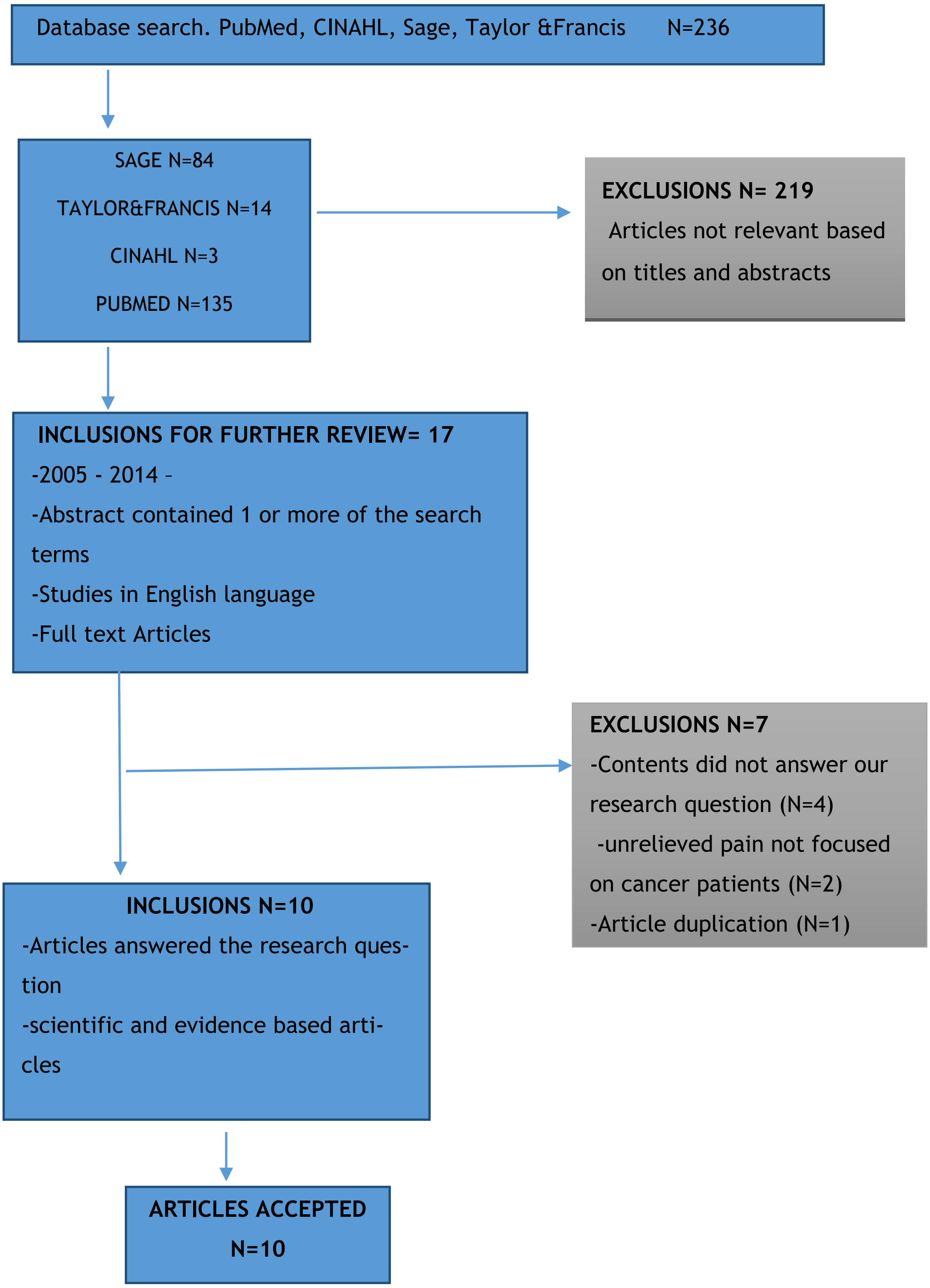
Figure 1 illustration of the processes of data selection



4.4 Data extraction

The purpose of the data extraction was to extract findings in a consistent manner. According to Kitchenham (2004), this enables later data synthesis and interpretation. A data extraction form was required during the course of data extraction to accurately and unbiasedly record obtained information from primary studies as pointed out by Kitchenham (2004). It was designed in consideration of the volume of selected information. The data extraction form was to play four main functions. To act as a summary of selected studies, to assess the eligibility of the current study because it directly links to the review questions and criteria, act as a historical record throughout the review process and also to act as a resource of analysis as advised by(Higgins & Green, 2011).

In this study, data was extracted from all the included studies by two reviewers independently. Extraction of data was done upon mutual agreement and reconciliation of differences, this was to establish reliability and avoid data entry errors (Wright, Brand, Dunn& Spindler 2007).
Data extraction was based mainly on the purpose statement of this thesis in order to ensure that the data obtained was relevant to this study.
This process was guided by the research questions and the extraction criteria.
Where data contents overlapped, only data from the most recent source was considered. If essential material was missing from referenced original publications, the referenced article was sought for depth on the issue. All final selected data was agreed upon by two researchers. Selected articles needed for this study are listed showing the source, study objectives, title of articles, and participants during the study and findings in appendix 1

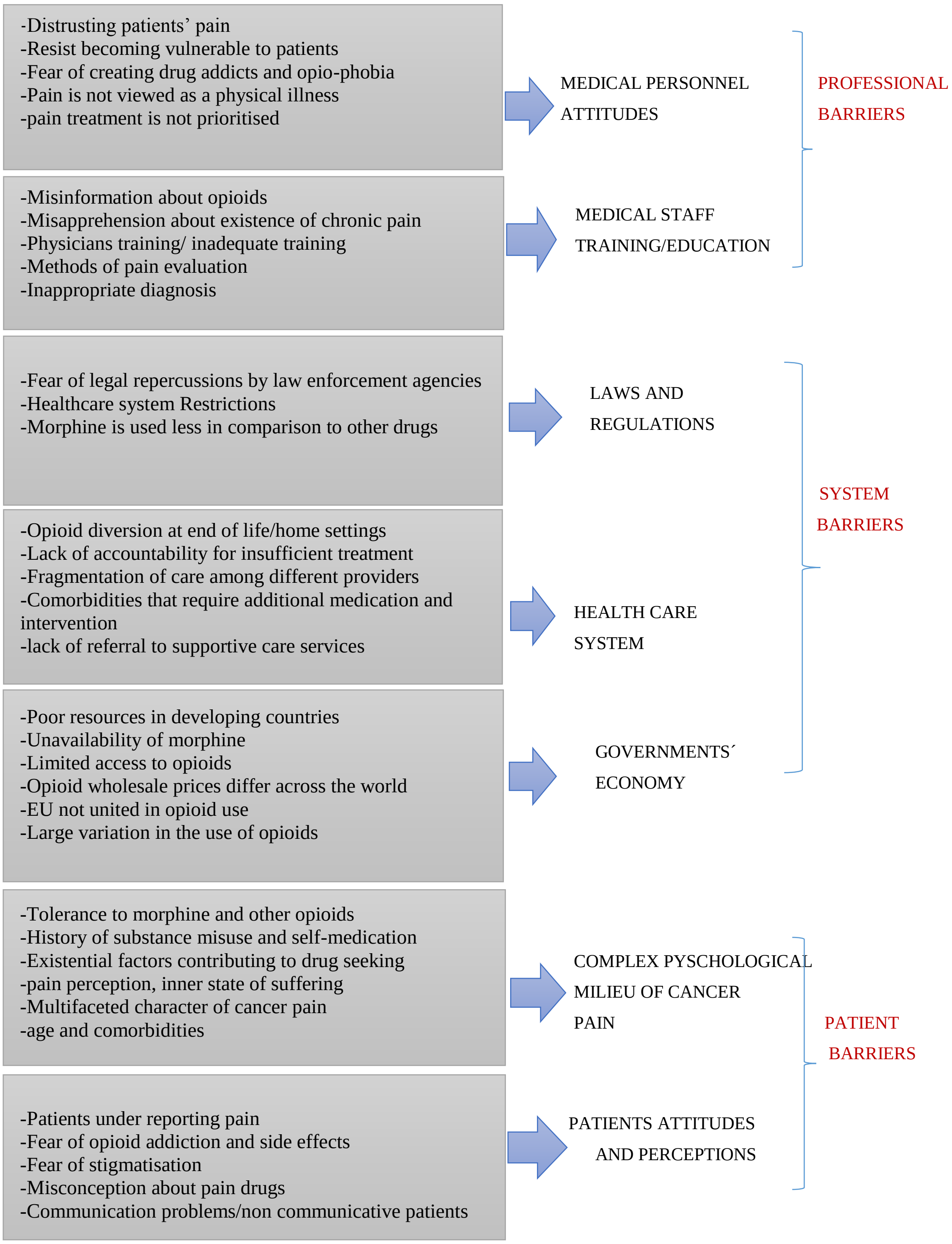
4.5 Data Analysis

Data analysis is the core step of the systematic literature review. It involves collating and summarising data extracted from primary studies (Kitchenham, 2004).
In this study, qualitative approach of data analysis was used to answer the writers' research questions by systematically exploring researches on a topic, and putting the findings from selected studies together (Seers 2012).

A thematic analysis was employed to summarise information in the articles with the aim of identifying and bringing together emerging, recurring themes in the literature. Thematic analysis aims at "preserving data in its original form" as mentioned identified by Coughlan, Cronin & Ryan (2013). There was no data transformation in a bid to maintain accuracy and reduce personal bias. The data analysis process was done by both reviewers in two face-face meetings and 3 Skype video calling sessions.

A coding system was used to outline the main points being made in the literature. Since the studies being reviewed included both research and non-research literature, the coded information came from both the findings and discussion sections respectively. Once the initial codes were made from each study, the next step eliminated replications, highlighted emerging themes and grouped the codes that had similarity categorically as illustrated below.

Figure 2**Main themes and categories of contributing factors to unrelieved cancer pain**

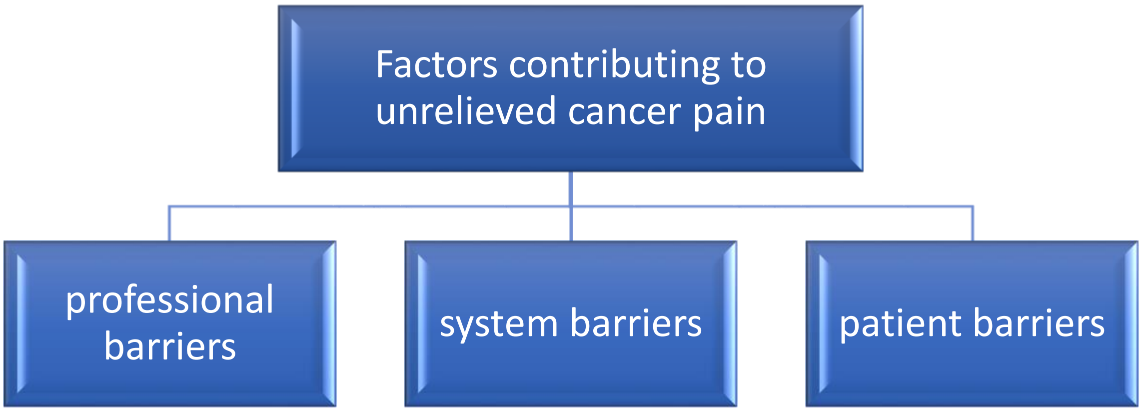


RAW DATA	SUB-CATEGORIES	MAIN CATEGORY
-Distrusting patients' pain -Resist becoming vulnerable to patients -Fear of creating drug addicts and opio-phobia -Pain is not viewed as a physical illness -pain treatment is not prioritised	MEDICAL PERSONNEL ATTITUDES	PROFESSIONAL BARRIERS
-Misinformation about opioids -Misapprehension about existence of chronic pain -Physicians training/ inadequate training -Methods of pain evaluation -Inappropriate diagnosis	MEDICAL STAFF TRAINING/EDUCATION	
-Fear of legal repercussions by law enforcement agencies -Healthcare system Restrictions -Morphine is used less in comparison to other drugs	LAWS AND REGULATIONS	SYSTEM BARRIERS
-Opioid diversion at end of life/home settings -Lack of accountability for insufficient treatment -Fragmentation of care among different providers -Comorbidities that require additional medication and intervention -lack of referral to supportive care services	HEALTH CARE SYSTEM	
-Poor resources in developing countries -Unavailability of morphine -Limited access to opioids -Opioid wholesale prices differ across the world -EU not united in opioid use -Large variation in the use of opioids	GOVERNMENTS´ ECONOMY	
-Tolerance to morphine and other opioids -History of substance misuse and self-medication -Existential factors contributing to drug seeking -pain perception, inner state of suffering -Multifaceted character of cancer pain -age and comorbidities	COMPLEX PYSCHOLOGICAL MILIEU OF CANCER PAIN	PATIENT BARRIERS
-Patients under reporting pain -Fear of opioid addiction and side effects -Fear of stigmatisation -Misconception about pain drugs -Communication problems/non communicative patients	PATIENTS ATTITUDES AND PERCEPTIONS	

5 Findings

This section presents the findings of the research study based on 10 reviewed articles in relation to the purpose statement and research questions. The findings related to factors contributing to unrelieved cancer pain are presented under three main descriptive categories.

Figure 3Factors contributing to unrelieved cancer pain



5.1 Professional barriers

Three articles discussed significant health care professional barriers to adequate cancer pain relief. These were put into two categories including medical personnel attitudes and medical personnel training.

5.1.1 Medical personnel attitudes

Bhavani (2006) argues in a review article that the fear of creating drug addicts by placing chronic pain sufferers on opioids for extended periods of time reduces the likelihood of pain treatment success as this fear and ignorance pervades the mind-sets of society and shapes the development of laws and ultimately affect, and even deter the physician’s practice of pain management.

Bhavani (2006) argues further as far as medical personnel attitudes are concerned that there is a misapprehension about the existence of chronic pain in the health care system and that therefore distrusting patients’ pain is a contributing factor to it’s under management stating that Patients often lack objective physical evidence that proves the existence of their pain. There is no “pain-o-meter” or bright line litmus test to objectively verify a patient’s level of pain. Physicians do not trust patients’ subjective experience since it is not as easily quantified as pulse, blood pressure, temperature and respirations. Patients’ self-reports of pain at face value are left as the most reliable indicator of the existence and intensity of pain making hard to manage effectively.

Rowley, Mclean, O'Gorman, Ryan, & McQuillan(2010) argue that patients with a history of substance misuse were less likely to be prescribed strong analgesics than those with no such history, due to concerns regarding adverse effects of opioids, or concerns regarding iatrogenic opioid dependence and thus reported more uncontrolled symptoms and more psychiatric distress associated with unrelieved pain.

In a qualitative study by Gibbins, Bhatia, Forbes& Reid (2013), participants discussed the role of healthcare professionals and the culture around pain within the medical profession. They acknowledged that they did not perceive that pain was important to healthcare professionals, and these thoughts were consolidated in that they were rarely asked about it routinely. One subject states,

"I honestly think, when you've got something wrong with you like liver cancer and bone cancer and all of this, they want to treat your problem, the liver cancer and all of it. Pain comes like second they want to try and cure your cancer with treatment, chemo, this, that and all of it…."

5.1.2 Medical staff training and education

Chih-Yi Sun, Borneman, Ferrell, Piper,Koczywas, Choi (2009) highlight inadequate education and training in cancer pain assessment as major contributor to unrelieved pain in a study conducted on 38 cancer palliative patients. There was a gap in the screening, re-assessment, and follow-up evaluations of pain. Overall, only 7.8% of subjects were screened for pain at each clinic visit. There was no correlation with pain rating documentation and re-assessment at subsequent follow-up visits. Only 2.6% of subjects had the quality of their pain documented. Seventy-six percent of patients had pain ratings of moderate severity (4–6) and 24% had severe pain (7–10). There was very limited (7.9%) documented pain screening, no documentation of numerical pain ratings or evidence of reassessment.

Misinformation about opioids and lack of sufficient opioid education was cited as a contributing factor to unrelieved pain. Bhavani(2006) argues in his review that In an effort to avoid prescribing opioids, many physicians make a frequent error in the treatment of chronic pain by prescribing substitute classes of medication, namely non-steroidal anti-inflammatory drugs (NSAIDS) and COX-2 inhibitors which may be insufficient in chronic pain treatment.

5.2 System barriers

The system barriers were sub categorised unto three parts including laws and regulations, healthcare system and the government economy.

5.2.1 Laws and regulations

Bhavani (2006) argued in his review that despite the efficacy of opioids in the treatment of chronic pain, fear of increased regulatory scrutiny criminal investigation or even criminal prosecution by state medical licensing boards and drug enforcement agencies is another prominent reason for the under prescribing of opioids that may in turn contribute to unrelieved pain.

He added that often, regulations regarding prescribing of opioids are vague and ambiguous, causing physicians to be uncertain about what constitutes legitimate opioid use.

5.2.2 Healthcare system

Chih-Yi Sun et al (2009) cites lack of referral to supportive care services as a contributor to unrelieved cancer pain as no patients in the 39 subject study sample received a consult to a pain specialist and there was no documented pain education. Only 5.2% of subjects received a social work consult and there were no other psychosocial support consults.

One overall observation was that patients seen in the outpatient clinic setting had much less supportive care available as compared to the inpatient setting.

Gilson, Maurer, Le Baron, Ryan, Cleary (2012) in a multivariate study of 177 countries found a direct overall association between the aggregate consumption of five opioids (including morphine) and the level of palliative care development in country’s healthcare system even when controlling for influences of the other predictor variables.

In a review article on Palliative Care in Gynaecologic Oncology, Rezk, Timmins &Smith (2011) cites fragmentation of care among various providers and lack of accountability for insufficient pain treatment. The statement did not provide reference to the context of information.

Opiate diversion is cited in a case presentation article by Baumrucker, Carter, Vanderkieft, Stolick, Harrington, Sheldon, Morris (2009) as a contributing factor to unrelieved pain as a result of the health care system structure which facilitates outpatient hospice control and the right to die at home. Palliative care provided in the home setting gives countless individuals access to pain medicine originally intended for the dying person and opens doors for opioids’ abuse by caretakers.

There are currently no established recommendations to guide practice in managing cancer pain in patients with a history of substance misuse on MMT.

Rowley et al (2010) in a study reviewing Cancer Pain Management in Patients Receiving Maintenance Methadone Therapy presents underlying comorbidities as a contributing factor Patients may have comorbidities such as HIV/AIDS, which may require additional interventions and medications, complicating management of their pain.
They add that Patients may have previous experiences substance abuse or self-medicating to remove pain and psychological distress, and in particular, dependence on substances such as benzodiazepines and alcohol has been shown to be a poor prognostic indicator for cancer pain control. Misusers may have frequent episodes of intoxications and withdrawal, which may alter the intensity of their pain experience, making it harder to manage.

5.2.3 Governments

Gilson et al (2012) relay in a Multivariate analysis of how a countries' government and health-care system influences on opioid availability that an inadequate national opioid distribution system and government and health-care system infrastructure can affect its opioid consumption level. They add that although opioids such as morphine are considered essential medicines in the provision of palliative care and for treating cancer pain, middle-income countries often lack such medications.
The multivariate study results on 177 countries showed that commitment and extent of government spending on resources to health positively predicted the aggregate consumption of opioids indicated for treating severe pain e.g. the purchasing of essential medicines or financing educational initiatives for practitioners on the use of opioids for pain management was deemed to influence opioid consumption patterns.
Adherence to international treaty obligations also predicted higher opioid consumption.

In a 2005 editorial, Dale, Klepstad & Kaasa point to a review on the use of opioid analgesics in different European countries and presented data on the sales of opioids (codeine, tramadol, morphine and fentanyl in nine European countries from 2001 to 2003 which observed that morphine is used little in comparison to the other drugs, there are large variations in the use of opioids both in respect to total consumption and choice of opioids between European nations, the trends with respect to an increase and decrease in the use of opioids vary between countries and opioid wholesale prices differ considerably between countries.
This editorial however presented second hand research information that is not current.

5.3 Patient barriers

These are the contributing factors to unrelieved pain that were directly stemming from the patients or appeared to be channelled through them.

5.3.1 Patients attitudes and perceptions

Gibbins (2014) et al, In Qualitative study of what patients with advanced incurable cancer want from the management of their pain, talked about the sedative side effects of patients medication, which made them reluctant to take more among which they indicated that day-time sleepiness was a threat to their usual self thus contributing to unrelieved pain. Shown in the face-face interviews. “Yeah it does make you sleepy. Oh you start illusions and all sorts of things, you know, if you have too much of it.” (Charles)
Interviewer: “And what worries you about increasing your medication up?
Michael: “Well I take so much now. (Laughs) I’m sleeping”

Patients expressed that they wanted to be pain free but did not actually expect to be ‘free of pain completely’ or ‘painless’, they wanted to ‘take the edge off’, ‘ease up’ or ‘keep a grip’ on the pain. “…So I know it’s not going to be terribly likely; there’s always going to be some level of discomfort somewhere”. (Mary)
This perception that pain is inevitable in cancer or is to be expected contributes to it being unrelieved in palliative care.

Almost all of the 12 participants reported not using their medication as prescribed, which frequently led to a ‘vicious cycle’ whereby they took only enough medications to ‘take the edge off’. Patients admitted to an attitude of taking the medications only when they felt pain was interfering with their everyday tasks or when they were becoming dependent on others.
“But of course there’s always this er – this feeling that if you haven’t got any pain, why take drugs? Why take something? So it took a little while to kind of get over, you know, that. That you have to take the drugs even though you’re not in pain at that moment.” (Mary)
“I don’t like taking any medication of any sort really until the pain gets sort of unbearable, and then I’ve got to take something.” (Charles)

Underreporting pain was highlighted in the interviews as Patients acknowledged that they were reluctant to disclose pain perhaps because they were rarely asked about it, did not feel it was important to healthcare professionals and found it challenging to communicate their pain. E.g. “I normally wait for someone to ask me, you know, ‘How is your pain? How is your pain?’ and then you – then I’ll tell them.” (Sarah)
In chin-YI-Sun’s study, subjects who were currently receiving chemotherapy treatments were more likely to believe that communication of pain might distract physicians from treatment of underlying disease more still Subjects with pain who were receiving chemotherapy were also more likely to believe that “good patients” do not complain about pain.

Chih-Yi Sun (2009) et al, the study found that there was a strong belief that pain medicines are addictive, and that cancer patients are at high risk of developing addiction.

Subjects also believed that their body becomes tolerant to the effects of pain medicine and the medications would not provide pain relief in the future.

Important knowledge deficits were seen as contributing factors to unrelieved pain as they existed with regards to the cause of pain, addiction with opioids, stopping pain medicine suddenly, and the need to increase pain medicine as being a sign of addiction.

5.3.2 Multifaceted character of cancer pain

Mori, Elsayem, Reddy, Bruera &Fadul (2011) in a 3 case presentation of patients with cancer highlights a patient's inner state of suffering, underlying psychosocial and or spiritual distress related to end-of- life issues as a common untreated contributing factor to unrelieved pain. These factors may influence pain perception and addressing the pathophysiology of pain alone without the other aspects contributing to suffering may be futile. They argued that unrevealed psychosocial distress resulting from physical, psychological, social, spiritual, and or practical issues may amplify pain expression and trigger a vicious cycle of increased pain expression, anxiety, escalation of opioids and benzodiazepine use, and impaired cognitive function.

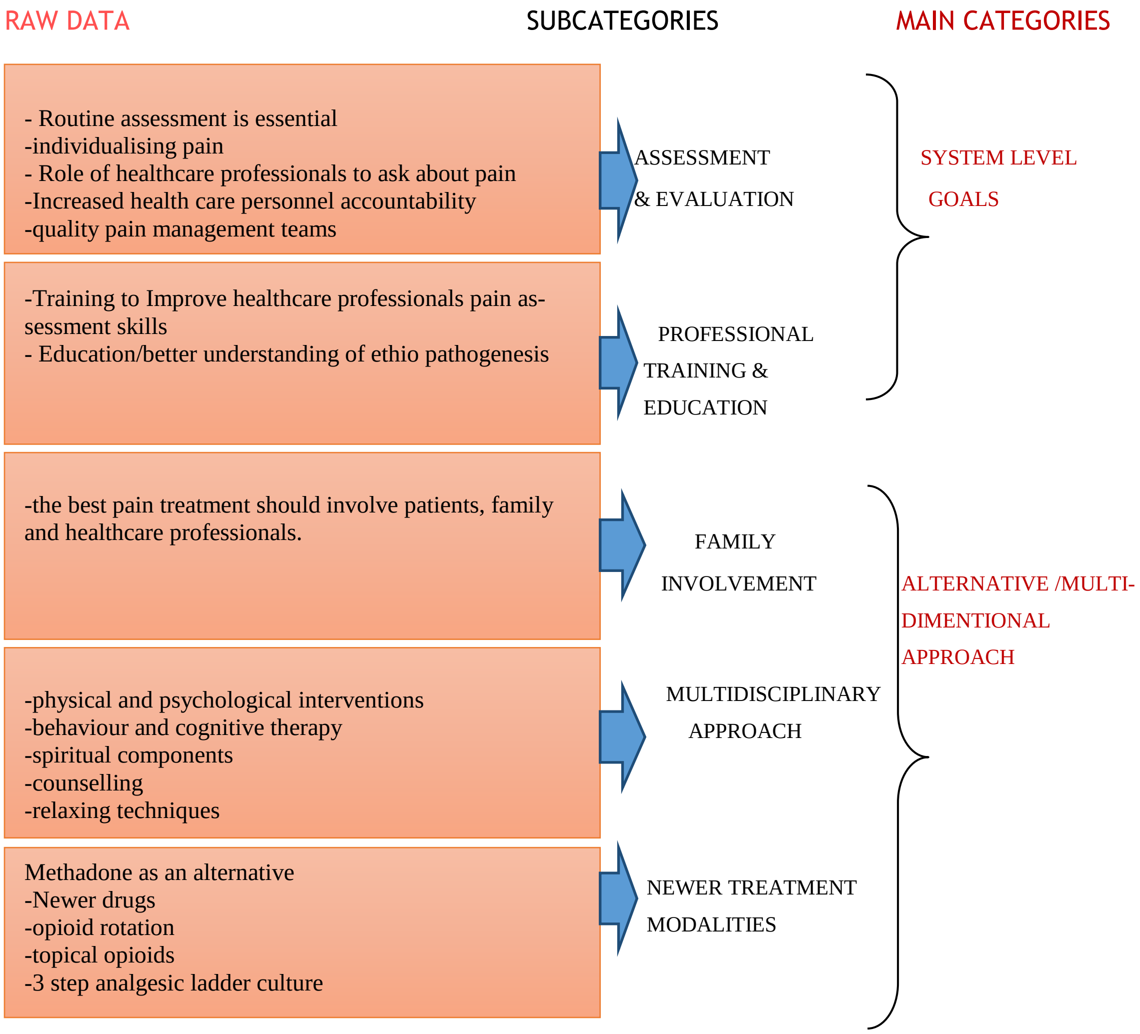
Rowley (2010) et al Study on cancer patients with a history of opioid misuse, relayed that if patients have had a history of substance abuse or self- medicating to remove pain and psychological distress they are prone to "chemical coping" which can become a barrier to optimal cancer pain management as dependence on substances such as benzodiazepines and alcohol has been shown to be a poor prognostic indicator for cancer pain control. Misusers may have frequent episodes of intoxications and withdrawal, which may alter the intensity of their pain experience. Prior abuse may leads to increased tolerance and refractoriness to analgesia from opioids other than methadone. They are also less likely to be prescribed strong analgesics than those with no such history, and thus reported more uncontrolled symptoms and more psychiatric distress than other patients.

Rowley adds that patients' fears of being stigmatized can further complicate management of their pain, as they may be fearful to disclose a history of past, or current, substance misuse in case needed pain medication is withdrawn.

5.4 Implication for healthcare practioners

None of the studies directly referred to the nurse's role in tackling and minimizing the problem of unrelieved cancer pain among patients in palliative care. The Nurses' role/ involvement was however deduced from areas where healthcare professionals were referred to as illustrated in the diagram below.

Figure 4 Main themes and categories for interventions

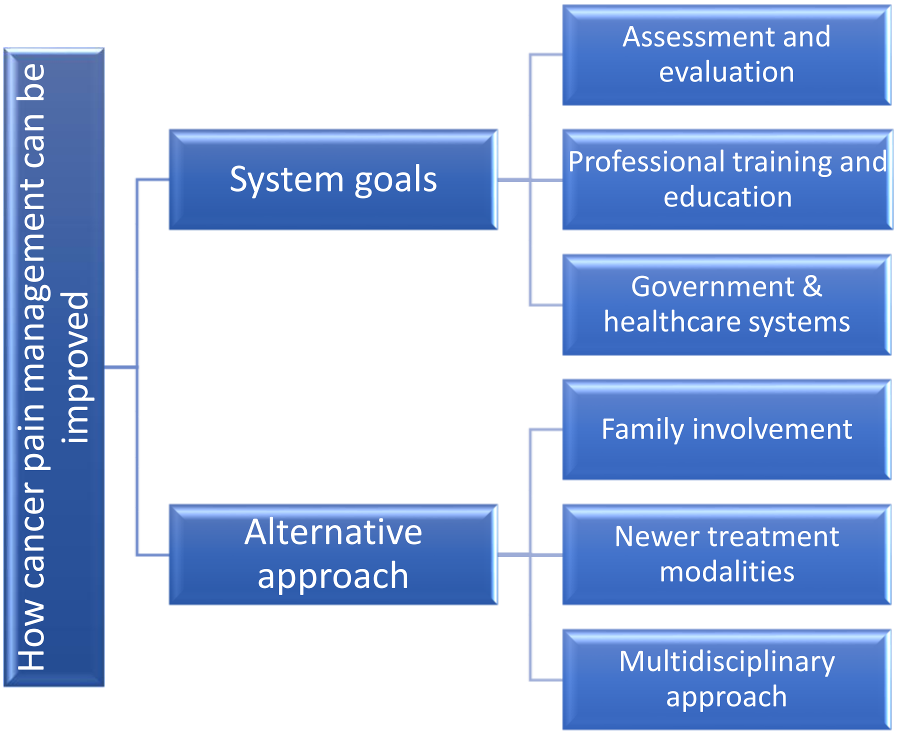


6 Discussion

This research set out to identify the contributing factors to unrelieved cancer pain in palliative care patients and how nurses could contribute to improving the current pain management situation. The findings of the study have a great implication on the nurses' practice in the effort to decrease the occurrence of unrelieved pain in palliative care patients and can be incorporated in the wider context of nursing as discussed below.

In order to maintain focus on our main topics of discussions, we make mention of our findings and base our discussions on them throughout the different subsections.
Figure 5 below illustrates the main categories used in the discussion.

Figure 5 how cancer pain management can be improved in palliative care



6.1 System Goals

6.1.1 Assessment and Evaluation

The lack of healthcare institutional mechanisms for routinizing the assessment and treatment of pain has been an attribute of unrelieved pain. One of the main objectives of palliative care for cancer patients is the relief of pain through different approaches but essentially, medication. According to our findings, pain is often undertreated because of factors arising from both the patients and the doctors. In some situations, patients do not report pain, in other instances, they do underreport pain. In instances when patients do report pain, some doctors are shown to respond by prescribing non opioid medications. Non opioids, though suitable for some kinds of pain, do not provide optimum pain relief to patients with advanced cancer. In reference to our findings, the fear among physicians of creating drug addicts and the stubborn refusal to acknowledge patients' expressions of pain among some physicians is fundamental in the under treatment of pain. In this context, the role of the physicians could be seen as using their special skills to listen, assess, monitor/measure vital signs and in turn provide the necessary pain treatment.

The role of the nurse however, in cases where patients do report pain is to advocate for the patient. The ICN (2006) code of ethics for nurses mentions that for the nurse, primary responsibility is to people requiring patient care and that a part of fulfilling that duty is assuming the advocacy role. Since pain assessment uses facial expressions and numbers 1- 10. I.e. medical personnel must depend mainly on patients' own description and expression of pain to commence any treatment on pain. The nurse being the patients' immediate care giver is ethically obligated to trust the patient experience and advocate for/ represent the cause of the patient to prescribing physicians until the desired outcome of pain relief is achieved. The nurse has direct access to the physician and may be better able to paint clearly the patient situation/medical needs.

More still, in cases where patients do not report pain, the nurse ought to use their own cancer palliative care expertise and judgment to ensure pain relief for the patients. This can be through directly inquiring from the patients about their pain experience, observing how far the patients engage in activities of daily living during their care work. Nurses could guide patients into describing when, how and the kind of pain experienced under different situations. The use of certain terms may go a long way into specific description of the pain experienced i.e. the relevant medication for its alleviation. This role is crucial because nurses spend most of their time close to their patients and they, in turn make reports to the physicians in charge about any health changes. In this situation, nurses can properly document and report the pain status as experienced during the care period. Some nurses learn to differentiate break through pain and the normal chronic pain that patients with advanced cancer tend to experience. I.e. enabling the appropriate treatment as needed.

6.2.2 Professional Training and Education

In light of the above discussion, one would argue that doctors' training ought to give them a better perspective on pain and its modalities. However, our findings point to misapprehension of pain by doctors and medical personnel in general. This therefore leads us to the specialization particularly by both doctors and nurses in palliative care. Training opportunities within the field greatly equip medical personnel in understanding, assessing and treating palliative cancer patients. Medical personnel who choose to train in this area are fundamentally endowed with special assessment skills of disease progression, monitoring and the management of surrounding symptoms. An important area that is very well covered is pain management and control with the use of opioid medication. Pain modalities are important because this is no ordinary pain and will not respond to ordinary pain medications. Unlike general practitioners, palliative doctors and nurses have a better understanding of opioid use and are not afraid to increase doses or change medications when needed. Training of medical personnel therefore solves issues of misapprehension of pain as well as settling fears related to creating addicts of patients.

Nurses in palliative care can rightfully take the initiative to ask for further training. As stipulated in the healthcare act, the nurses have a right to this training should it be required.

"Health centers shall be responsible for the provision of expedient multidisciplinary research, training, and development services" (Finnish Health care act 1326/2010).

6.2.3 Governments and Healthcare System

According to our findings the Human Development Index (HDI) of any given country measures the availability of resources towards national development issues including the provision of health care. In the context of our thesis, the differences in HDI between Lower Middle Income Countries (LMICs) and their developed partners account for disparities in the availability of resources dedicated towards palliative cancer care and treatment. In some LMICs, the lack of government commitment which is often worsened by limited education/information on the importance of palliative care has left very limited resources and in many instances no national policy on palliative care (Webster et al. 2007) i.e. heightening such disparities. The implication of limited/no resources towards palliative care means that majority of dying cancer patients have no access to interventions such as surgery, chemotherapy, radiation and opioids.

Furthermore, despite international advocacy by bodies such as the World Health Organization (WHO) on the importance of opioids for intractable pain, many LMICs have very strict rules on the production and supply of opioids within their borders. Though strict controls may be legitimately aimed to curb abuse of opioids, they have at the same time impeded on medical personnel's efforts to relieve chronic pain which is typical among advanced cancer patients. Another implication of limited national resources is the inability to afford large quantities of opioids to supply health systems and to enable the necessary training of medical personnel in the treatment and assessment of palliative cancer patients.

With fragmentation in policy, knowledge and opioid supply often results fragmented interventions. The consequences among others include limited/no pain relief at all or late referrals to palliative services for cancer patients. In the LMICs, such services are not always available nationwide (Webster et al. 2007) but only in the capital or city areas and within the private sector.

Policy makers and health professionals need to understand why lifting unnecessary regulations is important for patients suffering painful conditions and nearing death. This can be achieved through engaging in advocacy and education about the need for palliative care services and correct opioid use (Webster et al. 2007). Education of policy makers and the general public can be done by the health care professionals who directly engage in the care of palliative patients and thus understand what kind of painful conditions and transitions they undergo. Nurses, doctors and other knowledgeable individuals should join their voices locally through educative fairs and with international bodies to advocate for the proper equipment and training of palliative care departments. Policies at the national levels will go a long way into providing favorable regulations for the supply of opioids and bringing palliative services closer to people.

Our findings revealed that there is a large variation in opioid use between countries due to cultural differences. In Europe for example, the north- south divide point to the fact that Italy and Portugal as southern countries have a lower consumption of both morphine and fentanyl where as in the United Kingdom, Norway and other northern countries are high consumers. The reason cited is that people feel that to be able to tolerate pain is being 'man-enough'. Opinions are divided in this matter. However socially constructed norms have a great influence on people's daily lives including the pain relief. It can also be argued that, a culture of constant education and awareness of the general public pervades many northern countries enhancing awareness on many topical issues, in this case, cancer pain. Public knowledge makes it possible for individuals to make informed decisions on opioid use. In many developed countries, it is often the case that national televised campaigns, activities, special cancer days, ribbons, leaflets, advertisements and information is available through the media, making it possible to seek and find help. Participation of nurses in such events is crucial because they can get to explain to the public the meaning of pain and suffering for palliative cancer patients. Cultures are developed through time, through constant awareness and education of the general public. Such cultures of evading opioid use can be slowly supplanted with informed scientific knowledge to the public.

6.2 Alternative Approach

6.2.1 Family Involvement.

The best palliative cancer pain treatment ought to involve patients' families and health care professionals. With the help of the family the patient and healthcare professionals particularly nurses can establish realistic comfort and function goals. For example in the scenario, where the patient just wanted to be able to walk and do more chores at home, it would be hard to achieve total pain control at the same time due to the sedative effects of cancer pain medications.

It was also evident in our findings that many patients prefer to spend the last days of their lives with loved ones in familiar surroundings. However, there are shortcomings associated with such settings. For example, family members are often physically and mentally derailed while taking care of loved ones, having opioids in home settings also runs the risk of diversion particularly if there is a dependent relative or caregiver. More still, patients may skip medication doses due to slight improvement in their pain or their general condition. Furthermore, the fear of the side effects of medications such as fear of addiction, sedation, constant fatigue and restriction to bed may lead patients skipping some dosages until they feel totally compelled by the severity of pain or the disease. This defeats the objective of palliative care which is for the patients to have as pain free last days as possible.

In direct relation to the above, the role of nurses becomes important because of their direct involvement in patient admission, stay and discharge from hospitals. The nurses' role in educating patients and/or their loved ones on the how and when to take prescribed medications is vital. Patients ought to be informed about the use of the drugs, side effects and the implication of skipping or diverting medication. This will go a long way into preventing situations of helplessness due to untreated unrelieved pain.

6.2.2 Newer Treatment and Diagnostic Modalities

The importance of opioids in the effective treatment of various intractable painful conditions as is the case for cancer is undeniable. Newer medication modalities can be put in use for the effective management of cancer pain in a bid to reduce the cases of unrelieved cancer pain in palliative care. According to our findings, there are 3 steps in opioid use which involve the gradual increase in opioid medications from low to high doses with progressive cancer/pain in patients and tolerance to the medications. Compared to other pain medications notably NSAIDs, opioids are very potent and can have a long half-life. Moreover, altering their administration routes to subcutaneous, intravenous and intrathecal makes some opioids ten times more potent than when administered orally or transdermally. However, despite their effectiveness, some factors about opioids make their use complicated and are thus worth addressing. For example, our findings portray that a history of opioid abuse may greatly compromise their effectiveness in future use. A past of opioid dependency could for example mean that a patient may require less opioids for the treatment of pain. In mentioning this, it is important to note that opioids can be used for a varied number of reasons including as analgesics for different kinds of pain, for the treatment of heroin addiction, to relieve anxiety and for chemical coping. It is thus inaccurate to believe that it is only people with a history of drug addiction per say who fall in the risk category of having a history of opioid use. Long term opioid use has been shown to induce neuroplastic changes which make the achievement of pain control more difficult than in patients who are opioid naive(Rowley et al. 2010).

In addition to the above, the lack of uniform conversion scales for different opioids make their use complicated particularly given the varied half-life and potency. Switching to methadone for instance from morphine is complicated by variable half-life and potency ratios (Rowley et al. 2010). This factor is further complicated by the differences in individual pharmacokinetics which literally means that, what applies to one person may not apply to another.

Not only that, the stigma associated with opioid use often leads to denial or lack of mention among patients about previous or ongoing use or abuse of opioids. When medical personnel are ill equipped about a patient’s drug history, this tends to negatively affect the ongoing or prospective treatment.

Due to their proximity to patients during the care process, nurses could contribute by gaining patient’s confidence in regard to opioid use. When reassured that their information will be treated confidentially as obligated by the Nurses’ oath, some patients may be forthcoming about a past of opioid use of any. When attained, such information can go a long way in enhancing the palliative pain management process for such patients

6.2.3 Multidisciplinary approach

Though pain is a central aspect in palliative cancer care, it is important to note that pain is very dynamic - often negating one antidote. According to our findings direct sources of pain have been associated with surgical procedures, chemotherapy and metastasized tumors that often affect surrounding nerves, bones and the spine. Another source of pain is attributed to chronic co-morbidities such as diabetes, heart disease, osteoarthritis and HIV/AIDS. In our study, the presence of chronic diseases together with advanced cancer can be likened to ‘tangible’ or direct sources of pain where relief can be directly addressed by specialized medical personnel and different relevant interventions

On the other side, apart from the obvious diagnosable sources of pain among cancer patients, other subtle sources have been identified to tremendously cause discomfort and pain among palliative cancer patients. These are areas associated with the environment, social and psychosocial areas of life. Palliative cancer patients have been known to be affected by depression, anxiety, worries such as leaving young children or loved ones behind and feelings of guilt or even fears of life after death. When unresolved, such situations affect pain relief processes and greatly undermine the whole treatment process.

This piece of evidence that highlights the importance of Non pharmacological and complimentary methods involving multi- professional teams which are important in assessing and providing relief within their professional skills. Teams involved usually include different specialized medical doctors, physiotherapists, social workers, counselors, religious authorities and most importantly nurses. The role of the nurse in such instances is to identify the need for this multi-professional approach. Their role is very central because they have more contact with the patients. Nurses in hospitals and home settings are in the position to assess the sources of distress through observation, interaction with patients and significant others and hence to make recommendations to physicians in charge on the possible multidisciplinary approaches that could alleviate such situations. Nurses’ knowledge in pharmacology can also go a long way in enabling easy detection of drug interaction and side effects when making reports on the patients to physicians.

In conclusion, pain relief is central to the duties of healthcare professionals. In the cancer palliative care as well as all other health care settings it worth to note that they are also ethically obligated to relieve pain. The researchers stand in agreement with the statement that “the challenge to pain reformers lies in moving people not in pain to acknowledge and treat those who are” (Blacksher, 2001). In the same vein, we are inclined to agree that “how we as healthcare professionals think about pain influences how we respond to it. Our ability and willingness to detect it, report it, hear it, trust it, and treat it relies, in part, on what we understand pain to be and to mean and therefore any effort to improve pain management will have to work not only at institutional, regulatory, and political levels but, simultaneously and explicitly, at the conceptual” (Blacksher, 2001).

7 Ethical considerations

Since ethical values and considerations should be taken into account at all stages of the research process(Oliver, 2010), the thesis topic was decided upon in the presence of two thesis supervisors on a thesis day. A thesis contract and plan was drawn up, written and forwarded to the thesis supervisor for approval. Prior to data research process, the methodology was agreed upon and studied in-depth by both researchers and a meeting with the librarian was arranged in a bid to guide the data search process. The thesis was written in stages and forwarded to the supervisor for review and permission to progress through the next stages. This thesis produces valuable findings which are both relevant to the research question, purpose statement and aims of the study.

This study wasa systematic literature review so there was no need for informed consent. There was also no participants-researcher relationships, confidentiality or anonymity issues to be considered (Oliver, 2010).

In reference to gaining access, the information and research data was rightfully accessed with student passwords through the NELLI portal.

The researchers were obligated to quote and reference the information sources in respect to owner publication rights. The data references were listed according to the Laurea guidelines in the reference section.

Both researchers exercised ethical values throughout the process. The workload was fairly shared, there was mutual respect and accountability. There was no conflict of interest during the process. Bias was avoided during the research by both researchers producing ideas independently on the same articles and later merging them into a common body.

7.1 Trustworthiness

For trustworthy information, four academic electronic databases were used to collect data through NELLI portal. These included PUBMED, CINAHL, Taylor & Francis, and SAGE. The data collection was conducted by two researchers.

A Pre-defined protocol was in place to minimize possible researcher bias and the process was bench marked against the criteria at all times. Researchers found a common understanding areas of divided opinions by the two researchers were discussed until a consensus was reached.

English was an agreed criterion which favoured full comprehension of the studies by both researchers and thereby minimised misinterpretation and errors.

Data was collected from full text articles written between 2006 and 2015 to ensure that information was based on current knowledge and information.

To avoid over generalisation of the results (Aveyard, 2010), Our discussion was largely based on our findings in an effort to answer our research question and In addition to that, we made efforts through our discussion to relate our findings to health care settings while emphasizing the role of the nurse as an important participant and contributor in our research topic.

8 Limitations and recommendations.

Even though the aims and research of the purpose were fulfilled and research questions answered, the thesis has its limitations. Acknowledging shortcomings in our research enables the reader to put our results into context

We would like to point out that as novice researchers, we might have benefitted more from the use of more experienced researchers who would have aided us in a much broader search involving more databases, critique and bringing together of the literature (Aveyard 2010). Such efforts would however require extra financial resources and time which we unfortunately could not afford at this level of study. The major limitation of this study was the set criterion/ predefined protocol that was to be followed in a way that it created boundaries that may have led to missing out on relevant and essential data as discussed below.

The search being limited to articles in full text and in the English language due to translation time and interpretation precision excluded a lot of potentially relevant articles published on other languages.

The time frame within which the articles had to be written also eliminated a lot of relevant data that this research could have benefited from. More still, for some articles there was limited access through other libraries.

The study also suffered a lack of quality, evidence material. It produced a number of editorials, with weak evidence to support particular arguments. Only two of the articles presented first-hand research results. With this in perspective, we would like to point out that the lack of original qualitative and quantitative research papers for inclusion in our study makes the applicability of the results limited only to certain health care situations and settings. Further research would have to be done to augment on the results of this paper.

Despite the above, our research topic provided the opportunity to share with the reader the findings of other studies and to relate our research question to the larger body of knowledge through highlighting a gap in the knowledge in cancer pain in palliative care. The data search found that a lot of articles addressed chronic cancer pain but only few really focused on cancer pain in palliative care and what patients want out of that care. For future studies, the writers recommend further research in the field of cancer pain in palliative care as specific research type studies on palliative care for cancer patients would give a better insight on why the high numbers of unrelieved pain in cancer patients continue to elude medical personnel.

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Tables

Figures

Appendix 1

Appendix

Table of selected Literature

source	**Research title**	**Aim of study**	**Type of study**	**Main Findings/ significance of the study**	**Strengths and limitations**
Chih-Yi Sun et al (2007)	Overcoming Barriers to Cancer Pain Management: An Institutional Change Mode	pre-intervention findings related to barriers to pain management	Qualitative research using interviews and participants observation	Barriers were focused around screening, documentation, reassessment, and follow-up of pain, Lackof referrals. Lack of referrals to supportive care services for patients was also noted.	100 subjects were interviewed
Rowley. et al (2010)	Review of Cancer Pain Management in Patients Receiving Maintenance Methadone Therapy	Explore why patients on MMT have difficult to manage pain, the optimal management of their pain, and the increasing role of methadone as an analgesic agent in cancer pain.	Qualitative research conducted using a retrospective chart review	In all, 80% of the patients had documented difficulty in pain management. All patients required adjuvant agents in addition to opioids to manage their pain. For 9 (75%) of the 12 patients, the dose of methadone did not change significantly throughout the course of their illness	4-year study long of12 patients' study of subjects referred to the palliative care service with cancer pain who were on MMT. All had difficult to control pain, and a third required 5 or more analgesic agents.

Mori.M et al (2012)	Unrelieved Pain and Suffering in Patients With Advanced Cancer	knowledge of the risk factors for poor pain control	Case presentation of patients with advanced cancer	Multidimensional approach allows multidimensional assessment and treatment of cancer pain but also address the underlying psychosocial and or spiritual distress.	Proposes an algorithm of multidimensional approach to unrelieved pain and suffering in patients with advanced cancer.
Thapa.D et al (2011)	Cancer pain management current status	Aims to discuss reasons for under treatment, tools of pain assessment, cancer pain and anxiety and possibly carve new approaches for cancer pain management in future.	non-systematic review article	Poor resources in developing countries, unavailability of morphine, physicians opophobia, problems with communication, a multifaceted dynamic target	Carves new approaches to the management of cancer pain.
Gibbins J. et al (2014)	What do patients with advanced incurable cancer want from the management of their pain? A qualitative study	To explore how patients with advanced cancer describe the control of pain and what they want from management of this pain	Qualitative study using face-to-face interviews	Four themes emerged: maintaining role, self and independence; compromising/modifying expectations; role of healthcare professionals; and meaning of pain in context of advanced cancer.	Twelve interviews took place which gave good insight. The number was however too small to represent the cancer population.

Appendix 1

Manjiani.D et al (2014)	Availability and Utilization of Opioids for Pain Management: Global Issues	seeks to clarify the challenges related to opioid delivery. The considerable negative physical and mental consequences of chronic pain are discussed for the general and palliative care population.	Review article	The improvement of pain education in undergraduate and postgraduate training will benefit patients and clinicians. The promise of new medications, along with the utilization of multimodal approaches, has the potential to provide effective pain relief to future generations of sufferers.	Provides Comprehensive guidelines for improvement.
Baumrucker.J.S et al (2009)	Diversion of Opioid Pain Medications at End-of-Life	Highlight the dangers of opiod diversion at the end of life	Case presentation	Opiate diversion in the home setting as a major contributing factor to unrelieved pain among cancer patients.	Provides the social-work , medical ,legal, nursing and ethics perspectives on opiate diversions in the home setting.
Rezk Y. et al (2011)	Palliative Care in Gynaecologic Oncology	Evaluation and alleviation of pain in palliation	Review article	Highlights a real need for more emphasis on palliative care education in training programs	addresses some of the common symptoms experienced by this group of patients in a practical management-oriented approach

Ola Dale et al (2005)	EU not united in opioid use	Highlight the underutilization of step 3 opioids, as a cornerstone of symptomatic pain treatment in cancer patients	editorial	(1) morphine is used little in comparison to the other drugs; (2) there are large variations in the use of opioids both in respect to total consumption and choice of opioids between European nations; (3) the trends with respect to an increase and decrease in the use of opioids vary between countries; and (4) opioid wholesale prices differ considerably between countries	Benchmarks different opioid usage in Europe and how it affects the management of pain
Gilson A. M et al (2012)	Multivariate analysis of countries' government and health-care system influences on opioid availability for cancer pain relief and palliative care	examine countries’ government and health-care system influences on opioid availability for cancer pain and palliative care, as a means to identify implications for improving appropriate access to prescription opioids	Multivariate study	Findings demonstrate that a limited number of predictor variables characterizing a country’s government and health-care system infrastructure can explain its opioid consumption level, with the greatest influence being very high Human Development Index.	Uses different domains for analysis. Including acquisition, education, national policy, medication distribution guidelines.