

# **An Implementation Study to Improve Cancer Pain Management in Jordan Using a Case Study**

A thesis submitted to the University of Manchester for the degree of Doctor of Philosophy in the Faculty of Medical and Human Science.

2011

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## Table of contents

Table of contents .....	2
List of tables .....	7
List of figures .....	9
List of pictures.....	9
List of Abbreviations.....	10
List of appendices .....	11
Abstract.....	12
Declaration .....	13
Copyright statement.....	13
Dedication.....	14
Acknowledgments .....	14
The Author.....	15
<b>1. Chapter One: Introduction .....</b>	<b>16</b>
1.1 Background of the problem.....	17
1.2 Thesis organization.....	18
1.3 Study context description .....	19
1.3.1 General information .....	19
1.3.2 Jordanian culture .....	20
1.3.3 Healthcare system in Jordan .....	22
1.3.4 Nursing in Jordan.....	24
1.4 Summary .....	26
<b>2. Chapter Two: Literature Review .....</b>	<b>27</b>
2.1 Introduction.....	28
2.2 Search strategy.....	28
2.3 Quality issues .....	30
2.4 Cancer pain .....	32
2.4.1 Aetiology .....	32
2.4.2 Cancer pain prevalence .....	33
2.4.3 Pain classification.....	34
2.4.4 Cancer pain assessment .....	37
2.4.5 Measurement tools.....	46

2.5 Cancer pain management.....	53
2.6 Barriers to cancer pain management.....	57
2.7 Nursing role in pain management .....	70
2.8 Summary .....	71
<b>3. Chapter Three: Theoretical Framework .....</b>	<b>72</b>
3.1 Introduction.....	73
3.2 Translating knowledge into practice .....	73
3.3 Research utilization determinants.....	74
3.4 Diffusion of innovation theory .....	78
3.5 Promoting action on research implementation in health services (PARIHS) .	80
3.6 Change theory .....	82
3.7 Study framework.....	83
3.8 Summary .....	85
<b>4. Chapter Four: Pilot Work .....</b>	<b>86</b>
4.1 Introduction.....	87
4.2 Context assessment.....	88
4.2.1 The evidence .....	88
4.2.2 The context.....	88
4.2.3 Facilitation .....	96
4.3 Driving versus restraining forces .....	97
4.4 Was this study site applicable?.....	99
4.5 Instrument testing.....	100
4.6 Summary .....	101
<b>5. Chapter Five: Research Method .....</b>	<b>102</b>
5.1 Introduction.....	103
5.2 Case study aims.....	103
5.3 Study design.....	104
5.3.1 The case study .....	104
5.3.2 Types of case study: .....	105
5.3.3 The case and its units of analysis.....	107
5.3.4 Theoretical propositions.....	107
5.3.5 Generalization and the case study.....	108

5.4 Summary .....	109
<b>6. Chapter Six: Pre-Implementation Work.....</b>	<b>110</b>
6.1 Introduction.....	111
6.2 Aims.....	111
6.3 Access to setting and approaching participants.....	111
6.3.1 Level one: higher administrative levels.....	112
6.3.2 Level two: intermediate managerial level.....	115
6.3.3 Level three.....	116
6.4 Administration support.....	116
6.5 Champions .....	117
6.6 Sample and recruitment .....	119
6.6.1 Healthcare providers .....	119
6.6.2 Patients and their family caregivers.....	119
6.6.3 Medical records .....	120
6.6.4 Others.....	120
6.7 Data collection techniques .....	121
6.7.1 Questionnaires survey .....	122
6.7.2 Semi-structured interviews .....	124
6.7.3 Observation .....	127
6.7.4 Document review.....	129
6.7.5 Archival records.....	130
6.8 Rigour.....	131
6.9 Summary .....	133
<b>7. Chapter Seven: Data Analysis.....</b>	<b>134</b>
7.1 Introduction.....	135
7.2 Analysis in case study .....	135
7.3 Preparing the data for analysis.....	135
7.3.1 Quantitative data.....	135
7.4 Statistical analysis .....	137
7.4.1 Descriptive statistics .....	138
7.4.2 Bivariate analysis.....	138
7.5 Qualitative data and analysis .....	140
7.5.1 Analysis.....	141
7.6 Summary .....	144



<b>8. Chapter Eight: Cancer Pain Management: Results of Pre-Implementation Work.....</b>	<b>145</b>
8.1 Introduction.....	146
8.2 Description of the main units of analysis .....	146
8.2.1 Patients .....	146
8.2.2 Family caregivers.....	148
8.2.3 Healthcare workers .....	149
8.3 Cancer pain prevalence, severity and interference with daily living life .....	149
8.4 Pain assessment and management in the oncology unit .....	153
8.5 Pain management adequacy in the Oncology Unit.....	155
8.6 Barriers to cancer pain management.....	157
8.7 Factors contributing to inadequate cancer pain management .....	167
8.8 Summary .....	179
<b>9. Chapter Nine: Nurses Education and Evaluation Work.....</b>	<b>180</b>
9.1 Introduction.....	181
9.2 Education programme .....	181
9.3 Evaluation .....	185
9.4 Data collection techniques .....	185
9.4.1 Interviews.....	186
9.4.2 Medical files .....	186
9.4.3 Observation .....	187
9.5 First follow-up.....	187
9.6 Second follow-up.....	187
9.7 Summary .....	188
<b>10. Chapter Ten: Results of the Evaluation Work .....</b>	<b>189</b>
10.1 Introduction .....	190
10.2 Patients' characteristics .....	190
10.3 Pain prevalence and severity.....	191
10.4 Pain reporting .....	193
10.5 Tool adoption and sustainability.....	195
10.6 Adequacy of pain management.....	196
10.7 Nurses' experience of the BPI.....	200

10.8 Summary .....	205
<b>11. Chapter Eleven: Discussion, Conclusions and Recommendations .....</b>	<b>206</b>
11.1 Introduction .....	207
11.2 Transcultural use of PARIHS model .....	208
11.3 Implementing the evidence: lessons learnt .....	211
11.4 Barriers to cancer pain: a multi-factorial problem .....	216
11.5 Pain monitoring programme outcomes .....	219
11.6 Strengths and limitations of the study .....	222
11.6.1 Study limitations .....	222
11.6.2 Study strengths and contributions to knowledge .....	224
11.7 Conclusions.....	226
11.8 Recommendations .....	227
References .....	230
Appendices .....	247

**Word count: 66 724**

## List of tables

Table 1.1 Number of hospitals and beds in Jordan by sector.....	23
Table 2.1 Physiological pain classification.....	32
Table 2.2 Cancer pain prevalence .....	34
Table 2.3 Cancer pain classification systems .....	36
Table 2.4 Research studies that have implemented a pain assessment tool in practice.....	42
Table 2.5 MPQ and BPI main features.....	50
Table 2.6 Levels of cancer pain medication .....	54
Table 2.7 Studies exploring healthcare providers-related barriers to cancer pain management.....	58
Table 2.8 Patient-related barriers to cancer pain management.....	66
Table 2.9 Family caregiver-related barriers to cancer pain management .....	69
Table 3.1 Characteristics of good innovation .....	78
Table 3.2 Innovation decision making process.....	79
Table 6.1 Champions' suggestions .....	118
Table 6.2 Data Collection in pre-implementation stage .....	122
Table 6.3 Interview guide .....	125
Table 6.4 Interview personnel .....	126
Table 6.5 Reviewed documents .....	129
Table 7.1 Thematic Analysis Process .....	141
Table 7.2 Thematic analysis example .....	143
Table 8.1 Patients' demographics.....	147
Table 8.2 Disease-related patients' characteristics .....	148
Table 8.3 Family caregivers' demographics .....	148
Table 8.4 Descriptive statistics for pain intensity measures .....	151
Table 8.5 Pain interference .....	151
Table 8.6 Relationship between patients' age and pain interference indicators ....	152
Table 8.7 Nurses' pain assessment practice.....	153
Table 8.8 Nurses' perception of pain assessment tool.....	154
Table 8.9 Indicators of pain management in the unit.....	156
Table 8.10 Means and CI of BQ sub-scales.....	158
Table 8.11 Independent t-test results analysing the difference in mean total BQ score between two groups .....	159

Table 8.12 Spearman’s correlation coefficient analysing the relationship between total BQ score and age, and pain severity indicators .....	159
Table 8.13 The mean scores for the BQ subscales.....	160
Table 8.14 Independent t-test results analysing the difference in mean total BQ score between two groups .....	161
Table 8.15 Mean scores and CI for BQ sub-scales. ....	162
Table 8.16 Independent t-test results analysing the difference in mean total BQ score between two groups .....	163
Table 8.17 Dependent t-test results analysing the difference in mean total BQ score between two groups.....	163
Table 8.18 Patients’ response on additional comment made according to their category .....	165
Table 8.19 Misconceptions and examples from nurses’ responses .....	178
Table 9.1 Participants’ role in the evaluation work .....	186
Table 9.2 Interview questions .....	186
Table 10.1 Patients’ characteristics .....	190
Table 10.2 Comparisons between patients in pre- and post-implementation .....	191
Table 10.3 Pain prevalence through study stages.....	192

## List of figures

Figure 2.1 Searching Procedure .....	31
Figure 2.2 VAS .....	47
Figure 2.3 The WHO ladder of analgesic cancer pain treatment.....	53
Figure 3.1 Research Utilisation Model .....	84
Figure 4.1 Pain assessment and management steps in the Oncology Unit .....	93
Figure 4.2 Nursing department structure and reporting .....	95
Figure 6.1 Levels of access .....	113
Figure 8.1 Distribution of worst pain score .....	150
Figure 8.2 The distribution of patient PMI scores.....	155
Figure 8.3 The distribution of the total score of BQ – patients.....	157
Figure 8.4 The distribution of total BQ for family caregivers .....	160
Figure 8.5 The distribution of BQ scores for healthcare provider participants .....	162
Figure 10.1 Distribution of worst pain score .....	193
Figure 10.2 Nurses’ pain reporting before and after the intervention .....	194
Figure 10.3 The use of pain assessment tool in daily practice .....	195
Figure 10.4 PMI scores by study stage .....	197
Figure 10.5 The impact of using tool on PMI.....	199

## List of pictures

Picture 1.1 Map of Jordan .....	19
Picture 4.1 Oncology Unit entrance .....	90
Picture 4.2 Typical patients’ room .....	90

## List of Abbreviations

ANOVA	Analysis Of Variance
BNI	British Nursing Index
BPI	Brief Pain Inventory
BQ	Barriers Questionnaire
CDSR	Cochrane Database of Systematic Reviews
CI	Confidence Interval
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CNO	Chief Nurse Officer
CNOA	Chief Nurse Officer Assistant
EAPC	European Association of Palliative Care
FC	Family Caregiver
HN	Head Nurse
IASP	International Association for the Study of Pain
JCI	Joint Commission International
JNC	Jordan Nursing Council
JNMC	Jordanian Nurses and Midwives Council
MOH	Ministry of Health
MPQ	McGill Pain Questionnaire
N	Nurse
NHS	National Health Service
NRS	Numerical Rating Scale
PARIHS	Promoting Action on Research Implementing Health Services
PMI	Pain Management Index
PMP	Pain Monitoring Programme
RCT	Randomised Control Trial
RD	Resident Doctor
SD	Standard Deviation
SPSS	Statistical Package for the Social Sciences
UM	Unit Manager
VAS	Visual Analog Scale
VRS	Verbal Rating Scale
WHO	World Health Organization

## List of appendices

Appendix 1: Hawker’s assessment tool .....	247
Appendix 2: Brief pain inventory (long form).....	250
Appendix 3: Brief pain inventory (short form) .....	252
Appendix 4: McGill pain questionnaire (long form) .....	254
Appendix 5: McGill pain questionnaire (short form).....	255
Appendix 6: Hospital approval .....	256
Appendix 7: Consent form .....	257
Appendix 8: Information sheet .....	259
Appendix 9: University of Manchester ethics committee approval.....	266
Appendix 10: Demographic data sheet .....	267
Appendix 11: Barrier questionnaire.....	269
Appendix 12: Permission to use the BQ .....	273
Appendix 13: Arabic barriers questionnaire .....	274
Appendix 14: Permission to use the BPI .....	278
Appendix 15: Arabic BPI .....	279
Appendix 16: Example of observation notes .....	281
Appendix 17: Data extraction sheet .....	282
Appendix 18: Pain indicators comparisons between two group.....	283
Appendix 19: The mean score for patients resapons on BQ .....	285
Appendix 20: The mean score for family caregivers’ response on BQ.....	286
Appendix 21: The mean score for healthcare providers’ response on BQ .....	287
Appendix 22: Education course lectures handout. ....	288

## **Abstract**

### **The University of Manchester**

Abstract of thesis submitted by Mohammad Al Qadire on 14 October 2011 for the Degree of Doctor of Philosophy, entitled:

#### **An Implementation Study to Improve Cancer Pain Management in Jordan using a Case Study**

Managing the symptoms of cancer effectively is one of the most important challenges facing health care providers. Many symptoms are reported by cancer patients, including, pain, depression, distress and change in life style. Pain continues to be the most frequently reported symptom, however, cancer pain is treated inadequately and cancer patients continue to suffer pain. The use of pain assessment tools is essential to effectively manage cancer pain. Despite that, research findings indicate that pain assessment tools are routinely not used in practice. In addition, there is a paucity of data about cancer pain management in Jordan, and no published information is available about adult cancer pain assessment and barriers to optimal pain management in the country.

A single-site case study with mixed methods was used to implement and evaluate a pain monitoring programme (PMP). The PMP was comprised of a pain assessment tool and included pain education of 6 hours for nurses, the goal of which was to improve cancer pain management. This case study was conducted in a referral hospital in the northern part of Jordan. Overall, 130 patients and their medical records, 6 physicians, 12 nurses, 50 family caregivers, two nurse administrators, and two Islamic scholars participated in this study. Quantitative and qualitative data were collected, using observation, semi-structured interviews, medical chart audit and questionnaires that included a demographic data sheet (DDS), brief pain inventory (BPI), and barriers questionnaire (BQ). The study utilized the Promoting Action on Research Implementation in Health Services (PARIHS) and aspects of change theory model as a framework to guide the study. Quantitative data were analysed using both inferential and descriptive statistics using SPSS release 17. Qualitative data were translated from Arabic to English and thematically analysed. It was found that pain was prevalent among Jordanian cancer patients who were frequently under-medicated. Barriers to cancer pain management were identified and they were related to patients, healthcare providers and the setting (such as lack of knowledge, and belief in God's Will). Moreover, introducing the PMP into practice might improve the adequacy of cancer pain treatment. The results of this case study showed that the implementation process is multi-layered and complex. Using the Champions, nursing administration support, and recognition of the need for change, and education were seen as determinants of successful implementation process within the Arab-Islamic culture. The PARIHS model was found to be helpful in guiding the process of knowledge translation and was suitable to the Arab culture.

The study results highlight that each implementation process should be designed based upon the needs, culture, and norms of its context. In addition, it confirmed the need for assessing pain in order to have better pain management. Overall, it is suggested that having PMP in force in each healthcare setting may serve the ultimate goal of optimal cancer pain management.



## **Declaration**

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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## **Dedication**

This thesis is dedicated to all cancer patients who are suffering pain throughout the world.

## **Acknowledgments**

Although only my name appears on the first page, many people have been generous with their help and support during this study and I would like to thank them here. First, my thanks go to the School of Nursing and Midwifery in Al albayiet University, which awarded me a scholarship to pursue full-time doctoral studies. I am particularly grateful to Professor Karen Luker and Dr Clifford Richardson, my research supervisors, for their support during the last three years. Thank you for the guidance and empathy during the hard times of my study.

Thank you to my family, in particular my parents who always keep supporting my decisions and thanks for being proud of me. And many thanks to my brothers and sisters who were always encouraging me to carry out my PhD study. Thanks to my friends in the UK and Jordan for their continuous love and confidence. Thanks for Maen Jezawi, Salam Khateeb, Abdullah Shdefat, Mohammad Hijjawwi, and Mohammad Ghattas for their continuous empathy and sharing the difficult times together. Thanks to all participants in my study for making my work real and possible.

My special thanks go to my wife Wafa, my daughter Rama and my son Faris for enlightening my life and giving me the strength to accomplish this work. They were inspiring me and taught me that even the largest task can be accomplished if it is done one step at a time.

## **The Author**

The author completed his Bachelor's degree in Nursing in 2003, and then worked as an oncology nurse for three years. This raised his interest to enrol in a Master's programme pertaining to oncology nursing in 2004. In 2005 he was appointed as Head Nurse of an established Oncology care unit. By 2006 he gained his Master's degree and got a post in a research centre in Saudi Arabia. The author worked for two and a half years as a Research Assistant in the clinical Research and Empirical Ethics Department in King Faisal Specialist Hospital and Research Centre. In January 2009 he commenced his doctoral studies. The author's research interests are related to cancer symptoms' management in general and pain in particular, palliative care nursing and empirical ethics.

# **1. Chapter One: Introduction**

## **1.1 Background of the problem**

The incidence of cancer is rising and its treatment is costly to the health services and individuals worldwide (Higginson and Costantini, 2008). According to the Jordanian Cancer Registry, about 5862 new cancer cases were diagnosed during 2007 (Taraweneh and Nimri, 2007). When an individual receives a diagnosis of cancer it is perceived as potentially life threatening, and many symptoms are reported by cancer patients, including pain, depression, distress, and change in lifestyle. However, pain continues to be the most frequently reported symptom (Berry and Dahl, 2000; Everdingen et al., 2007). The International Association for the Study of Pain (IASP) defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (Merskey and Bogduk, 1994). Pain is a universal human experience, and the World Health Organization (WHO) declared some time ago that cancer pain is a worldwide problem which needed more collaborative work to reach the optimal level of control (Stjernsward and Teoh, 1990). Cancer patients currently live longer than previously because of earlier diagnosis and developments in treatment medications and techniques. However, patients are exposed to painful diagnostic procedures and cancer and its treatment can be painful (Portenoy and Lesage, 1999). Therefore, cancer patients are expected to experience pain. Although guidelines and pharmacological interventions exist to manage cancer pain, poor assessment and under-medication is well-documented in the UK, US, Canada, France, and Asia (Breivik et al., 2009).

Recently, Everdingen et al. (2007) conducted a systematic review in order to determine pain prevalence among cancer patients. They reviewed 54 articles published over 40 years, and found that 64% of cancer patients experience pain in the advanced stages, 54% during the treatment period (chemotherapy, radiotherapy and others), 33% after completion of the treatment regimen, and the prevalence in all types (pooled prevalence) was > 50% (Everdingen et al., 2007). In addition, one-third of cancer patients described their pain as moderate to severe (Everdingen et al., 2007; Potter et al., 2003). A recent European survey on pain prevalence showed that 56% of cancer patients experienced moderate to severe pain monthly (Breivik et al., 2009). Pain control is a vitally important goal, as neglected pain can cause patients to lose hope, impede their response to treatment and negatively affect their quality of life (Al-Atiyyat, 2008; Portenoy and Lesage, 1999; Sykes et al., 2003). In addition, the use of a pain assessment tool is advocated as essential to effectively manage cancer pain (Raphael et al., 2010a). Despite this, research findings indicate that pain assessment tools are not used routinely in daily nursing practice (de Rond et al., 1999; Finley et al., 2008; Martoni

et al., 2007). Whilst there is evidence on the prevalence of cancer pain and its treatment in Western countries, there is as yet no such information about pain among Jordanian cancer patients. There is paucity of data about cancer pain management in Jordan, with no published information available about cancer pain assessment, documentation, management, and barriers to cancer pain management. This study employs a case study approach for the implementation and evaluation of a pain monitoring programme in a Jordanian hospital. This study is designed to provide an in-depth understanding of the implementation process within the context of Islamic Arabic culture, and to provide preliminary information about the current cancer pain management practised in Jordanian hospitals.

The author previously worked as an oncology nurse in the study hospital for three years, and observed that patients seemed to be suffering pain without adequate treatment. Many cancer patients were in pain in the unit but they were silent, and few of them were treated for pain. This motivated the author to investigate this topic further and shed the light on cancer patients suffering in Jordan.

## **1.2 Thesis organization**

This thesis comprises eleven chapters; it starts with the introduction chapter. Chapter 2 provides overviews of the related literature covering cancer pain prevalence assessment and management. It also deals with barriers to cancer pain management. Chapter 3 presents the theoretical framework which underpinned the study. Chapter 4 describes the pilot work that was undertaken prior to the main study. It demonstrated that study was timely and feasible within the hospital. Chapter 5 outlines the theoretical knowledge of the used research method. It highlights the justification for the use of case study design and deemed it to be suitable to answer the study inquires. It also defines the case of interest and its unit of analysis. Then chapter 6 provides an account of the pre-implementation phase working methods in terms of getting access, sampling, data collection methods, data resources and justification of the used data sources and methods. In chapter 7 data analysis techniques that were used in the study are presented. Chapter 8 details the results of the pre-implementation phase that were about the status of cancer pain management in the oncology unit prior the introduction of the change (pain monitoring programme (PMP)). It also highlighted the available barriers to cancer pain management in the unit as well. Chapter 9 provides an overview of the provision of the PMP that consisted of education sessions and the use of pain assessment tool (Brief Pain Inventory BPI). So, this chapter detailed information of the education course then deals with the evaluation working method in terms of data collection and follow-up procedures. Chapter ten presents the

results of the post-implementation evaluation work that also included comparing cancer pain management status before and after the introduction of the PMP in the unit. Nurses' experience of using the BPI inventory is also presented. The final chapter (chapter eleven) discusses the main study findings and sheds light on the study limitations and strengths. It ends with recommendations for clinical practice, policy makers, and researchers.

### 1.3 Study context description

To set the study in context, a description of the culture, healthcare system and nursing in Jordan follows.

#### 1.3.1 General information

##### 1.3.1.1 Jordan the land

Jordan is a small country (with an area of about 35,475 square miles) located in the centre of the Middle East. It is surrounded by Syria to the north, Iraq to the east, Saudi Arabia to the southeast and Palestine to the west (see map, below) (Federal Research Division, 2006). It is mainly covered by desert except for the cooler north-western part of the country, which receives more rain than other parts, although this fluctuates from year to year (Federal Research Division, 2006). Jordan also has a fertile valley which is a part of the Great Rift Valley. This used to supply Jordan with many crops such as vegetables and fruits (Federal Research Division, 2006).

**Picture 1.1 Map of Jordan**



**Source:** <http://www.wordtravels.com/Travelguide/Countries/Jordan/Map>

### **1.3.1.2 Jordan population**

According to the Jordan National Census in 2004, Jordan's total population is approximately 5.1 million. Jordan is divided into 12 cities, of which Amman is the largest, with 2 million inhabitants (The Hashemite Kingdom of Jordan Department of Statistics, 2004). However, 78 percent of inhabitants live in urban areas (Multicultural America, 2006).

The Jordanian population comprises 51.5% males, and 94% Muslims. In addition, 6% are Christians, including various denominations such as Greek Orthodox, Roman Catholic, Greek Catholic, Armenian Orthodox, Assyrian, Maronite, and assorted Protestant churches among others (Federal Research Division, 2006; The Hashemite Kingdom of Jordan Department of Statistics, 2004). Jordan adopts the religious freedom principle, thus everyone has the right to practice religious beliefs without fear of restraint (Multicultural America, 2006). Only 2% of Jordanians are non-Arab, being mainly Caucasians, Chechens, Armenians, Turkmen and Gypsies. According to a US report (2006), about 33 percent of the Jordanian population is under 15 years old, 62 percent is between 15 to 64 and only about four percent are older than 65 (Federal Research Division, 2006). Average life expectancy for Jordanians is 78 years (Jordan Ministry of Health, 2008). Arabic is the official language, but English is widely understood and used in higher education institutions, hospitals and large companies (Federal Research Division, 2006).

### **1.3.1.3 Education**

The Jordanian government reported literacy rates for 2003 as 90.1%. Primary and secondary education until the age of 15 is free and compulsory. The government is working on improving the output of education processes, and about 18% of the total budget is dedicated to education (Federal Research Division, 2006; Multicultural America, 2006). There are about 26 universities (private and public) in Jordan, and females comprise half of attendees. The Government is working to improve the Jordanian work force's competitiveness internationally.

### **1.3.2 Jordanian culture**

The culture of Jordan is the Arabic Islamic culture, which comprises people's beliefs, rituals and values. However, Western culture is apparent in the daily life of Jordanian people, expressed in dress, architecture and even spoken language (Federal Research Division, 2006). Non-Arab minority groups in Jordan have been assimilated into the indigenous culture to the extent that it is difficult to distinguish



them from native people. Jordan has a reputation for the acceptance and tolerance of others (Multicultural America, 2006).

Jordanian districts have their own specific cultural characteristics, but they remain within the overall Arabic Islamic cultural sphere. It is very difficult to describe the country's culture in a few pages, but the main features of Jordanian culture that might be related to this case study have been highlighted.

### **1.3.2.1 Cultural aspects in daily life in Jordan**

People are habitually greeting each other as they pass in the streets, even people who don't know each other. It is common for people to invite each other for lunch or dinner at home, and all are happy to accept the invitation. In some areas it is even considered an insult not to accept an invitation (Multicultural America, 2006).

Women usually dress modestly and even conservatively in rural areas, and revealing a woman's body is not appreciated. Most women wear headscarves, and some women veil their head and face. The separation between men and women is maintained everywhere in public, although there are no official regulations in this regard (Multicultural America, 2006). The traditions, culture and Islamic beliefs govern the way people deal with each other. Men and women cannot date, socialize or have sexual intercourse before marriage. In most areas of Jordan (except for some high social class districts) women and men are not supposed to appear in public with each other without being engaged or married (Multicultural America, 2006).

### **1.3.2.2 Decisions within the family**

Decisions are usually negotiated within the family, mainly by the father and mother. There is an assumption that decisions should not be taken in the absence of the head of the family (Gharaibeh and Abu-Saad, 2002). The modern Jordanian family shares these decisions, but in some geographical areas the older male member is dominant and some other relatives can contribute to the decision. The family is the single unit of the Jordanian community. It has its own rules that can penalize or motivate its members. For example, if a member went against the rules, this might result in that member's social ostracism. With the advent of globalization these traditions are on the wane, but it can still be seen in rural areas.

### **1.3.2.3 Gender issues**

Women can work and earn the same amount of money for the same work as men, and sometimes get extra payment (Multicultural America, 2006). Despite difficulties such as the need to obey the husband and to adhere to traditional mores, women practice many professions, including taxi drivers, teachers, nurses, and even ministers. Same sex friends can hug, hold hands, and kiss each other in public; restrictions apply only to the interaction of men and women (Multicultural America, 2006). It is normal to initiate conversation with a woman in a work environment or chat, but any form of physical contact is prohibited. In healthcare settings, male nurses or doctors can take care of female patients. However, some women or men prefer to be treated by a healthcare professional of the same gender. It is common practice that a woman is chaperoned when treated by a male healthcare worker.

### **1.3.2.4 Religious practice**

Muslims pray five times a day, either at home or in the *Masjid* (mosque), and it is normal to hear the call for prayer in public and church bells on Sundays. All adult male Muslims are expected to attend the communal Friday midday prayer (*Dohar*) in the Masjid. For reasons of hygiene and social taboo, Muslims and non-Muslims should remove their shoes when entering a Masjid. Flip-flop sandals should be worn in bathrooms. When sitting with others, it is disrespectful behaviour to raise the bottom of one's shoes in the face of others, or on a coffee table (Multicultural America, 2006).

### **1.3.3 Healthcare system in Jordan**

Jordan has a well-developed healthcare system in comparison to other countries in the region (Federal Research Division, 2006). The prevalence of Human Acquired Immunodeficiency (HIV) is 0.1 percent, Jordan has been malaria-free since 2001, and tuberculosis has decreased by half since 1990 (Federal Research Division, 2006; Jordan Ministry of Health, 2008). According to a Ministry of Health report (1999), about 70% of the Jordanian population are medically insured, and the government is working to increase this percentage to reach comprehensive medical insurance coverage (Dwayne et al., 1999). It is believed that this figure has increased since this report was released 12 years ago, and because many actions were taken to increase the insurance coverage. For example, two years ago children under the age of six and senior citizens were added to the medical insurance umbrella. Generally speaking, the health care system in Jordan can be divided into two sectors: public and private (Jordan Ministry of Health, 2008).

### 1.3.3.1 Public health

This sector includes:

- 1- Ministry of Health (MOH) hospitals and primary medical centres: these are operated by the MOH and are fully funded by the government; this provision is available all over the country in cities and villages. All citizens of Jordan can be treated in these hospitals without paying.
- 2- Military Royal Medical services: these are composed of large hospitals distributed throughout the whole country, operated by the leadership of the armed forces. The health services are provided to soldiers and their families, and civilians can access these services under some circumstances.
- 3- University hospitals: these hospitals are affiliated with two universities (the University of Jordan and the Jordan University of Science and Technology). They are referral hospitals for complicated cases.

### 1.3.3.2 Private health sector:

The private sector is operated by personal investment, and it provides about 36% of available hospital beds in the country, see table 1.1. The private sector is parallel and complementary to the public sector, and it is well-developed, being the destination for many foreign patients who come from other countries (i.e. Iraq, Egypt, Sudan, and Syria) for medical treatment.

**Table 1.1: Number of hospitals and beds in Jordan by sector**

Health sector	No. hospitals	No. beds	Percentage
Ministry of Health	28	4333	39
Military Royal Medical Services	12	2129	19
University Hospitals	2	1026	9
Private hospitals	56	3712	33
<b>Total</b>	<b>98</b>	<b>11200</b>	<b>100</b>

Source: (Jordan Ministry of Health, 2008)

### 1.3.3.3 Primary healthcare services in Jordan

The Ministry of Health (MOH) provides primary care services through an extensive network of medical centres in the Kingdom. These centres provide various medical

services, such as: general medicine, dentistry, maternity and paediatric care, and health education as well as specialized health promotion services (e.g. smoking cessation clinic) (Jordan Ministry of Health, 2008).

MOH classifies its medical centres into three categories:

- 1- Comprehensive Medical Centres: provide general medical care, laboratory tests, and x-ray. In addition dental care is available. No inpatient care.
- 2- Elementary Medical centres: located in small villages. Provide general medical care only and serious illnesses are refers to the comprehensive medical centre or hospital.
- 3- Maternity and childhood care centres: solely provide care for women and their babies. These services include follow-up care for pregnant women, vaccination, and family planning, in addition to growth and development follow-up for children.

Patients are expected to visit these centres prior going to main hospitals. Services at these centres are available for all inhabitants in Jordan. In some cases a small fee could be charged.

#### **1.3.3.4 Cancer treatment**

Cancer can be diagnosed at primary or tertiary medical care settings. If cancer has been diagnosed at a primary medical setting, the patient is usually referred to the nearest setting where cancer treatment is available, where the diagnosis is confirmed and treatment initiated. All inhabitants are eligible for free cancer treatment regardless of their medical insurance status. This includes all related expenses such as admission, all types of cancer therapy, and also pain medications. Alternatively, patients can go directly to a private hospital if they wish to pay the cost of medical care.

#### **1.3.4 Nursing in Jordan**

Professional nursing began more than 50 years ago. The nursing profession has started to gain community respect, and it is now widely known and appreciated. Jordan currently supplies most of the Arab Gulf countries with a nursing work force.

Nursing education in Jordan has grown rapidly. It was started in associate nursing colleges, and bachelor degree courses began in 1972. Now there are at least 12 nursing schools with bachelor degree programmes, three schools grant master

degrees, and one school launched a PhD programme in 2005. In addition, the Jordanian Nurses and Midwives Council (JNMC) was established in 1972 to regulate the nursing profession, monitor nurses' conduct and prevent nurses' abuse in the work environment (Jordan Nurses & Midwives Council, 2009). Each nurse should register with the council, and nurses are not allowed to practice without being registered. According to the JNMC there are 18 874 registered nurses and midwives, 53 percent of whom are males (Jordan Nurses & Midwives Council, 2009). The JNMC provides continuous education for nurses to maintain and extend their knowledge, besides skills such as acute care, cancer care, and life support courses (Jordan Nurses & Midwives Council, 2009). In 2003 the Jordanian Nursing Council (JNC) was established, and its members are from academic and clinical areas. The JNC aimed to enhance the efforts to support nursing as a profession, and to improve education and nursing research (Jordanian Nursing Council, 2009). The JNC set the strategic plan for the nursing profession and standardized nursing care in Jordan as far as possible (Jordanian Nursing Council, 2009).

#### *Pain management education in nursing schools*

It was not possible to find literature related to pain education in Jordanian nursing schools. Instead, pain education was examined using course syllabuses and the content of lectures on pain management. The syllabuses of three main courses were 'Fundamentals of Nursing Practice' (theory and clinical), and 'Adult Health Nursing' One and Two (theory and clinical). These syllabuses belong to four universities, from which the nurses in this study graduated, that are the University of Jordan, Jordan University of Science and Technology (JUST), the Hashemite University, and Al al-Bayt University.

#### *Courses content*

The 'Adult Health Nursing' courses (theory and clinical) are second year level courses. Course objectives and goals did not include pain management skills teaching or any similar topic. Syllabuses contained almost nothing about pain. Course syllabuses varied in length, ranging from two to twelve pages. There were topics usually linked to pain, such as cancer management and pre- and post-operative nursing care, although pain was not specifically covered under these topics. However, the clinical parts as written included nothing about pain.

In regard to 'Fundamentals of Nursing Practice', which is a first year level course, one lecture entitled pain or pain management was found in all schools' syllabuses. This lecture was only one hour long, and no further details were given about its content in the three syllabuses. Only the syllabus belonging to the nursing school in

JUST, included objectives and sub-headings for the lecture content. The objectives were mainly concerned with pain physiology, and other areas of pain received little or no attention. The main goal was to teach students about the various types of pain, and to differentiate between pain threshold and pain tolerance. The last one was to identify barriers to effective pain management. Therefore, it was clear that nurses were equipped with only one contact teaching hour to manage pain and master its art.

## **1.4 Summary**

Jordan has a Westernised system of healthcare; in general nurses are well-educated, but have little specific education on pain management and therefore gain most of their expertise in this area from working in clinical practice. As mentioned earlier, the author's informal observations of pain management on a cancer unit in Jordan suggest that this is an area that requires further investigation. Jordan represents a culture (Arab culture) about which little is known with regard to cancer pain management. Therefore, the next chapter examines the available literature on the topic.

## **2. Chapter Two: Literature Review**

## **2.1 Introduction**

This chapter starts with a description of the used search strategy and the quality issues of the reviewed studies, and provides an overview of cancer pain aetiologies, classification, assessment and management. It provides a description and discussion of previous studies that implemented a pain assessment tool into practice. In addition, the chapter discusses the barriers to effective cancer pain management, and the nursing role in cancer pain management.

## **2.2 Search strategy**

The search strategy was influenced by the nature of the project, which is intended to explore a process of the implementation of a pain monitoring programme. It was clear that reviewing the literature on pain assessment, management and the barriers to adequate cancer pain management was essential prior to conducting the study. This is because it was needed to identify if similar work had been conducted in Jordan or not. In addition, it provided a background for the researcher to understand cancer pain management's main concepts, and develop a research method to be used in the study. The search used a systematic approach. Initially literature published from 1990 to 2010 was included; the year 1990 was marked as important because of the publication of the WHO report and guidelines on cancer pain management (Jadad and Bowman, 1996; MacCaffery and Pasero, 1999). At the same time, seminal older articles were used due to their value and impact on the field. Literature on pain assessment and management were included dating from 1995. This is because it was thought that assessment techniques or management interventions that were published before 1995 may not be up to date. The area before 1995 can be described as the formulation of the fundamentals of advanced knowledge of pain and its management process. Therefore, published articles from the last 15 years were targeted. The search was started in 2009, and the final update was in June 2011. The search terms that were used in this search were the following:

**Pain assessment, pain management, cancer pain assessment and management ± Jordan, barriers to cancer pain management ± patient or healthcare providers, pain assessment tool into practice ± implementing, using, introducing, and feasibility.**

In general, for each review a list of possible search terms was developed to search the following databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, British Nursing Index (BNI) and the Cochrane Database of Systematic Reviews (CDSR). In addition, Google Scholar was also used to search



for grey literature posted on websites of nursing or pain research groups, and it was also possible to connect with different databases. This was helpful in locating new articles that were not identified by the databases search. Searching databases using the generated search terms yielded more than one thousand articles. Searching and reading the suggested results would be very time-consuming. Thus, the following limits were applied to the search:

- 1- The search was limited to English literature (in Jordan, health literature is usually published in English).
- 2- Date limits from 1990-2010 for the articles about barriers to cancer pain assessment, and from 1995 for the rest of literature about cancer pain assessment and management were used.
- 3- Literature that related to **cancer** pain in **adult** patients only was included, with the exception of one study which was conducted on paediatric patients in Jordan, which was included because it was the only study found relating to cancer pain in Jordan.

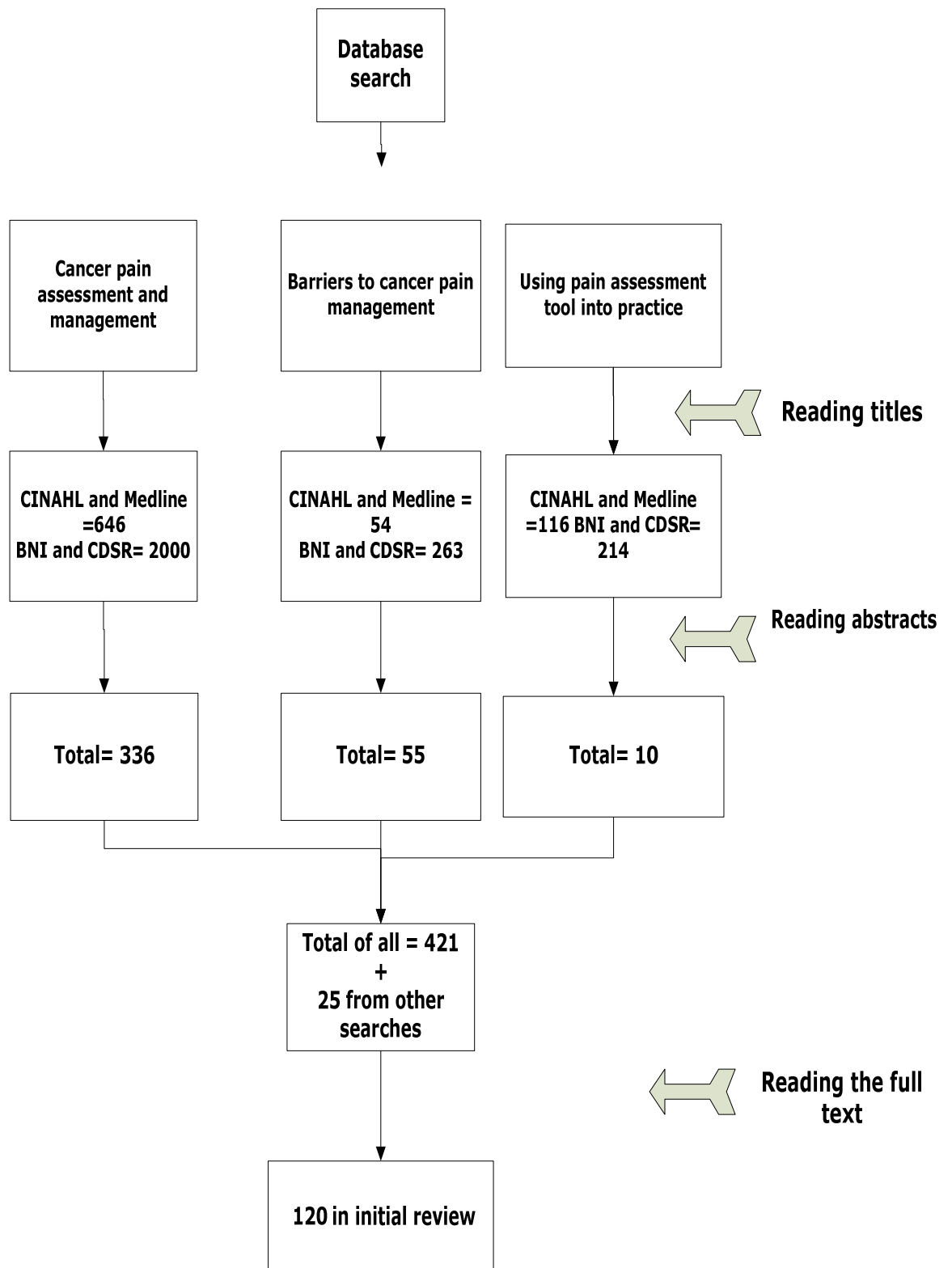
Despite the applied search restrictions, the search terms still resulted in a large number of studies. The search procedure was as follows (see figure 2.1): the researcher firstly put the search terms in the database search engine; the results appeared and then researcher read through the articles' titles. Then, the related articles were saved to a folder. Secondly, the researcher read article's abstracts to exclude unrelated articles and then the full texts were extracted. Thirdly, the researcher read the full articles and used them in the review. However, at this stage other articles were excluded for reasons such as: non-cancer population, not related to cancer pain assessment, included a cognitive therapy or articles related to cognitively impaired patients.

The reference list of articles was checked to identify further possible studies. This was conducted to ensure comprehensive coverage and to check for any significant work of which the researcher might be unaware. Also, some significant authors in the field were contacted and asked about unpublished work if available, or to ask for articles unavailable online or as hard copies. This resulted in gathering 55 related studies. Furthermore, the email alert features of the databases were utilized, which enabled the researcher to be up to date with newly published studies. Overall, 120 articles were eligible for the review.

## **2.3 Quality issues**

Hawker's et al (2002) tool was used to assess the quality of research papers used in cancer pain assessment and barriers sections. In Hawker's method, a number of areas are rated on a 4-point scale from 1 (very poor) to 4 (good). The areas included abstract and title; introduction and aims; method and data; sampling; data analysis; ethics and bias; findings/results; transferability; implications and usefulness (Hawker et al., 2002)(see appendix 1). Therefore, each article was assigned a score out of 36 (the maximum score that an article can get). The researcher used this tool because it can be used for qualitative and quantitative studies. In addition, giving the score may provide the reader with an overall estimation of paper quality. There is no cut-off point in score that distinguishes good quality from low quality articles; therefore, the higher the total score, the better the quality. Quality issues were considered for each single paper and were indicated within the text or in the form of a collective discussion of the reviewed papers. Suggestions for further research were also indicated.

**Figure 2.1: Searching Procedure**



## 2.4 Cancer pain

### 2.4.1 Aetiology

Cancer pain may result from tumours invading pain-sensitive structures such as bone, soft tissue, nerves, viscera and blood vessels, or from cancer treatment (Raphael et al., 2010a). Pain categories have been described as nociceptive pain (somatic and visceral) and neuropathic pain (see table 2.1). The nociceptive pain results from the direct activation of nociceptors caused by cancer infiltration of tissue, or as a complication of cancer treatment regimens. On the other hand, neuropathic pain is caused by damage in a central or peripheral component of the nervous system. Neuropathic pain is difficult to treat (Patt, 1993), however, understanding and identifying the underlying pain cause can help in planning and acting to eliminate the pain and suffering, and in selecting the right treatment choice (Skarin et al., 2000). Table 2.1 was constructed using information from the following sources: (Patt, 1993; Portenoy and Lesage, 1999; Raphael et al., 2010a; Raphael et al., 2010b; Sykes et al., 2003).

**Table 2.1 Physiological pain classification**

Pain Categories		Mechanism	Characteristics	Treatment
Nociceptive	Somatic	Activation of Nociceptive receptors by: mechanical, thermal and chemical (ATP, Prostaglandin E1, E2) stimulus	Constant, sharp, localized and described as; aching, throbbing or gnawing	Opioid, neurological blocking by medication or surgery NSAIDs
	Visceral	Damaged to sympathetically innervated organs or by chemical irritation	Deep, dull, squeezing, sometimes nausea, vomiting, changes in blood pressure and pulse rate.	Opioid
Neuropathic		Damaged parts of nervous system	Discomfort, tingling, numbing, pressing, unpleasant, or unbearable	Antidepressant, anticonvulsants, aspirin, corticosteroids, or electric stimulation of brain and spinal cord

## **2.4.2 Cancer pain prevalence**

Cancer pain is one of the worst experiences for cancer patients and their families (Deandrea et al., 2008). In a published systematic review about cancer pain over the last forty years, Everdingen et al. (2007) reported that more than 50% of cancer patients experienced pain. The review searched seven databases. It was well-conducted and provided strong evidence. The data about cancer pain prevalence information can be found in articles which may discuss topics that are not solely about prevalence. Therefore, this made searching and locating such information a time-consuming, difficult, and daunting task. However, table (2.2) summarizes the information about pain prevalence among cancer patients, and it is consistent with Everdingen et al.'s (2007) review. Most of these studies were conducted in specific institutions (local rather national), and they included relatively small numbers of patients. Furthermore, these studies in general were not originally designed to evaluate pain prevalence. Taking these concerns into consideration, the generalizability of such studies is limited and restricted to their context. For example, Forgeron et al.'s (2006) study, although conducted in Jordan, had information about pain among paediatric cancer patients, but used a small number of patients (n= 35).

No large-scale prevalence study has been performed in Jordan. This study may help in evaluating the magnitude of cancer pain to help policy makers to set future plans to fight cancer pain in the country. This can be achieved through the accumulation of cancer pain studies, and the current study serves this ultimate goal. Therefore, systematic reviews that are well-conducted may provide strong evidence, such as that of Everdingen et al. (2007). However, studies that included as many patients as 1000 or more, including all areas of the country of interest (representative sample), and random patients' selection also may provide a trustworthy evidence to depend on.

**Table 2.2 Cancer pain prevalence**

<b>Author, year</b>	<b>Country</b>	<b>Sample</b>	<b>Pain prevalence</b>	<b>Quality score</b>
(Forgeron et al., 2006)	Jordan	35	57%	23
(Ger et al., 1998)	Taiwan	296	69%	18
(Wang, 2008)	China	923	68%	15
(Bruster et al., 1994)	UK	5150	61%	30
(Menzies et al., 2000)	UK	186	28%	20
(Yun et al., 2003)	Korea	655	70%	21
(Breivik et al., 2009)	Czech Republic Denmark Finland France Ireland Israel Italy Norway Romania Sweden Switzerland UK	5084	70%	25
(Larue et al., 1995)	France	601	57%	23
(Beck and Falkson, 2001)	South Africa	263	35.7%	22
(García de Paredes et al., 2010)	Spain	8615	30%	26
(Holtan et al., 2007)	Norway	1337	52%	25
(Okuyama et al., 2004)	Japan	282	60%	22

### 2.4.3 Pain classification

Accurate pain categorization is important because it assists in understanding pain, and in addition it fosters better communication among health care providers by using a common language. No accepted classification system has emerged for malignant or non-malignant pain (Hjermstad et al., 2009; Melzack and Turk, 2001; Von Korff et al., 2000). Pain can be classified according to chronicity, pathophysiology, diagnosis and onset, each of which classifications has its own pros and cons (Caraceni et al., 2002; Hjermstad et al., 2009; Patt, 1993).

Firstly, based on chronicity, pain is divided into two categories; acute and chronic. Acute pain, which could last for hours, days and even weeks, is correlated with high stress levels and needs immediate treatment (Melzack and Turk, 2001; Schaible and Richter, 2004). In contrast, chronic pain lasts for months or even years, and is associated with chronic progressive diseases (e.g. cancer, arthritis and COPD).

Chronicity classification might provide information about pain duration, but not other pain aspects (Carr et al., 2010).

Secondly, physiological classifications differentiate between two main types of pain: nociceptive (somatic and visceral) and neuropathic pain. Each category has characteristics and treatment options (see table 2.1). Therefore, treatment may be initiated instantly after putting the patient's pain in one of these categories. However, this classification is not sensitive to individual differences among each group, such as gender, age, cognitive status, diagnosis, personal response to treatment and cultural background (Patt, 1993; Von Korff et al., 2000). This classification system does not completely describe the pain experience.

Thirdly, pain can be classified according to the disease name, for example low back pain, cancer pain and angina pain. On one hand, this classification implies a cause of pain and possible treatment interventions, but on the other hand, it is not sensitive to other factors contributing to the pain experience such as cultural background, attitudes and beliefs and spiritual needs (Melzack and Turk, 2001; Patt, 1993; Sykes et al., 2003).

Fourthly, pain onset might be a criterion for classification; constant pain, which is continuous in nature, might be treated with analgesic infusion (syringe drivers). In addition, unpredictable breakthrough pain might occur with eating, moving or socializing. In such pain, the use of Patient-Controlled Analgesia (PCA) or decreasing intervals between doses could be the treatment (Hjermstad et al., 2009; Patt, 1993). Intermittent pain is another form of pain, which is controlled by providing PRN doses.

Although these are commonly utilised classifications, they are not sufficiently descriptive for the complex and multidimensional nature of pain. There is a need for a formal and internationally accepted classification system (Caraceni, 2001). Researchers and clinicians recognize this need, but currently no such system has been forthcoming. Three formal classification systems relevant to cancer pain are available (see table 2.3). Unfortunately, they are only partially validated and not commonly used in research or clinical settings (Caraceni, 2001; Hjermstad et al., 2009; Nekolaichuk et al., 2005).

**Table 2.3 Cancer pain classification systems**

<b>Classification system</b>	<b>Characteristic</b>	<b>Validity</b>	<b>Use</b>
Pain Taxonomy	Divide pain into malignant or non-malignant pain Not able to predict pain prognosis Neglect main pain concept	Not validated	Only one study (Grond et al., 1996)
Cancer Pain Prognostic Classification Scale (CPPCS)	Comprises four domains: worst pain, emotional status, use of daily > 60 mg of opioid and presence of mixed pain Able to predict pain prognosis	Not validated	Only one study (its development study) (Hwang et al., 2002)
Edmonton Staging System for Cancer Pain (ESS-CP)	The recently revised scale contained five domains: mechanism of pain, incidental pain, cognitive status, addictive history and psychological distress	Content validity, Inter-rater reliability	Few studies (Bruera et al., 1989; Bruera et al., 1991; Bruera et al., 1995; Fainsinger et al., 2005; Nekolaichuk et al., 2005; Fainsinger and Nekolaichuk, 2008)

### **2.4.3.1 Formal classification systems**

The International Association for the Study of Pain (IASP) developed a pain taxonomy (see table 2.3). Based on this taxonomy, chronic pain is divided into malignant and non-malignant. For each division, five domains were assigned; location, affected body system, temporal, intensity, onset and causative factors (Hjermstad et al., 2009). The taxonomy seems to have only been used in one study (Grond et al., 1996). Grond et al. (1996) described pain site, causes and pathophysiology among 2266 cancer patients. They used the IASP classification in pain syndrome coding. However, no justification for the use of this classification was given by the authors. This classification does not aim to predict pain prognosis and does not contain major pain concepts such as breakthrough pain and incidental pain (Caraceni, 2001).

A second classification is the Cancer Pain Prognostic Classification Scale (CPPCS), which was developed by Hwang et al. (2000)(see table 2.3), which comprises four domains: worst pain rated on numerical rating scale (11points); emotional status, adapted from the Functional Assessment of Cancer Therapy (FACT-G); opioid dose more than 60 mg daily; and having mixed pain or not (Hwang et al., 2002). Thus, a patient's pain may be classified as a good or bad prognosis for treatment. Unfortunately, the CPPCS was used only in its development study (Hwang et al., 2002). However, the development study was very well-conducted. It included 74



cancer patients with pain, and used logistic regression analysis in order to select the factors that may affect pain prognosis among cancer patients and eventually to be included in the CPPCS contents, but using data from only 74 patients (a relatively small number) inhibits the results' transferability.

Another classification system more widely used is the Edmonton Staging System for Cancer Pain (ESS-CP). This originally contained seven domains: mechanism of pain, incidental pain, psychological distress, addiction history, cognitive, tolerance and opioid treatment. The ESS-CP was revised and adapted to overcome its limitations, such as difficulties in defining some of its domains (i.e. incidental pain)(Bruera et al., 1995). Another reason for the revision was to improve its ability to predict pain prognosis and improve its use by healthcare providers (Bruera et al., 1995; Nekolaichuk et al., 2005). Therefore, in the revised version, two domains were removed (tolerance and opioid treatment). In addition, addiction history was adjusted to addictive behaviours (Hjermstad et al., 2009; Nekolaichuk et al., 2005). Recently, a study was conducted to validate the ESS-CP (Nekolaichuk et al., 2005). A Delphi survey technique was used and four rounds of experts' revisions conducted. The expert panel comprised national (Canadian) and international experts. Most of the participants agreed on the five domains structure of ESS-CP, but they revised the definitions of incidental pain, psychological distress, addictive behaviours and cognitive dimensions. These results suggested that ESS-CP is valid for use with cancer pain. The use of systematic validation method was the main strengths of this study. However, another study was conducted to estimate the inter-rater reliability for the ESS-CP, 619 cancer patients with pain were included from multi-cancer centres across Alberta province in Canada (Fainsinger and Nekolaichuk, 2008). It was found that it is a reliable (inter-rater reliability ranged from 0.67 to 0.95) tool to be used to predict pain prognosis.

In regard to the practice in Jordan, only anecdotal evidence exists, since nothing was found in the literature. The researcher worked for four years as a nurse in Jordanian hospitals. From this experience it is known that an informal classification system is currently used in most of the hospitals in Jordan. Specifically, body part or cause is often utilised, for example it is common to hear a nurse say patient x has low back pain or a physician will write in the medical notes that a patient is suffering post-operative pain. A robust classification of pain does not appear to be in force in Jordan at this time.

#### **2.4.4 Cancer pain assessment**

Pain is a multidimensional and subjective phenomenon (Bourbonnais and Bouvette, 2004; Carr et al., 2010). Its subjectivity is the challenge to healthcare providers,

and getting agreement on one method for pain assessment a difficult mission. Although it is the case that to achieve the most effective pain management a comprehensive pain assessment is required (Cleary, 2000), completely valid and reliable pain assessment tools are not yet available (Hjermstad et al., 2008). In addition, there is no consensus on a single pain assessment tool. One explanation for this is the complex nature of pain and its subjectivity (Katz and Melzack, 1999; Hjermstad et al., 2008). In anticipation of reaching a consensus on assessment or discovering an objective pain measure, pain screening should be integrated into nursing practice. Cancer pain assessment should include history-taking, initial pain assessment, physical examination, and laboratory and radiography study (MacCaffery and Pasero, 1999). History-taking can be time consuming; it also can elicit issues that may facilitate the pain treatment. Healthcare providers should ask about previous pain episodes, and its related characteristics such as pain quality, and factors that increase or decrease the pain feelings. History-taking includes asking about current medications, non-pharmacological interventions, and other diseases (Davis and Walsh, 2004).

Initial pain assessment is intended to identify the cause of pain and initiate appropriate treatment (Portenoy and Lesage, 1999). Initial pain assessment includes intensity, location, onset, intensifier and nullifiers, and radiation. Pain intensity can be assessed by asking patients to rate their pain on an 11-point pain scale (Davis and Walsh, 2004). A number of tools designed to measure pain intensity are discussed in the following section. It is also important to determine pain location, since it is needed to identify whether the pain is localized or disseminated over the whole body, so that suitable treatment can be established (MacCaffery and Pasero, 1999). For example, localized pain may be treated with local application of treatment, such as radiotherapy. Also, it is useful in distinguishing the actual pain source. In addition, timing is important since it can help to identify pain occurrence patterns that might be associated with certain activities or end of drug effects. Furthermore, assessing the aggravating or alleviating factors is crucial, and taking these factors in consideration may lead to reduced medication use and a synergic effect on reducing pain severity (Davis and Walsh, 2004). Finally, recognizing pain radiation helps in detecting the cause of pain, and in the cancer pain context it may indicate disease progression and enable the re-evaluation of cancer treatment regimen (Cleary, 2000).

Based on the information from patient history and an initial assessment, a carefully conducted physical examination may be needed. This examination should cover what was suspected from the aforementioned steps. However, it may also cover skin lesion assessment, enlarged node, assessment for bone metastases, and neurological examination. Laboratory or radiographs may then be suggested.

Radiographs should only be considered when expected to be clinically useful (Davis and Walsh, 2004; Wellman, 2000).

Pain-related information should be communicated and passed between nurses across shifts rotation and with other professionals (MacCaffery and Pasero, 1999). Furthermore, a good assessment practice that the nurse should learn is to ask the patient about pain, since patients may be reluctant to report pain unless asked (Rhodes et al., 2001).

The current guidelines on pain assessment recommend the use of a pain assessment tool in daily routine practice (Berry and Dahl, 2000; Cormie, 2009) using a pain assessment tool in practice can establish systematic pain assessment procedures. There is a need to select a pain assessment tool that balances between the need for detailed data about pain and shortage of time such as the Brief Pain Inventory (BPI). The use of a pain assessment tool is still not part of routine nursing practice everywhere. It has been found that nurses positively perceived the use of such tools but in practice they rarely use them (de Rond et al., 1999). Although efforts have been made during the previous two decades, a recent study shows considerable gaps in pain assessment and management even in the well-developed countries. A study that was conducted in the USA to evaluate the extent of the use of evidence-based practice in cancer pain assessment and management (Herr et al., 2010) found that only 32% of patients were given the available and suitable evidence-based practice care. In addition, they found that 69.7% of patients were assessed for pain. However, re-assessment of pain after treatment was conducted only in 5.3% of cases, and re-evaluation of treatment plan after assessment was conducted in 35.7% of cases. A written pain management plan was only found in 0.6% of the reviewed cases (Herr et al., 2010). This was a part of large, multi-central Randomised Clinical Trial (RCT), which included 399 patients from 60 hospice care settings. Large sample size, randomization, and collecting data using many methods are the main strengths of the study, which improved its outcome validity.

#### **2.4.4.1 Implementation of pain assessment tool in practice**

Many studies have been conducted to implement a pain assessment tool in practice (see table 2.4), but few studies have examined their long-term use (Bourbonnais and Bouvette, 2004). In addition, many of these studies were conducted with the purpose of the development or validation of a specific pain assessment tool (Blenkharn et al., 2002; Puntillo et al., 2002; Tittle et al., 2003b; Uki et al., 1998), so they were excluded from the review because they focused on the psychometrical tool features. The previous implementation studies acknowledged that there are

pre-requisites that should be taken into consideration when implementing a pain assessment tool into nursing practice, which includes teaching the nurses about the tool and increasing the awareness of the need for effective pain management. In most of the implementation studies, education sessions were given to nurses. These sessions varied in length from minimum 30 minutes to maximum three hours. It is believed that combining education with the introduction of a pain assessment tool enhances the success of implementation (Bourbonnais et al., 2004; de Rond et al., 2001). This combination leads to emergence of the concept 'Pain Monitoring Programme' (PMP), which means introducing a pain assessment tool in practice, combined with pain education. In addition, it was recommended to use a change model or framework, which is an important determinant of successful and sustained use of the tool (Bourbonnais and Bouvette, 2004; Carr et al., 1997; de Rond et al., 1999; Finley et al., 2008). Moreover, some studies urge the need to involve nurses and other professionals in the process. On the other hand, the complex nature of pain, difficulty in interpretation of the pain score and lack of time are major obstacles for the use of pain assessment tool (Bourbonnais and Bouvette, 2004; Carr et al., 1997).

Most of the implementation (see table 2.4) studies utilised quasi-experimental designs or a type of survey. Quasi-experimental designs may fit the oncology area because of their flexibility, as they adapt to the complex nature of cancer and its consequences. It might be difficult to select patients randomly to be included in clinical randomized trials. In addition, attrition rates may be higher in cancer patients. Furthermore, it is not always possible to have a control group that is equal to the intervention group. However, quasi experimental designs alone were not enough to understand the implementation process experience. Studies that used quasi-experiment design were not able to explain why the tools were used, their flaws, or how the implementation was conducted. Some authors recognized this fact and added focus group interviews to their methods, such de Rond et al. (2000), whilst one recent study (Finley et al., 2008) used action research to provide a better understanding of the implementation process. Finally, using a survey or chart audit alone may result in a superficial description of the implementation process. Therefore, this may suggest that using a mixed research method is recommended in implementation studies.

De Rond et al. (1999) conducted a study that aimed to implement a pain monitoring programme comprised of providing nurses education about pain and introducing a pain assessment tool into practice in three hospitals. The study results were published in five articles (de Rond et al., 1999; de Rond, 2000a; de Rond et al., 2000b; de Rond et al., 2000c; de Rond et al., 2001). This study was conducted over two stages, the first of which was to collect basic information, and

the second was to implement and evaluate the impacts of the PMP on cancer pain management practice. Positive impacts of the PMP on the nurses' knowledge, and assessment practice and analgesic prescriptions were reported. In addition, Bouvette et al. (2002) studied the implementation of PMP into practice. A quasi-experimental design was used. Pilot work prior to the main study was utilized to increase the chance of tool adoption. The results show an improvement in pain assessment practice, and the tool was used for 93% of patients in the setting. Furthermore, Finley et al. (2008) conducted a study to implement PMP in Jordan as collaborative work with a specialised cancer hospital to improve pain management for paediatric patients. The action research approach was used. This allowed the use of focused and open interviews, observation and chart audit as means of data collection. They found that PMP had improved nurses' knowledge, morphine administration and the use of pain assessment tool. Table 2.4 shows information about the previous implementation studies.

Three studies detailed the process of implementation adequately (Bouvette et al., 2002; de Rond, 2000a; Finley et al., 2008). Other studies were brief and did not give adequate details to help the reader to interpret the results or to replicate the study. Some authors, such as (Choi et al., 2006; Devi and Tang, 2008), suggested that the use of a pain assessment tool leads to a decrease in patients' pain level. It is believed that this conclusion may not be accurate, given the weak methods and the lack of rigour and adequate analysis. For example, in these two studies, the researchers did not use interviews or statistical analysis, or even observation. Therefore, the results should be read carefully and examined against available knowledge before use.

No study identified the impact of using a pain assessment tool on the adequacy of pain management, or pain reporting practice. However, most of the studies evaluated the percentage of tool use, satisfaction of patients with pain management, and sometimes the amount of opioid use. In addition, most of the studies were conducted in Western countries (see table 2.4); only one study was conducted in Jordan, which targeted Jordanian paediatric cancer patients, although the principal investigator was not Jordanian or Arab. Being a non-Arab researching Arabs may inhibit the ability of the researcher to understand cultural differences or the small details of processes due to language barriers and unfamiliarity with procedures, norms and rituals within another culture. It was the only study conducted in Jordan, and it contains themes such as barriers to cancer pain management from the point view of the family and health caregivers, so it was included in the review.

**Table 2.4 Research studies that have implemented a pain assessment tool in practice**

<b>Author (country)</b>	<b>Design</b>	<b>Sample</b>	<b>Frequency</b>	<b>Follow up</b>	<b>Conceptual/Theoretical framework</b>	<b>Main findings</b>	<b>Quality score</b>
Carr et al., 1997 <b>UK</b>	Pilot study (survey)	Elderly patients	Not indicated	NA	NA	<ul style="list-style-type: none"> <li>- The use of pain assessment tool might improve the communication of pain with the healthcare context.</li> <li>- Teaching nurses about pain management and the use of pain assessment tool would increase the possibility of integrating pain assessment tool in the daily nurses' practice.</li> </ul>	15
de Rond et al., 1999 <b>Netherlands</b>	Quasi-experimental	Oncology (50%) and non-oncology patients	Once a day	One nurses' survey after six months	NA	<ul style="list-style-type: none"> <li>- The use of pain assessment tool found to be feasible within the daily nurses practice.</li> <li>- It was found that the majority of nurses (69.6%) held positive perceptions of the use of the pain assessment tool</li> <li>- It was hinted that the better pain was assessed, the better it was managed.</li> <li>- The implementation study should be customized according to the context needs and culture.</li> </ul>	20

<b>Author (country)</b>	<b>Design</b>	<b>Sample</b>	<b>Frequency</b>	<b>Follow up</b>	<b>Conceptual /Theoretical framework</b>	<b>Main findings</b>	<b>Quality score</b>
Rhodes et al., 2001 <b>USA</b>	Chart Audit	Oncology outpatients	Once	over eleven months	NA	<ul style="list-style-type: none"> <li>- The overall pain documentation increased from 1% to 75% after the use of pain assessment tool.</li> <li>- The use of Visual Analogue Scale (VAS) was feasible and led to identifying many patients with pain.</li> </ul>	20
Bouvette et al., 2002 <b>Canada</b>	Multi-central studies using chart audit and focus group	Palliative care settings	Not indicated	Once after three months	Lewin's theory was used to explain study results	<ul style="list-style-type: none"> <li>- The change theory explained some of challenges faced during the implementation pilot study.</li> <li>- Identifying the context culture was an important deterrent of implementation process success.</li> <li>- The tool was used in 93% of cases.</li> </ul>	27

<b>Author (country)</b>	<b>Design</b>	<b>Sample</b>	<b>Frequency</b>	<b>Follow up</b>	<b>Conceptual /Theoretical framework</b>	<b>Main findings</b>	<b>Quality score</b>
Choi et al., 2006  <b>Korea</b>	Survey	Cancer patients	Not indicated	NA	NA	- The results show that there was a decrease in pain intensity after the tool use, an increase in the use of strong opioids, and improvement in patient satisfaction with pain management.	18
Martoni et al., 2007  <b>Italy</b>	Chart audit	Cancer patients	Twice a day	NA	NA	- The use of pain assessment tool (VAS) was feasible, and patients complied with use. - One main reason was behind non-compliance with tool use was that it compromised cognitive status.	22



<b>Author (country)</b>	<b>Design</b>	<b>Sample</b>	<b>Frequency</b>	<b>Follow up</b>	<b>Conceptual /Theoretical framework</b>	<b>Main findings</b>	<b>Quality score</b>
Finley et al., 2008 <b>Jordan</b>	Action research	Paediatric cancer patients	Once	Once	Used to explain some aspect of the study but it was limited	<ul style="list-style-type: none"> <li>- Pain was prevalent among patients (57%), and only 35% received pain medications.</li> <li>- The barriers to cancer were abundant and various. The main barriers were fatalism, misconceptions about opioids, and lack of regard for patients' pain self-report.</li> <li>- Some results were culturally specific, and different from Western-reported findings, for example nurses believed that having a policy is effective and better than education in changing practice.</li> <li>- The tool was used in 80% of the check charts.</li> </ul>	26
Devi and Tang, 2008 <b>Malaysia</b>	Survey	Post-operative patients	NA	NA	NA	<ul style="list-style-type: none"> <li>- This study was very weak and had many flaws, which made using any results problematic and ineffectual.</li> </ul>	9

In summary, assessing the context of change before introducing the tool can give the researcher a chance to design a change process that fits in with the specific settings (contextual needs and culture). Thus, identifying barriers and facilitators in the context and choosing a valid and easy to use tool may enhance its continuous use.

#### **2.4.4.1 Knowledge gaps:**

Based on this review, the following gaps have been identified:

- 1- No study investigated the impact of using a pain assessment tool on the adequacy of pain management for adult cancer patients.
- 2- There is a need to use both quantitative and qualitative methods to enhance our understanding of the implementation process.
- 3- There is a need to use a theoretical framework to guide the implementation process and explain its results. This would maximize the benefits of the implementation studies.
- 4- Cancer pain in Jordan is an area that is worthy of extensive research since few studies have been conducted.

#### **2.4.5 Measurement tools**

Pain assessment tools are commonly used in clinical and research settings and optimally should meet the following criteria: a) have ratio scale properties (Melzack and Turk, 2001); b) free of bias; c) be valid and reliable; d) appropriate for clinical and research use; e) generalizable; f) sensitive to pain changes; g) easy to use; h) able to separately assess sensory and affective pain domains; and i) be able to evaluate subjects' reliability and accuracy (Gordon, 1998; Melzack and Turk, 2001).

A plethora of pain measurement tools are available, but no one tool is universally accepted as yet, and most of these instruments were developed for personal or research purposes (Caraceni, 2001; Hjermstad et al., 2008; Hjermstad et al., 2009). Two reviews that aimed to identify the available pain assessment tools were found. The first review identified eighty pain assessment tools that were developed in the period between 1966 and March 2003 (Holen et al., 2006), whilst the second review covered the period between 2003 to March 2008, and found eleven additional tools (Hjermstad et al., 2008). Measurement tools were divided into two broad categories, uni-dimensional and multidimensional.

### **2.4.5.1 Uni-dimensional**

The three most widely used scales are Visual Analogue Scale (VAS), Verbal Rating Scale (VRS), and Numerical Rating Scale (NRS). In general, they are valid, reliable and feasible, but each only measures one domain, pain intensity (Caraceni, 2001; Katz and Melzack, 1999; Von Korff et al., 2000). According to the European Association of Palliative Care (EAPC), all three scales are considered to have equal value for use in palliative care settings (Caraceni et al., 2002).

#### **2.4.5.1.1 Visual Analog Scale (VAS)**

A standard VAS consists of a 10 centimetre long horizontal line with two ends marked with the words 'No pain' on the left and 'Worst imaginable pain' on the right side (see figure 2.2). In some cases, it is presented in a vertical alignment. However, patients are asked to mark pain on this line, and then the distance from no pain to the patient's mark measured. This value represents pain intensity (Haefeli and Elfering, 2006).

#### **Figure 2.2 VAS**

No pain\_\_\_\_\_ Worst imaginable pain

The main advantage of using a VAS is that a ratio scale can be used, for example it is possible to say a patient's pain reduced by 20% after a certain intervention (Katz and Melzack, 1999), and VAS is sensitive to pain changes after pharmacological interventions (Haefeli and Elfering, 2006). On the other hand, 7 to 11% of patients failed to use VAS, especially elderly and cognitively impaired people (Ho et al., 1996). Distance measuring and explaining of the procedure for using VAS can be time-consuming and susceptible to measurement error (Haefeli and Elfering, 2006), therefore mechanical VAS was developed. In this VAS, the patient positions a slider on a linear scale. Hence, there is no need for pen and paper, or even measurement, as on the reverse side of the scale there are numerical values that match the position chosen by the patient. It has been to be as valid and reliable as a paper VAS, although people with physical disabilities may not be able to use either form of the scale (Haefeli and Elfering, 2006).

#### **2.4.5.1.2 Verbal (descriptor) Rating Scale (VRS)**

A Verbal Rating Scale consists of four to six words (adjectives). These adjectives are arranged from low to high and include commonly used words to describe pain levels such as no pain, mild pain, moderate pain and severe pain. Patients are asked to choose the adjective that best describes their pain. Verbal Rating Scales are said to be easier to use than VAS (Haefeli and Elfering, 2006). However, their

sensitivity is questionable because of the small number of descriptors available to choose from. In addition, the distances between adjectives are not equal. Thus, data yielded are considered ordinal, and non-parametric statistics should be applied (Gélinas et al., 2008). Furthermore, these adjectives might be perceived differently by different people, thus affecting results and interpretations (Ho et al., 1996).

#### **2.4.5.1.3 Numerical Rating Scale (NRS)**

A Numerical Rating Scale comprises 10, 20 or 100-point horizontal line. Sometimes numbers are enclosed in boxes. Patients are required to choose numbers that match their pain intensity. They are sensitive to pain changes, but less so than VAS, which theoretically contains unlimited numbers (Ho et al., 1996; Von Korff et al., 2000). The NRS is said to be easier to use when compared with VAS, and can be used verbally by phone or face-to-face. This means that it can be used with elderly people or patients with physical disabilities. It can also be presented in different languages without undergoing translation, and it is valid and reliable (Hjermstad et al., 2009). In a study conducted to validate the use of the verbally administered NRS in assessing cancer pain (Paice, 1997), the convergent validity method was used. The verbally administered NRS was correlated with VAS and a simple descriptor scale (SDS). It was found that verbal NRS correlated highly with VAS ( $r = 0.847$ ,  $P < 0.001$ ) and SDS ( $r = 0.708$ ,  $P < 0.001$ ). In addition, fifty percent of participants preferred the use of the verbally administered NRS. Nevertheless, these results should be interpreted cautiously, given the small sample ( $n = 50$ ) and the weakness of convenience sampling.

#### **2.4.5.2 Multidimensional tools**

There is a plethora of multidimensional instruments available in the literature. Most of these tools are disease-specific, partially validated and were developed without using systematic methods (Hjermstad et al., 2009). Of these tools, two were systematically developed and validated in different languages and cultural backgrounds. This section focuses on these most commonly used tools; the Brief Pain Inventory (BPI) and the McGill Pain Questionnaire (MPQ) (Caraceni, 2001) see table 2.5). The short forms of these tools are recommended for use in cancer pain by the European Association of Palliative Care (EAPC) (Caraceni et al., 2002).

##### **2.4.5.2.1 Brief Pain Inventory (BPI)**

The BPI is constructed of 23 self-report items and covers two main domains; pain intensity and pain interference (Cleeland, 1994; see appendix 2). Patients rate their pain on a (1-10) point numerical scale for the current, worst, lowest and average pain in the preceding 24 hours. The numerical scale starts with the words no pain

and ends with pain as bad as you can imagine (Cleeland, 1994). Thus, the higher the score in this subscale, the more severe is the pain. Subscales for pain interference ask patients to rate how much pain impacts on their activity and mood on a 1 to 10 numerical scale. Interference scales start with words no interference and end with interferes completely (Cleeland, 1994). In addition, patients have the chance to express how they perceived the cause of pain. The completion of the BPI should not take more than 10 minutes, but a shorter form is also available (see appendix 3).

Although the BPI is commonly used with cancer pain (Tan et al., 2004), its use in non-malignant pain is documented (Jacob et al., 2008), and it has established validity in different cultural backgrounds (Cleeland, 2009). In addition, it was translated into Arabic, but has not yet been validated. Tittle et al. (2003) conducted a study to validate the use of BPI in surgical cancer patients. A descriptive correlation design was used to compare between surgical (n = 159) and medical (n = 229) cancer patients (Tittle et al., 2003). The results showed that the correlation between the two BPI subscales were almost identical for surgical and medical patients groups ( $r = 0.73$ ,  $r = 0.71$ ,  $P < 0.01$ ) respectively. Reliability was measured using the alpha coefficient for both (surgical:  $r = 0.97$  and medical:  $r = 0.95$ ) respectively, which renders it a highly reliable tool.

**Table 2.5 MPQ and BPI main features**

	<b>MPQ</b>	<b>BPI</b>
<b>Author</b>	Melzack and Torgerson 1971	Cleeland 1989
<b>Population</b>	Non-cancer patients, but used for cancer pain.	Cancer patients, but used for non-cancer pain.
<b>Short-form</b>	Yes	Yes
<b>Pain descriptors</b>	Yes	No
<b>Domains</b>	Sensory, affective, evaluative	Sensory and pain interference
<b>Translation</b>	Yes, exclusive of Arabic	Yes, inclusive of Arabic
<b>Validity</b>	Yes, but not in Arabic culture	Yes, but not in Arabic culture
<b>Sensitivity</b>	Yes	Yes
<b>Discriminative capacity</b>	Yes	No
<b>Easy to use</b>	Yes	Yes

In addition, Tan et al. (2004) conducted a study to evaluate the validity and reliability of BPI for pain assessment in non-cancer patients (Tan et al., 2004). The Roland-Morris Disability Questionnaire (RMDQ) was used as a gold standard for comparison with the pain interference subscale, 440 patients were recruited from a multidisciplinary pain setting. Alpha coefficient for internal consistency of BPI was 0.85 for the intensity subscale, and 0.88 for pain interference; therefore, it was considered reliable (Gélinas et al., 2008). In order to assess BPI construct validity, factor analysis was executed and reflected the two factors construction of BPI (Gélinas et al., 2008). Comparison between follow-up data through three visits (n = 97) showed the sensitivity of BPI for changes in pain intensity and pain interference. For example, mean pain level was 7.07 at the first visit, 6.63 in the second visit then 6.14 in the third. Finally, convergent validity was assessed; the correlation coefficient between pain interference subscales and RMDQ was 0.57. This means that they measured the same concept. In contrast, correlation between

the intensity subscale and RMDQ was weak ( $r = 0.40$ ). In short, BPI is a valid and sensitive instrument for use in the assessment of non-malignant pain in terms of pain intensity and interference

#### **2.4.5.2.2 McGill Pain Questionnaire (MPQ)**

The McGill Pain Questionnaire was introduced by Melzack in 1971 (see appendix 4), and it is a commonly used tool, particularly with non-malignant pain (Melzack and Turk, 2001). Four main domains are measured in the MPQ: sensory, affective, evaluative and miscellaneous. For each domain there are a group of words, which are assigned a numerical value. It also has VAS, body map and VRS. However, in order to evaluate patient pain, a five-point scale is used, referred to as Present Pain Intensity (PPI). Patients choose the words that best describe their pain and a total sum of word values is obtained. This sum is stated as Pain Rating Index (PRI) (Melzack and Turk, 2001). Many studies confirmed MPQ validity and sensitivity for treatment (Katz and Melzack, 1999). Furthermore, Melzack addressed the ability of MPQ to discriminate pain according to diagnoses (Melzack and Turk, 2001). Because of the shortage in the available time for patients to give detailed assessment, the short form of MPQ (SF-MPQ) was introduced into clinical and research settings (see appendix 5). The short form consists of 15 words to cover affective and sensory domains. Furthermore, it has similar psychometric properties to the long form (Ho et al., 1996). In a study to measure the coefficient correlation between the long form of MPQ (LF-MPQ) and the SF-MPQ and VAS (Dudgeon et al., 1993), only 21 cancer patients participated in the study. In addition, pain was measured three times over a period of 3-4 weeks. The results showed that SF-MPQ average scores are highly correlated with average scores of LF-MPQ ( $r = 0.90$ ,  $P < 0.001$ ). Moreover, the SF-MPQ was significantly correlated with VAS ( $r = 0.93$ ) (Dudgeon et al., 1993). Finally, the SF-MPQ might not cover all aspects of the pain experience, however, it is easy to use and quick to complete (only 2-4 minutes).

#### **2.4.6 Which instrument to use?**

In order to answer this question, providing the general features of the study population and setting might be helpful in making this decision. This study aimed to recruit adult cancer patients in a tertiary hospital in Jordan. Arabic is the official language in Jordan.

##### **Uni-dimensional tool**

The NRS is a valid, reliable and feasible assessment tool and also can be used verbally. Thus, NRS can be used in an Arabic population without translation, with

fewer burdens on fatigued cancer patients. On the other hand, it only assesses pain intensity, and data about other pain aspects often present in oncology patients could not be measured. It gives numerical values that are not easy to interpret. For example a score 4 out 10 may mean, to the patient, intolerable pain levels, while nurses might give this a different meaning. In addition, the same score in different patients may indicate different magnitudes. Therefore, combining pain severity with another pain dimension may provide a more meaningful picture than using severity alone.

### **Multi-dimensional tool**

Second choice, in case of a multi-dimensional tool being needed, is the BPI. The BPI has many features that make it useful to use in this study. It is already translated into the Arabic language and is currently under validation in Morocco (Cleeland, 2009). It was originally developed for use with cancer patients, and it is extensively validated in different languages and cultural backgrounds, which provides material for comparison. Recently, a BPI user guide booklet has become available, which indicated that the BPI was validated in 72 studies (Cleeland, 2009). In addition, the short form of the BPI contains simple adjectives and translation can give the exact meaning of the original English version into Arabic. In contrast, MPQ descriptors were not translated or validated into the Arabic language, and although a list of Arabic pain words has been generated (Harrison, 1988), they have not been tested. The complex words used in MPQ make correct translation difficult to achieve. In addition, Arabic people frequently describe their pain with different adjectives than a Western population. In addition, pain is a culturally sensitive experience; therefore, the MPQ descriptors might not be suitable for use in the Arabic culture. Finally with respect to the MPQ, all of these factors might affect the study results and the interpretations that based thereon.

In summary, many pain assessment tools are available for use, but multidimensional tools can provide a deeper and wider picture of cancer pain. Both BPI and MPQ are valid and reliable tools and commonly used in clinical and research settings. The BPI is the preferred tool, because it seems to be suitable for use in pain assessment with Arabic people. It is a valid tool that balances between the need for detailed data about pain and the shortage of staff time. Thus, BPI is appropriate for this study.

The second legitimate step after pain assessment is pain management. The following section focuses on cancer pain management.



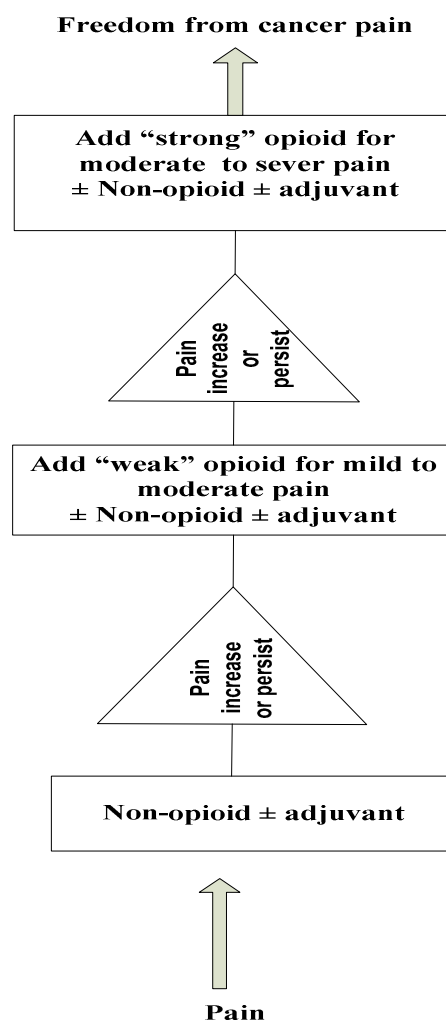
## 2.5 Cancer pain management

Cancer pain treatment can be divided into two main types: pharmacological and non-pharmacological interventions. Each type also has subtypes, which will be briefly reviewed, prior to discussing the adequacy of pain management in clinical practice settings.

### 2.5.1 Pharmacologic interventions

Pharmacological treatment is the most commonly used intervention in cancer pain treatment, but non-pharmacological interventions are also available. The World Health Organization (WHO) recognized the negative impacts of cancer pain on patient life quality and the importance of alleviating patients' suffering (Schug et al., 1990), and published the three-step pain management approach, the pain ladder (MacCaffery and Pasero, 1999) (see figure 2.3).

**Figure 2.3 The WHO ladder of analgesic cancer pain treatment**



According to this approach, mild pain should be treated with non-opioid medication such as Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) (Cormie, 2009; Schug et al., 1990). However, moderate pain can be treated with weak opioids; if pain persists or increases, a strong opioid can be added for severe pain. Pain medications should be given by the clock rather than PRN (Cormie, 2009; Schug et al., 1990). Based on the WHO ladder, three levels of pain medications were identified (Dickman, 2007; Skarin et al., 2000) (see table 2.6)

**Table 2.6 Levels of cancer pain medication**

<b>Level</b>	<b>Drug name</b>	<b>Indications</b>
<b>One</b>	Acetaminophen and Non-Steroidal Anti-Inflammatory Drugs (NSAIDs).	Mild pain
<b>Two</b>	Codeine, dihydrocodeine, and oxycodone can be used alone or in combination with one of the NSAIDs.	Moderate pain
<b>Three</b>	Morphine, hydromorphone, fentanyl and methadone	Persistent moderate pain or severe pain

Cancer pain comprises both nociceptive and neuropathic elements at the same time. Hence, combining two or more pain medications that work for the two pain types is a legitimate option. This would improve the pain relief action, reduce the required dose, and decrease unwanted side effects (Dickman, 2008). In addition, in a systematic review conducted to evaluate the effectiveness of using the WHO approach in treating cancer pain, it was found that between 69 to 100% of patients' pain could be relieved using the WHO step ladder (Jadad and Bowman, 1996). However, this review included only eight studies which used different designs, making meta-analysis impossible. In addition, there were no control groups to be compared with. However, it confirmed that the status of pain free could be possible with the use of the WHO approach. Also, it has been reported that eighty percent of cancer pain can be treated by embracing the rule of by mouth, by the ladder, by the clock (Zech et al., 1995), which means that pain medications should be given by the oral route using the WHO steps on a regular basis.

However, like other pharmacological preparations, pain medications have their adverse effects which might hinder patients receiving optimal pain management. Fortunately, these adverse effects are well-known and treatable, for example respiratory depression may occur with opioid naïve patients (patients who received narcotics for first time), however the body develops tolerance to respiratory depression with subsequent doses, and if necessary reversal agents are available and to treat respiratory depression. In addition, constipation is a common opioid adverse effect, and health care providers should anticipate its occurrence from the first dose and commence laxatives (Cleary, 2000; Dickman, 2007; Skarin et al.,

2000). Moreover, as a result of morphine metabolites, a skin rash may develop and can be treated with anti-histamines (Dickman, 2007; Skarin et al., 2000). Finally, nausea, vomiting, sedation and somnolence are additional adverse effects, to which the human body becomes tolerant after five to six days of regular opioid doses (Brown, 2009).

### **2.5.2 Non-pharmacological approaches**

Non-pharmacologic interventions can be divided into two main categories; physical and behavioural interventions. Physical interventions include heat or cold, massage, exercise and splinting, whilst behavioural approaches include relaxation, guided imagery and hypnosis. Nurses may lack the training, time and authority to practise such interventions (Cleary, 2000; Skarin et al., 2000; Sykes et al., 2003). For example, body massage can relax muscles and improve the feeling of comfort, and applying heat also may relieve muscle spasms. On the other hand, applying cold may alleviate inflammation and oedema. In addition, guided imaginary is another strategy that has been used to treat cancer pain. It is known to decrease stress, distract the patient from feeling pain, and help patients to feel control over their cancer and its treatment (Cleary, 2000; Skarin et al., 2000). It is reported that nine out of ten cancer patients used a non-pharmacological intervention to treat pain, alongside regular treatment (Yates et al., 2005). In another study, it was found that the percentage of complementary interventions used to treat pain ranged from 6 to 34% among cancer patients, and the most frequently used strategy was distractions like reading and watching television (Tasso and Behar, 2004). Studies that examined the effects of using the non-pharmacological (complementary) interventions for pain relief among cancer patients (Gorman et al., 2008) showed that they were effective only in a few cases (Gorman et al., 2008; MacCaffery and Pasero, 1999). Therefore, non-pharmacological interventions can be used as adjuvant therapy (Patt, 1993; Sykes et al., 2003). It is believed that these interventions are capable of drug sparing and enhancing patient comfort (Patt, 1993) but further evidence is required to support this claim.

### **2.5.3 Adequacy of cancer pain management**

It has been a challenge for healthcare providers to manage cancer pain, despite the availability of a vast range of treatment options. Unfortunately, pain is prevalent among cancer patients (Deandrea et al., 2008). However, many studies have reported that cancer pain is frequently undertreated. For example, a retrospective study conducted in Canada surveyed cancer patients' medical charts for the adequacy of pain management. It was found that of the 1000 included charts, 25% of patients appeared to be treated inadequately for their pain (Mitera et al., 2010).

In Jordan, Forgeron et al. (2006) reported that from 20 children with pain, only seven were prescribed pain medication, (the only information which was found in the literature related to cancer pain in Jordan). In Taiwan, of 113 cancer patients with pain, 69% (78) did not receive adequate pain management (Ger et al., 1998); these examples reflect the global nature of this problem.

A recent review of the literature on the adequacy of pain management, which included 26 studies conducted in the USA, UK, France, India, China, Japan, Greece, Germany, Italy, Israel, Korea, Taiwan, South Africa and the Netherlands, showed that 43% of cancer patients with pain were inadequately treated (Deandrea et al., 2008). This review provided fair evidence about the state of cancer pain management worldwide. This was a well-conducted systematic review and provides fair evidence, but searching only one database is a significant weakness. The original studies were generally retrospective and surveys, and most of them were local (to a city or institution), and included small numbers of patients. However, they still provide invaluable data that can aid in future planning to eliminate cancer patients' suffering. In addition, the Pain Management Index (PMI) equation developed by Cleeland et al. (1994) is commonly used to estimate the adequacy of analgesic treatment of pain. In the context of Jordan, little is known about how cancer pain is treated, and whether patients receive adequate treatment.

## **2.6 Barriers to cancer pain management**

Pain continues to be a problem for most cancer patients. It has been proposed that many barriers hinder patients from receiving the optimal management, including patient- and provider-related factors.

### **2.6.1 Healthcare providers-related barriers**

Various studies have shown that healthcare providers (physicians and nurses) do not adequately manage cancer pain (Beck, 2000; Bernardi et al., 2007; Finley et al., 2008; Gallagher et al., 2004; Glajchen, 2001; Kearney et al., 2003; Rawal et al., 1993; Ward et al., 1993). Healthcare providers-related barriers include (see table 2.7): lack of information regarding pain assessment, management and the consequences of unrelieved pain (Beck, 2000; Bernardi et al., 2007; David et al., 2003; Gallagher et al., 2004; Johnson et al., 2005; Kearney et al., 2003). Furthermore, they may have negative perceptions of cancer pain, cancer patients and cancer itself (Bernardi et al., 2007; Ger et al., 2000; Kearney et al., 2003). Moreover, poor communication between nurses, physicians and patients is a well-documented phenomenon (Beck, 2000; David et al., 2003); poor communication may lead to less pain being recognized and then poor treatment. An ethnographic study conducted in South Africa found that the lack of coordination of the healthcare providers' efforts to fight pain (lack of team work), and conflict between healthcare providers (physicians vs. nurses) may hinder optimal pain management (Beck, 2000).

**Table 2.7 Studies exploring healthcare providers-related barriers to cancer pain management**

Author, year, country	Sample size/type	Design	Main reported barriers to cancer pain management						Quality score
			Lack of Knowledge	Fear of addiction and drugs side effects	Negative attitudes	Poor communication	Reluctance to prescribe medication	Poor assessment	
Beck, 2000, South Africa.	62 from different professions <b>Theoretical</b>	Ethnographic	√	√	-	√	√	√	28
David, 2003, USA.	22 nurses 54 patients <b>Convenience</b>	Focus group	√	√	√	√	-	√	24
Johnson et al., 2005, USA.	867 nurses <b>Convenience</b>	Survey	√	√	√	√	√	-	22
Furstenberg et al., 1998, USA	695 doctors 1008 nurses 396 pharmacist <b>Random</b>	Survey	√	-	-	-	-	√	25
Anderson et al., 2000, USA	29 doctors 28 nurses <b>Convenience</b>	Survey	√	-	-	√	-	√	21
Ger et al., 2000, Taiwan	204 doctors <b>Convenience</b>	Survey	√	√	√	√	√	-	24
Kearney et al., 2003, UK	163 mixed professions <b>Convenience</b>	Survey	√	-	√	-	-	-	23
Roenn et al., 1993, USA	897 doctors <b>Convenience</b>	Survey	√	√	-	-	√	√	25

Author, year, country	Sample size/type	Design	Main reported barriers to cancer pain management						Quality score
			Lack of Knowledge	Fear of addiction and drugs side effects	Negative attitudes	Poor communication	Reluctance to prescribe medication	Poor assessment	
Elliott and Elliott, 1992, USA	243 doctors <b>Convenience</b>	Survey	√	√	-	-	√	-	21
Elliott et al., 1995, USA	145 doctors <b>Convenience</b>	Survey	√	√	√	-	-	-	23
MacCaffery and Ferrell, 1995	1428 nurses <b>Convenience</b>	Survey	√	√	√	-	-	-	21
Eftekhar et al., 2007, Iran	122 doctors <b>Convenience</b>	Survey	√	√	-	-	√	√	24
Wallace et al., 1995, USA	108 nurses <b>Random</b>	Survey	√	-	-	-	√	-	26
Yu et al., 2001, China.	427 doctors <b>Convenience</b>	Survey	√	√	-	-	√	√	24
Sapir et al., 1999, Israel	176 doctors <b>Convenience</b>	Survey	√	-	√	-	√	√	23
Morley-Forster et al., 2003, Canada	100 doctor <b>Convenience</b>	Survey	√	√	√	-	-	√	18

Author, year, country	Sample size/type	Design	Main reported barriers to cancer pain management						Quality score
			Lack of Knowledge	Fear of addiction and drugs side effects	Negative attitudes	Poor communication	Reluctance to prescribe medication	Poor assessment	
Vortherms et al., 1992, USA	327 nurses <b>Random</b>	Survey	√	√	√	-	√	-	27
Devi et al., 2006, Malaysia	1253 doctors <b>Convenience</b>	Survey	√	√	√	-	-	-	25
Krick et al., 1994, USA	141 pharmacist <b>Random</b>	Survey	-	√	-	-	√	-	18



In the only study to date conducted in Jordan on cancer pain management; nurses believed that patient self-reporting concerning pain was not valid. In addition, they believed that the use of non-pharmacological interventions alone can relieve cancer pain, and that having a pain management policy is enough to improve practice, without education (Finley et al., 2008). This study was a part of a pain monitoring programme implementation study, and only explored a few nurses' opinions (14 nurse), which should be taken in consideration before building on the results. This variation in barriers may be related to the different cultural context of the studies. There are mutual barriers between Western, Asian, African, and Arabic culture, while each culture may have specific barriers. This takes us back to the fact that pain experience is totally subjective, multidimensional and culture-specific.

### **Lack of knowledge**

Healthcare professionals have been found to lack appropriate knowledge to assess and manage cancer pain (Bernardi et al., 2007; David et al., 2003; Eftekhar et al., 2007; Elliott et al., 1995; Finley et al., 2008; Johnson et al., 2005) (see table 2.7). A study exploring nurses' knowledge on cancer pain management in Taiwan (Lai et al., 2003) used a large-scale survey (national level) and included 1797 nurses working in all Taiwan districts. This survey provided good evidence that nurses lacked the required knowledge to manage cancer pain adequately. In addition, it was reported that nurses with a bachelor degree or more, previous pain education, and long working clinical experience with oncology patients had a high number of correct answers on the pain knowledge questionnaire. Another study in Italy confirmed that nurses have a low level of knowledge regarding cancer pain management (Bernardi et al., 2007), 287 nurses were surveyed using the Nurses' Knowledge and Attitudes questionnaire (NKA). The sample of nurses was selected to represent all nurses in Italy. It was found that nurses got mean average scores of 21.4 out of 39 (maximum score) on the NKA questionnaire, indicating a low level of knowledge. In addition, there was a significant difference between the mean score of NKA between nurses who received pain education or did not ( $M = 22$ ,  $M = 20$ , respectively,  $P = 0.02$ ) (Bernardi et al., 2007).

It is reported that 50% of healthcare providers lacked sufficient knowledge of pain assessment and pain management, including the effects and side-effects of medication. For example, physicians did not prescribe laxatives concurrently with pain medication (Breivik et al., 2009; Rawal et al., 1993). Moreover, cancer pain was often treated similarly to non-malignant pain (Rawal et al., 1993). Furthermore, healthcare providers seem to focus on the treatment of cancer itself and neglect associated symptoms (Breivik et al., 2009). A phone survey was

conducted across eleven European countries plus Israel. This survey aimed to increase understanding of cancer pain and to explore cancer patient's pain experience, 5084 patients with pain from all type of cancer were interviewed. A numerical rating scale was used in the survey to record patient pain intensity. Moreover, survey questions were translated into all relevant languages. The phone interviews were carried out by well-trained research interviewers. It was found that patients were aware of their quality of life issues, and they urged the need for treatment of their pain and for more attention to be paid to life quality (Breivik et al., 2009). Recently, Oldenmenger et al. (2009) conducted a systematic review to identify barriers to cancer pain management (patient and healthcare provider-related). The Pub Med was searched for related studies. The results of the review indicated that the most common healthcare providers-related barriers were inadequate pain assessment and management, and lack of knowledge and training on cancer pain management (Oldenmenger et al., 2009). This systematic review was well-conducted and presented, and its results are compatible with the literature, but the few databases searched and not using a tool to assess the quality of non-randomised clinical trials were weakness.

Furthermore, other studies conducted in the USA (Coyne et al., 1999; Elliott et al., 1995; Furstenberg et al., 1998; Glajchen and Bookbinder, 2001; Krick et al., 1994; Mortimer and Bartlett, 1997; Xue et al., 2007), the UK (Clarke et al., 1996; Wells et al., 2001), Canada (Gallagher et al., 2004), Italy (Bernardi et al., 2007), Iran (Eftekhar et al., 2007), Turkey (Yildirim et al., 2008), China (Lui et al., 2008) and Taiwan (Ger et al., 2000) found that healthcare providers (physicians, nurses, and pharmacists) have a low level of knowledge regarding cancer pain management in general, mainly determined by inability to prescribe an adequate pain medication, conversion between routes and equivalent drugs, and side-effects management. Finally, pain education programmes for healthcare providers who are working with cancer patients was suggested to improve their knowledge regarding cancer pain management.

In summary, healthcare workers not only lacked knowledge and training about managing cancer pain, they also held myths and misconceptions about pain treatment which to the extent that cancer pain is left uncontrolled. Education may help to reach the ultimate goal of good pain management (Zhang et al., 2008). Teaching may result in fewer barriers, motivating patients to express feelings of pain and not hesitate to take pain medications. In addition, education may decrease patients' fear of addiction and tolerance.

## **Healthcare providers' attitudes and beliefs**

Healthcare providers frequently held negative attitudes and beliefs regarding cancer, cancer patients and cancer pain (Beck, 2000; David et al., 2003; Johnson et al., 2005; Kearney et al., 2003; Lui et al., 2008; Yildirim et al., 2008). For instance, Bernardi et al. (2007) reported that nurses tend to disregard or undervalue pain when it is reported by cancer patients. In addition, Elliott et al. (1995) indicated that 20% of physicians wrongly considered addiction a major problem in cancer patients, and they do not seem to know how to treat cancer pain effectively. Nevertheless, the use of non-validated questionnaires and small sample size compromise the reliability of this study. Fife et al. (1993) found that 84% of nurses recognised pain as an obvious problem in cancer patients compared to 73% of physicians. Physicians and nurses (76% and 67% respectively) believed cancer pain to be under-treated, but they urged the need to restrict the use of pain medication in advanced cancer (Fife et al., 1993). This conflict may indicate the discrepancy between what people believe and what they practice. Nevertheless, low response rates (15% and 24% for physicians and nurses respectively) and validity of the questionnaire used are major study weakness. A survey was conducted in 2008 including 143 nurses in Hong Kong to estimate nurses' knowledge and attitudes toward cancer pain. It found a discrepancy between nurses' attitudes toward pain management (it was positive) and the clinical practice (which remained problematic) (Lui et al., 2008). However, this survey included a small number of patients from a single setting, which may limit the transferability of its results. Furthermore, another study was conducted in 2001 to explore nurses' beliefs and attitudes toward cancer pain. The open-ended question approach was used and thematic analysis revealed that nurses negatively perceived the use of pain assessment tools and patient pain reporting (Young et al., 2006). Despite the weak sampling approach used in the study (Convenience) and small sample size (52 nurses), this study provided valuable information.

Finally, the healthcare system within which healthcare providers work might be one of the obstacles to optimal cancer pain management. For example, lack of pain medication is a barrier (Glajchen, 2001). In addition, strict policies and regulations on prescribing strong pain medication result in low prescribing and ineffective medication doses (Glajchen, 2001). Furthermore, it was found that insurance coverage, restrictive regulations concerning opioid dispensing, and individual financial status contributed to the inadequacy of cancer pain management (Joranson, 1994).

## **2.6.2 Patient-related barriers to cancer pain management**

Cancer pain management is not only hampered by healthcare providers' barriers, but the patients themselves may also block the potential for optimal pain relief. The most common patient-related barriers reported by Ward et al. (1993) included lack of knowledge about pain assessment and management, concern about addiction, fear of pain medication side effects, fear of tolerance, denial of pain (as it may mean disease progression) and poor communication between healthcare providers and patients. In addition, it is common that patients do not adhere to pain treatment regimens. For more details about patient barriers to cancer pain management, see table 2.8.

For instance, a survey of 170 Turkish patients using the Barriers Questionnaire (BQ) indicated that patients were concerned about addiction (mean score on addiction sub-scale was = 3.59 out of 5), and fear of the effects of pain medications on the immunity system was also high (M = 2.98). Most patients had some barriers (M total BQ= 1.94)(Bagçivan et al., 2009). Furthermore, an Australian survey of 114 patients in two oncology care settings reported that about 39% of patients tended to wait until pain became severe before seeking medications, and 32% preferred to spare pain medications for the worst pain. In addition, more than half of the patients did not talk to the healthcare providers about any issue related to their pain and its treatment, which may indicate poor communication of pain-related information (Yates et al., 2002). Sun et al. (2007) explored the barriers to cancer pain management among 50 American Chinese patients. It was found that patients hold high concerns related to addiction, tolerance and disease progression. In addition, the mean total of BQ was relatively high (M = 2.56). The small convenience sample was the main weakness of the study. In the last two decades, many studies investigated the barriers to cancer pain management and found similar barriers to those found in the above mentioned studies (see table 2.8) (Anderson et al., 2000; Bagçivan et al., 2009; Chung et al., 1999; Edrington et al., 2009; Gunnarsdottir et al., 2005; Jacobsen et al., 2009; Lin and Ward, 1995; Lin, 2000; Oldenmenger et al., 2009; Potter et al., 2003; Sun et al., 2007; Yates et al., 2002).

Culture is one of the main factors that may affect cancer pain experience (Davidhizar and Giger, 2004). Culture may form a barrier to cancer pain management if not considered during the course of pain management. It may affect pain reporting and medications use as well (Al-Atiyyat, 2009; Anderson et al., 2000; Cleeland et al., 1997).

Patients from different cultures may perceive pain differently, and if patients from minority cultural backgrounds (and ethnicities) are ignored, this may lead to inadequate pain treatment (Al-Atiyyat and Mohammed, 2009). For example, Beck (2000) reported that black people may tend to report pain less than people from white ethnicity. In addition, Forgeron et al. (2005) explored the barriers to cancer pain management in the Arab-Islamic culture of the parents of Jordanian child cancer patients. They found that the belief in God's Will may prevent patients from reporting mild to moderate pain and not requesting pain medications, therefore nurses should consider this while treating cancer pain in multicultural settings (Davidhizar and Giger, 2004).

Another large-scale survey was conducted in the USA to evaluate the ethnic differences in cancer pain experience (Im, 2007). Four hundreds and eighty patients (from four ethnic groups that are Hispanic, non-Hispanic (N-H) White, N-H African-American, and N-H Asian) were recruited and both one-dimensional (such VAS and NRS) multidimensional (such as BPI and MPQ) pain assessment tools were used to assess patients' pain. It was that N-H African reported less pain scores (on VAS and MPQ) level than other ethnicities. Overall all, white patients tend to express highest pain levels and the N-H Asian pain scores were the lowest on the all types of scales that were used in the study (Im, 2007).

In addition, a qualitative study that explored and compared pain meaning among two groups (Black Caribbean and White British) of cancer patients with pain was conducted in the UK (Koffman et al., 2008). Non-structured interviews were carried out and then analysed using the framework thematic analysis technique. It was found that both ethnicities perceived pain as an "enemy" and a contest that its treatment may goes beyond the use of pain medications only. On the other hand , only Black Caribbean patients reported that pain is a test from God and some of them saw pain combined cancer as "punishment" for doing something wrong (sin)(Koffman et al., 2008). The above mentioned studies confirmed that pain may have a unique meaning across cultures and this may affect seeking treatment behaviours. For example, Beck (2000), in her ethnographic study, reported that Black African cancer patients tend to seek help from witch doctors rather going to medical doctors or using medications to treat cancer pain.

**Table 2.8 Patient-related barriers to cancer pain management**

Author, Year, country	Sample size/type	Design	Main reported barriers to cancer pain management					Quality score
			Lack of Knowledge	Fear of addiction and drugs side effects	Linking pain with disease progression	Reluctance to report pain	Fatalism	
Bagçivan et al., 2009 Turkey.	170/patients <b>Convenience</b>	Survey	√	√	–	√	√	20
Sun et al., 2007, USA	83/ <b>Random Convenience</b>	Survey	√	√	–	√	√	19
David, 2003, USA.	22 nurses 54 patients <b>Convenience</b>	Focus group	√	√	√	–	–	24
Potter et al., 2003, Australia.	39/ <b>Convenience</b>	Survey	–	√	√	√	–	22
Kearney et al., 2003,UK	108/ <b>Convenience</b>	Survey	√	–	√	√	–	23
Yates et al., 2002, Australia.	114/ <b>Convenience</b>	Survey	√	√	√	√	√	23
Edrington et al., 2009, USA.	50/ <b>Convenience</b>	Survey	√	√	√	–	–	22
Paice et al., 1998, USA	200/ <b>Convenience</b>	Survey	√	√	√	√	–	22
Ward et al., 1993, USA	270/ <b>Convenience</b>	Survey	√	√	√	–	√	17

Author, Year, country	Sample size/type	Design	Main reported barriers to cancer pain management					Quality score
			Lack of Knowledge	Fear of addiction and drugs side effects	Linking pain with disease progression	Reluctance to report pain	Fatalism	
Chung et al, 1999, China.	39/ <b>Convenience</b>	Survey & interview	√	√	√	√	√	16
Anderson et al., 2000,	108/ <b>Convenience</b>	Survey	√	√	–	–	–	21
Ward et al., 1996, USA	35/ <b>Convenience</b>	Survey	√	√	√	√	–	18
Ward and Hernandez, 1994, Puerto Rico.	263/ <b>Convenience</b>	Survey	√	√	√	√	–	16
Lin, c., 2000, Taiwan.	80/ <b>Convenience</b>	Survey	√	√	√	√	√	19
Lin and Ward, 1995, Tiawan	63/ <b>Convenience</b>	Survey	–	√	√	√	–	26

Also, Im (2008) conducted a study to explore Asian American cancer pain experience using a qualitative approach. It was found that Asian believe that pain is a normal part of cancer as a disease, and they deemed that pain can be managed by having positive view or what they literally called a “positive thinking” (Im et al., 2008). Further, another consequent of ignoring the cultural aspect of cancer pain is the fact that patients in pain from minority groups are inadequately treated (Anderson et al., 2000; Anderson et al., 2009; Cleeland et al., 1997). However, culture also may affect the adherence to pain medications and lead to less pain medications are being taking by patients (Al-Atiyyat, 2009). Further research needs to be conducted in this area to shed the light on cultures that are little known about such as Arab-Islamic culture, and maybe there is a need to explore larger number of cancer patients who are in different disease stages. Finally, family caregivers are also contributors to the potential inadequacy of cancer pain management, especially once patients are being cared for at home (see table 2.9).

The aforementioned barriers hinder adequate cancer pain management, and barriers have been identified in various cultures (including both Western and Asian), but not the Arabic Islamic culture. Hence researching this topic is recommended because pain experience is culturally sensitive. In addition, the Barrier Questionnaire (BQ) developed by Ward et al. (1993) seems to be a suitable tool for use in this study, but it needs translation into Arabic.

Overall, most of the studies that explored the barriers to cancer pain management used survey methods and one of the available forms of BQ. The main concerns with these studies are that they were conducted within a local or single institution, sample was selected conveniently rather than randomly, and sample size was small. These are typical external validity threats which limit generalizability. Therefore, there is a need for large-scale (multi-centred) studies that utilise random sampling to ensure a representative sample and generalizable results.

Using well-validated questionnaires such as the BQ would improve internal validity. However, using many forms of it limits the ability to make a comparison across studies. This is because different forms use different numbers of items and sub-scales. Few studies used qualitative approaches, which may be explained by the early introduction of the BQ by Ward (1993). Thus, other barriers might be available but not detected simply because they are not covered by the BQ items. To discover these, more in-depth interviews or open-ended questions could be used alongside the BQ to evaluate the barriers to cancer pain management, especially when exploring different (non-Western) cultures.



**Table 2.9 Family caregiver-related barriers to cancer pain management**

Author, Year, country	Sample size/type	Design	Main reported barriers to cancer pain management					Quality score
			Lack of Knowledge	Fear of addiction and drugs side effects	Linking pain with disease progression	Reluctance to administer pain medication	Fatalism	
Lin, c., 2000, Taiwan.	168/ <b>Convenience</b>	Survey	–	√	√	√	–	22
Aranda et al., 2004, Australia.	75/ <b>Convenience</b>	Survey	–	√	√	√	–	20
Letizia et al., 2004, USA	151/ <b>Convenience</b>	Survey	√	√	–	√	–	16
Vallerand et al., 2007, USA.	46/ <b>Convenience</b>	Survey	√	√	–	√	–	18
Lin et al., 2000, Taiwan.	80/ <b>Convenience</b>	Survey	√	√	√	–	√	19

In summary, the studies reviewed here provide invaluable information that has increased the awareness of this problem within the healthcare community. Nurses are an essential part of this community and have an important role in pain management. The nursing role is explored in the following section.

## **2.7 Nursing role in pain management**

Cancer pain is a multidimensional phenomenon that involves all aspects of a patient's life; psychological, physiological, spiritual, and social. Adequate pain management is underpinned by proper assessment and suitable therapy (Nekolaichuk et al., 2005). However, nurses in particular have a unique role in managing cancer pain (MacCaffery and Pasero, 1999; Sykes et al., 2003). Nurses spend the longest time with patients among healthcare providers (MacCaffery and Pasero, 1999). One role is overcoming the barriers to optimal pain management; these barriers are related to patients, healthcare providers and the healthcare system, although this role is not exclusive to nurses. Through open communication and teaching, nurses can reduce barriers (Sykes et al., 2003). Unfortunately, all health care providers (including nurses) may be poorly educated about cancer pain management (MacCaffery and Pasero, 1999; Sykes et al., 2003; Zhang et al., 2008). Providing nurses with a well-structured teaching programme can improve nursing knowledge, which enhances nurses' confidence as patient advocates (Sykes et al., 2003; Zhang et al., 2008). The second role is conducting a complete pain assessment, since it is the responsibility of nurses to assess patients' pain. Thus, it is crucial for nurses to practise pain assessment as though it was the fifth vital sign (MacCaffery and Pasero, 1999; Sykes et al., 2003). The third role is administering the prescribed pharmacological pain medication. Although most nurses do not prescribe medications, their engagement in pain management is significant (MacCaffery and Pasero, 1999; Sykes et al., 2003). The revolution in pain medications, route of administration and highly technological equipments mean that patients are given complex treatment regimens. This complexity needs knowledgeable and skilled nurses to deal with this advancement and to monitor side-effects. Finally, patients' education about pain, medications, side-effects and non-pharmacological techniques is another nursing role. Therefore, nurses play a vital role in cancer pain management. A nurse who is knowledgeable and skilled in pain assessment and management has the confidence to lead the efforts of alleviating pain and advocate the patient's right of living free of pain (Sykes et al., 2003).

## **2.8 Summary**

In summary, the literature on pain prevalence, assessment and management in cancer patients have been reviewed, and barriers to cancer pain management presented. Research strongly suggests that completing an adequate pain assessment is required to improve the total pain management that patients receive. However, cancer pain continues to be inadequately treated, especially in developing countries (which have limited resources).

The growing literature suggests the use of PMP, which involves using a pain assessment tool and education for healthcare providers (nurses in particular) to improve cancer pain management and the quality of patient care. The use of both interventions together seems to be complementary and necessary to improve cancer pain management. The number of studies exploring the effects of such programmes is increasing; however, few of them have investigated the impact of such programmes on the adequacy of pain management and nursing practice.

This review highlighted the need for flexible but robust methods that can accommodate the implementation of PMP which is a complex, multi-dimensional, and an interrelated process.

This review suggests the use of the BPI as the tool to be implemented, combined with education (PMP). However, this tool needed to be tested in the proposed study setting to confirm its suitability to the context. Therefore, there was a need for pilot work before commencing the main study. In addition, the Barrier Questionnaire (BQ) was also nominated to be used in evaluating the barriers to cancer pain management in the study setting, after being translated into Arabic.

In addition, the previous PMP projects recommended the use of a theoretical framework to enhance the likelihood of success and understanding of the implementation process. Such a framework is needed to enhance the translation of research findings into practice. The next chapter discusses the theoretical framework used in this study.

### **3. Chapter Three: Theoretical Framework**

### **3.1 Introduction**

This chapter presents definition of the translation knowledge concept and provides an overview of the research utilization determinant. It also explains the theoretical framework used in the study. This framework draws from the previous work of selected models of transforming research evidence into practice that included: diffusion of innovation model (Rogers, 1995), promoting action on research implementing in health services (PARIHS) Kitson et al., 2008) and change theory (Lewin, 1951). It then explains the framework adopted in this study.

### **3.2 Translating knowledge into practice**

Nowadays there is an international consensus on the need for integrating research-based evidence into the daily practice of health care providers. However, of the huge amount of health research that is being published every year, only a small percentage of findings are implemented into practice (Lenfant, 2003). A number of models are available to translate knowledge into practice (Titler, 2007). Recently, a review identified the presence of 31 models and frameworks for planned change, 19 of which have not been tested or used in practice (Graham and Tetroe, 2007). However, the use of a conceptual framework may be helpful in improving the overall likelihood of adopting a proposed change. Such models guide and generate strategies to inform the translation of knowledge into practice. Therefore the use of a theoretical framework that would help the progress of change and explain its results is considered essential for future studies. In addition, many studies urged the need for such a framework to improve the likelihood of adopting and integrating the evidence into practice.

The term 'translating knowledge into practice' is frequently used in the literature. However, other synonyms are available, such as knowledge utilization, implementation research, research dissemination and research uptake (Lang et al., 2007). For the purpose of this study, the above mentioned terms are used interchangeably to indicate translating knowledge into practice. Alongside this variety, definitions for the term 'translating knowledge' are also available. For instance, Backer (1991) defined translating knowledge as "research, scholarly and programmatic intervention activities aimed at increasing the use of knowledge to solve human problems" (Backer, 1991). In contrast, a more sophisticated and comprehensive definition was presented by the Canadian Institute of Health Research, which defines knowledge translation into practice as "the exchange, synthesis and ethically sound application of knowledge - within a complex system of interaction among researchers and users - to accelerate the capture of the benefits of research for patients through improved health, more effective service and products, and a strengthened health care system" (Canadian Institute of health

Research, 2004). The essential message implied in these definitions is to benefit patients by getting research results into practice, in order to improve the health care outcomes related to patients, staff and systems.

This chapter identifies a suitable model or framework to be used in the study. However, listing and discussing all available models is beyond the scope of this section. Therefore, previous studies that have implemented a pain assessment tool or pain management intervention into nursing daily practice (Bourbonnais and Bouvette, 2004; Brown and McCormack, 2005) were used as a guide in the process of locating models and frameworks. In addition, published critiqued papers (Lang et al., 2007; Rycroft-Malone et al., 2002; Titler, 2007) on such models were also used. Thus, the three main models found to be related and useful to this work are presented and discussed in this below: 1) diffusion of innovation theory (Rogers, 1995); 2) promoting action on research implementation in health service (PARIHS) framework (Kitson et al., 1998); and 3) change theory (Lewin, 1951). These three models were selected because one of them (Lewin, 1951) is suitable for this study's construction, as it has three stages, which can help the researcher in conducting the study by providing tips for each stage. The PARIHS model seems to be helpful in assessing the context of change and in constructing a thorough understanding of the proposed change context, which improves the chance of getting the change adopted. Furthermore, the diffusion of the innovation model has been known for decades, and was expounded extensively by Rogers. This model helped the researcher to comprehend what the innovation diffusion is about. However, prior presenting those models, it is useful to provide the reader with an overview of factors that influence the research implementation process.

### **3.3 Research utilization determinants**

There are many factors that may affect research utilization and uptake into practice. These factors can be clustered into three main categories: adopters (individual), organization, and research evidence-related factors (Estabrooks, 2009; Greenhalgh et al., 2004; Grol and Grimshaw, 2003). It should be acknowledged that a considerable amount of research has been conducted in the UK within this field. Reviewing all the available studies was not possible because it is beyond the scope of this section, which focuses on providing the reader with an overview of the determinants of research utilization. Hence, the researcher mainly presents the results of systematic reviews and the work of researchers who have made a significant contribution to the field such as Estabrooks, Grol and Grimshaw, Rycroft-Malone, and Greenhalgh.

Firstly, regarding individual factors, Estabrooks (2009) reported that adopters' (i.e. nurses and doctors) characteristics can determine the level of research utilization in

practice. Estabrooks et al. (2003) conducted a systematic review that covered a wide range of databases but was limited to work published in English. It covered articles published between 1993 and 2000. They identified six categories as individual determinants of research use. These features mainly include personal attitude toward research, participation in research work, information quest behaviour, education, professional characteristics, and demographic factors (Estabrooks et al., 2003). Moreover, an update for this review was conducted (Squires et al., 2011a) and covered research papers published in four languages (English, Danish, Swedish and Norwegian) between 1998 and 2009. This review confirmed the aforementioned six categories and added a new category on critical thinking. In addition, there was consistent evidence that a positive attitude toward research would predict better use of its results in practice. It is acknowledged that although many studies were conducted within this area (different research methods were used), they failed to conclude clinical implications or guidelines that could enhance research uptake into nurses practice (Estabrooks, 2009). Although a large number of the studies explored individual`s determinants, the available evidence from these studies can only be described as weak (most likely coming from descriptive studies) and equivocal (Estabrooks, 2009). In regard to the nursing profession, it is reported that research findings are not completely integrated in practice and only a small percentage of nurses are using research findings (Boström et al., 2007; Estabrooks, 2009; Squires et al., 2011b; Thompson et al., 2007).

In order to change individual health care practitioners' attitudes toward research utilization a number of techniques have been used. A seminal review reported that many methods were used to enhance the use of research findings into practice, namely: education, audit and feedback, reminders, multidisciplinary work, media, quality improvement projects, financial supported intervention (e.g. reducing drug cost), client-focused interventions, and dual intervention (combining any two or more interventions) (Grol and Grimshaw, 2003). A recent systematic review aimed to explore the interventions used in implementing research into practice. Four interventions that were commonly used in knowledge translation included audit and feedback, computerised decision help, opinion leaders, and complex interventions (e.g. combining the use of education with feedback and audit). This review confirmed that complex intervention (i.e. using more than one method to deliver and evaluate the evidence being implemented) was the most frequently used and its use increased research use into practice (Boaz et al., 2011). This review did not explain how the quality of the included papers was assessed and it suffered from using a small number of studies (13), which may be a threat the external validity of its results.

Education of practitioners was one the most commonly used methods to change practice toward an evidence base and has been extensively tested in research (Profetto-McGrath et al., 2009; Rodgers, 2000; Stevenson et al., 2004; Tranmer et al., 2002; Tsai, 2003). The emphasis on education can also be seen in the field of improving cancer pain management (as shown in chapter 2). Some authors reported that education through using education packages was useful in changing personal attitudes, but in practice participants still were hesitant to use research findings (Stevenson et al., 2004). This was consistent with a review on the use of another form of education, namely a journal club, in translating knowledge into practice. The PARIHS model was used as a theoretical framework, and 10 articles were included. It was reported that journal clubs can be helpful in improving individuals' research utilization skills, such as research appraisal, but not putting research finding into clinical practice (Rogers, 2009). The results of this review should be interpreted in light of small numbers of reviewed studies, lack of clarity of search strategy and quality of research included. Overall, although education can be seen as cost effective and useful strategy, education alone was not enough to change practice toward research use (Grol and Grimshaw, 2003; Thompson et al., 2007). This may highlight the need for using a combination of methods (referred to as a complex intervention in the literature) to enhance the research uptake into routine nursing practice (e.g. education and audit or opinion leaders) (Dijkstra et al., 2006; Grol and Grimshaw, 2003; Thompson et al., 2007).

Secondly, organizational determinants are "those characteristics of a healthcare organization, or units within those institutions, and governance structures outside of those institutions that facilitate the dissemination and uptake of research findings" (Estabrooks, 2009, p. 227). Estabrooks (2009) reported that, within the nursing profession, those features have been less examined than individuals' determinants of research implementation. These determinants are divided into two sub-categories, structural and cultural (Greenhalgh et al., 2004). It has been advised that large institutions that are "mature, functionally differentiated and have decentralized decision-making patterns" are more likely to be receptive to research implementation and changing practice (Greenhalgh et al., 2004). On the other hand, cultural determinants are as important as structural factors. Cultural factors include the beliefs and norms prevalent within the institution (or its units)(Estabrooks, 2009). In addition, supportive administration and a good relationship with managers are deemed to improve research uptake into practice (Estabrooks, 2009). For example, Boström et al. (2007) found that nurses who worked under the supervision of a unit manger who is research-oriented were more likely to use research findings. Therefore, this may suggest the need to assess the organization readiness for change in terms of structural and cultural determinants.



This would enable researchers to customize the evidence being implemented to fit the context of change. This would hopefully enhance the uptake of research findings (Greenhalgh et al., 2004). For instance, a study was conducted to examine hospital characteristic that might affect nurses research use in their daily practice (Cummings et al., 2007). The PARIHS model was used as the theoretical framework. The results showed that hospital size, flexible administration (appreciative of research use), and environment that encourages nurses cooperation and gives time for research activities led to improving research use within the hospital (Cummings et al., 2007). Implementation science began around thirty years ago (Cummings et al., 2007), yet according to a systematic review conducted by Parmelli et al. (2011), no methodologically reasonable study has examined the effectiveness of the interventions used to change healthcare settings in terms of culture to facilitate evidence-based practice.

Thirdly, one of the most important determinants of research implementation is the characteristics of the evidence (which could be simply research results or new practice) (Greenhalgh et al., 2004; Grol and Grimshaw, 2003; Rycroft Malone et al., 2004). Evidence can be sought from four sources, namely: research results, working expertise, healthcare service customer (e.g. patients) or providers (e.g. nurses), and setting (the context)(Rycroft-Malone et al., 2004). Moreover, a systematic review examined the factors that influence the implementation of the evidence (i.e. clinical guidelines)(Francke et al., 2008). Literature was searched to locate previous reviews within this area. Only 12 reviews met the authors' inclusion criteria (Francke et al., 2008), and the studies' quality was low. It was found that guidelines that are easy to comprehend, and do not require special skills or resources, have a better likelihood of being implemented into practice. And also giving the adopters the chance to try the guidelines enhanced its adoption (Francke et al., 2008)

Furthermore, Rycroft Malone et al. (2004) examined the factors that underpin the processes of embedding research into practice. This study was carried out in two phases; the first was to construct the questions that should be asked in the second phase. Both focus group and semi-structured interview were used in data collection. It was found that nurses perceived 'evidence' as being the same as 'research findings', and they confirmed that they were willing to use the evidence that met their clinical expertise and fitted with the broader practice context (the setting where they work)(Rycroft Malone et al., 2004). In addition, Grol and Grimshaw (2003) in their review reported that evidence that is robust, good quality, easy to use, requires minimal changes to individuals' practice and organization routine, and is compatible with individual norms is more likely to be adopted and implemented. Overall, these characteristics can be mapped on to the innovation

attributes that were described by the early work of Rogers (2003) in this field, as discussed in the next section.

### 3. 4 Diffusion of innovation theory

This innovation theory was developed by Rogers who defined diffusion as the process by which an innovation is communicated through certain channels over time among members of a social system (Rogers, 1995). Rogers's theory proposed that new knowledge diffusion is underpinned by four main components: the innovation, time, communication and social system (Dooks, 2001; Rogers, 1995; Rycroft-Malone et al., 2002; Titler, 2007).

#### 3.4.1 Innovation

Innovation is an idea, practice, or object that is perceived as new by an individual (Rogers, 1995). It is believed that the innovation's characteristics strongly affect the innovation's diffusion, for example some innovations spread and are adopted quickly (e.g. satellite channel receivers), while it takes other innovations a lot longer (e.g. using seat belts in cars). Rogers suggested that certain attributes of the innovation influence the speed of uptake. These are the relative advantage of the innovation, compatibility, complexity, trialability and observability, all of which could affect the adoption of the innovation (see table 3.1) (Rogers, 1995). Innovation with such characteristics is more likely to be adopted rapidly.

**Table 3.1 Characteristics of good innovation**

<b>Relative advantage</b>	Innovation should be perceived as advantageous by individuals to be adopted, rather than being really advantageous.
<b>Compatibility</b>	Matched the norms, rituals, values and previous experience of the expected innovation users.
<b>Complexity</b>	Easy to comprehend and to use.
<b>Trialability</b>	Can be implemented as chunks rather than one piece.
<b>Observability</b>	It has instant, measurable and visible results

#### 3.4.2 Time

Time is an important component of innovation decision making, and hence affects the rate at which innovation can be utilised in practice (Rogers, 1995). The innovation decision process starts when an individual is introduced to the innovation for the first time, and extends until the decision is taken to reject or accept the use of the new change (Rogers, 1995). The innovation-decision comprises five steps (see table 3.2), and individuals need time to go through this process. These decisions, however, could be reversed, for instance the individuals may stop using the innovation, and hence a form of crystallisation of the new

system is required. Innovation users can be categorised into five types, based on their speediness of adopting the innovation: innovators, early adopters, early majority, late majority and laggards (Rogers, 1995).

**Table 3.2 Innovation decision making process steps**

<b>Step</b>	<b>Events</b>
Knowledge	Knowing the innovation and comprehending how it works.
Persuasion	The proposed users figure a feeling of like or dislike of the innovation.
Decision	Proposed users take steps that lead to adoption or rejection.
Implementation	Start using the innovation.
Confirmation	Adopter seeks support to confirm the decision that is made and implemented.

Adopters' characteristics affect the extent to which the innovation will be used and integrated into daily practice. These characteristics include education, motivation, values and favoured teaching method.

The adoption could be improved through conducting needs assessment before the implementation. Thus, the change will be based on individual or system needs, which may encourage their active participation in the whole process. In addition, audit and feedback should be conducted frequently during the implementation period and thereafter. However, this re-evaluation process should be valid, reliable and meaningful to the practitioner in order to maintain the whole process and its momentum (Titler, 2007). This could be applied to the implementation of PMP into practice by having a feedback strategy, which enables the researcher to evaluate the effects on the practice and process of pain management.

### **3.4.3 Communication**

Communication is defined as the way or method that the innovation is disseminated among individuals (Rogers, 1995). Interpersonal (face to face exchange) and social communication (media) are thought to be the most effective communication channels (Rogers, 1995). Public media such as newspaper, televisions and radio play a vital role in spreading new innovations. In addition, education is another effective communication means, but it is not effective if used alone (Rogers, 1995; Titler, 2007).

### **3.4.4 Social system**

It is the population of individuals who are functionally differentiated and engaged in collective problem-solving behaviours that makes up the social system (Titler,

2007). The implementation of the same evidence may produce different results in different contexts (social systems). This may be explained by the fact that each system has its own culture, norms, rites and patterns of communication. Thus exploring and knowing the implicit culture within the social system facilitates the successful diffusion and adoption of the new innovation. Fisher suggested that systems that appreciate creativity and have powerful administrations are more likely to adopt change (Fisher, 2004).

Opinion leaders, change champions and expert opinions are a vital component of the social system (Rogers, 1995; Titler, 2007). Opinion leaders are persons who are trusted role models and are used as resources for their colleagues. Therefore, if they used the evidence or adopted the change, it is more likely that others may also do so. Furthermore, they can recommend the use of the evidence. For example change champions also are expert practitioners in local settings and they are committed and motivated to provide high standards of care. Change champions use their relations with other disciplines to motivate and incorporate the change into daily practice. The successful diffusion of innovation requires the opinion leaders and change champions together. However, leader opinions can produce a wide range of effects. Additionally, the use of more than one change champion in the same setting may enhance their effects on the change process. In order to improve the adoption, both should meet the users of innovation frequently and act as guides for the whole process. Experts play a vital role in the change process. In addition, they have a broad knowledge base in certain topic areas ('topic experts'). Experts give the adopters the information about the evidence being implemented and provide feedback to the change team (Titler, 2007).

Rogers's model has not been empirically tested in the healthcare context (Fisher, 2004). In addition, the use of Rogers's model proposes that innovation and evidence-based practice are equivalent, which is not necessarily the case (Rycroft-Malone et al., 2002), which indirectly may mean that the process of implementing evidence such as Pain Monitoring Programme (PMP) somehow differs from the process of innovation diffusion (i.e. new software). For example, the implementation of PMP may be seen as a planned process that takes all the considerations and pushes toward the application of PMP in practice.

### **3.5 Promoting action on research implementation in health services (PARIHS)**

The PARIHS system was first introduced in 1998 by Kitson et al. Since that time, the PARIHS model has been revised twice (Kitson et al., 2008; McCormack et al., 2002). It is an heuristic conceptual framework for the translation of research

evidence into nursing practice (McCormack et al., 2002). This model proposed that successful implementation is a function of the relationship between the nature of the evidence, the context in which proposed change is to be implemented, and the mechanisms by which the change is facilitated (Kitson et al., 1998). Therefore, PARIHS addressed three important elements: evidence, the context and facilitation. The multi-dimensional structure of PARIHS makes it unique and capable of giving a full understanding of the implementation process. However, each dimension has sub-elements. All of these dimensions and their sub-elements are drawn on a low to high continuum.

### **3.5.1 Evidence**

Evidence is defined as the combination of research, clinical experience and patients' preference (Kitson et al., 1998). The more robust the evidence (in meeting staffs' clinical experience and patients' preferences), the greater is the possibility that the change will be successful. Conversely, if one of these elements is weak or ignored, the likelihood of the implementation failing is greater (Kitson et al., 1998; McCormack et al., 2002).

### **3.5.2 Context**

Context is the setting wherein the change or implementation will take place. In most cases, the environment of change is complex, dynamic and never static (Kitson et al., 1998). In addition, cultural, economic and political factors affect the environment and its readiness to change. Three sub-elements of context have been identified: culture, leadership and evaluation strategy. It is believed that recognition of the dominant culture in the setting enhances the successful implementation. The PARIHS authors acknowledge that settings with transformational leaders are more capable of change than settings with command and control leaders. Evaluation strategy is an important ingredient of the research and change process (Kitson et al., 1998), because it enables the recognition of resistance and difficulties at an early stage, enabling the change agents to intervene to overcome obstacles. In addition, evaluation may provide feedback on the effectiveness and efficiency of the implementation processes (Kitson et al., 1998). Therefore, implementation researchers should identify the evaluation strategy available in the context and determine how to use it in the prospective work. In the situation where there is no evaluation strategy, the researcher should establish a feedback strategy.

### **3.5.3 Facilitation**

Facilitation is a technique by which one person makes things easier for others (Kitson et al., 1998). Facilitation is vital in mediating change. Facilitation comprises three sub-elements: purpose, role and skills, and attributes. The facilitation depends on the characteristics of the person who intends to carry out this role and could range from general support to changing individuals' attitudes and behaviours (Kitson et al., 2008). The best change process can be tailored based on tentative results of the assessment of individuals' readiness to change and capability to tolerate the evidence being implemented (Kitson et al., 2008). Therefore, the facilitator constructs the change programme that meets individual needs (Kitson et al., 2008).

### **3.6 Change theory**

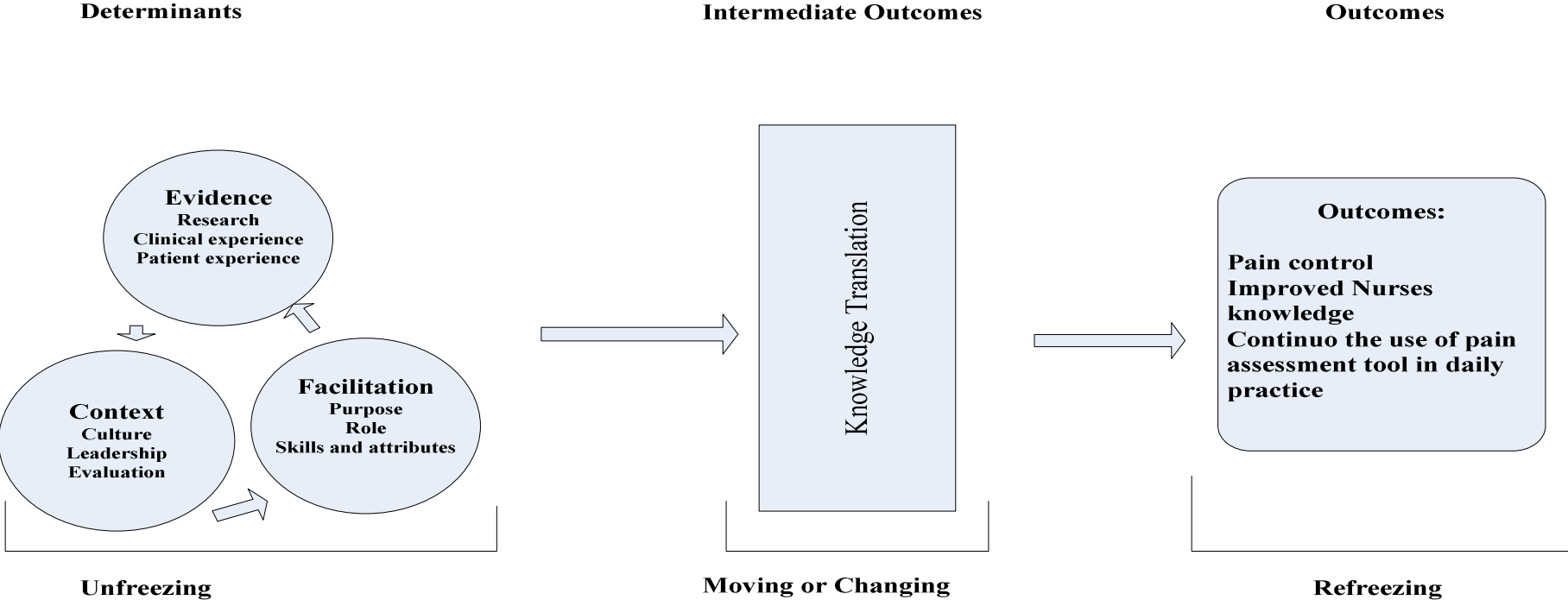
Lewin proposed that change is comprised of three stages: unfreezing, moving or changing and refreezing (Lewin, 1951; Rocchiccioli and Tilbury, 1998). Lewin's force field analysis revealed that each context has driving and restraining forces, which in turn govern the process of change. The context before the change usually is in status quo, therefore disequilibrium needs to occur to start the change process (*unfreezing*). In the first stage (*unfreezing*), the awareness of the need of change should be raised, through education, group discussion and familiarising staff with the new approach (innovation). The change agent should enhance and drive the context or staff toward unfreezing. Lewin reported three tactics to do so: disconfirmation, inducing guilt or anxiety and the creation of psychological safety. However, in this stage staff should recognize the importance of the proposed change and be encouraged to be part of this process. The second stage is the *moving or changing* stage, when the use of new innovation is started (*implementation*). The change agent should support staff during this period. Group discussion is an effective strategy to overcome problems or barriers during the implementation phase. In addition, audit and feedback could be used to evaluate the implementation process and confront resistance as it appears. The third stage is *refreezing*, which aims to maintain the change over time and bring the context to new equilibrium point. At this point the change agent should transfer the responsibility to the staff. Then, they will stand as change agents. In addition, the change should be incorporated in the daily routine of staff. This can be accomplished if the management decide on the new change to be used as policy, procedure or guideline (Rocchiccioli and Tilbury, 1998).

### **3.7 Study framework**

This study aimed to implement and evaluate a PMP into nurses' daily practice. However, there are numerous models and frameworks for change available in the literature. However, most of these models have similar steps to achieve the desired change, including: 1) choosing the area of change (identify the gap); 2) formulating the evidence; 3) tailoring the evidence to suit the context; 4) applying the evidence (start using); and 5) evaluating and getting feedback (Titler, 2007).

For the purpose of this study, the PARIHS model will be used as conceptual framework alongside change theory. In addition, the diffusion of innovation theory is used to provide an understanding of the implementation process in general. Time is an important aspect in any implementation study, and this study was conducted over three stages; pre-implementation stage (unfreezing), implementation of the pain monitoring programme (moving or changing) and post-implementation (refreezing). This was informed mainly by the change theory. In addition, Rogers classified innovation adopters according to how speedily they adopted the innovation. However, in the PARIHS model, the time aspect is not a feature. This makes PARIHS model an assessment tool that only can be used in assessing the context readiness to change, although the main reason behind it was to provide a framework to guide the implementation process. Thus, the use of two models (change theory and PARIHS) in this study is proposed, which is justified by the fact that implementation studies are difficult to condense into one theory or model due to their complexity (Estabrooks, 2009). Therefore, basically the researcher used the PARIHS model and change theory as the main underpinnings of this study. However, the diffusion of innovation is also used to aid with understanding the implementation process events. The challenge was to determine how to use the two frameworks, and it is believed that building the framework architecture may help make a clear image of what is to going on in the implementation. Therefore, a theoretical framework was customized using the three main elements of the PARIHS (evidence, context, and facilitation) and change theory, as shown in figure 3.1.

**Figure 3.1 Research Utilisation Model**





Based on these models, the aim was to transfer the evidence (Pain Monitoring Programme) into practice. The evidence is quite strong and its benefits have been established by previous literature. According to this model, there was a need for insight about the proposed place of change, and thus it was proposed that pilot work should be conducted before the main study.

### **3.8 Summary**

Three models of translating knowledge were reviewed; the Diffusion of Innovation Theory, Change Theory and the PARIHS model. All of them aimed to maximize the use of research evidence in practice. Two models were selected for use here; PARIHS and Change Theory. The PARIHS model seems to be suitable to guide the upcoming knowledge translation process since it was originally developed to enhance integrating research results into nursing practice. In addition, change theory provides a theoretical base to estimate what factors could facilitate or hinder the implementation process. These models suggested that the implementation process is likely to be multi-staged and both suggested early work to assess the readiness of the setting for change and to evaluate the possibility of doing the study within the chosen location. Therefore, pilot work was carried out. The next chapter discusses the pilot work.

## **4. Chapter Four: Pilot Work**

## **4.1 Introduction**

As previously stated, the original aim of the study was to implement and evaluate a cancer pain monitoring programme in nursing practice in a hospital in Jordan. Before committing to a study design it was necessary to find out if it would be possible to conduct the study and to describe the context of the study, so the selected hospital was approached. The approval from the hospital to conduct the pilot work and the main study was obtained (see appendix 6) (approval to conduct the pilot work alone is not allowed in Jordan). The pilot work was guided by the PARIHS and Lewin's model (see figure 3.1).

### **Aims of the pilot work:**

#### **1- Context assessment**

- To explore if it was possible to carry out the work at the selected hospital in terms of willingness of hospital administration to host this study and appropriateness of the hospital for the work.
- To assess the culture in the setting with respect to how the cancer pain management process is conducted.

#### **2- Instrument testing**

- Confirming the usability of the data collection instruments; it was expected to use the brief pain inventory (BPI), Barrier Questionnaire (BQ), and data extraction sheet within this area.
- Testing of questionnaires.
- Checking the adequacy of translation for some tools (BPI-short form, data extraction sheet and barriers questionnaire).

The pilot work was conducted before the main study to gain insight into the proposed study context. The researcher attended the hospital on daily basis for a period of two weeks. Informal meetings and discussions were conducted with CNO, unit manager, and unit nurses (7). Researcher wrote key notes from the participants and used them to construct the picture about current nurses' practice. In addition, cancer pain management policy and organization flow chart were reviewed and unit manager provided the researcher with information about nursing care style adopted in the unit, information about nurses' education level, patients' admission rates. Further, researcher oriented himself with the unit lay out and daily work routine through spending time in the unit and talking with nurses. Finally questionnaires (BQ, BPI, and DDS) were given to nurse (5), patients (4) and one

family caregiver to test translation adequacy. Thus and preliminary picture had been drawn about the unit culture (how thing is going there), cancer pain management practice and nurses. Based on this work possible study facilitators and barriers were identified to inform designing the main study. This is consistent with the aims of the pilot to understand the study context and to test the suitability and feasibility of the data collection instruments.

## **4.2 Context assessment**

The PARIHS model was used to provide contextual assessment. The PARIHS model suggests that the success of the implementation process is a function of the relationship between evidence, context and facilitation (Kitson et al., 1998). In the pilot work the three elements were applied in the study site, in order to identify the appropriateness of the site for the main study and to identify possible difficulties such as resistance or facilitators.

### **4.2.1 The evidence**

According to PARIHS, the evidence being implemented should be strong and match workers experience and patient's preference. This study is about implementing a PMP in practice to improve cancer pain assessment and management. Mounting evidence from the literature supports the importance of using PMP (pain assessment tools and education). Therefore, the intention here was to make use of the assessment tool easy and less time-consuming, in order to encourage healthcare providers to use such tools. Resulting in enhancement of the tool use and improving its compatibility with the busy nursing environment.

### **4.2.2 The context**

The context is the place in which the study was conducted, and comprises three sub-dimensions: culture, leadership and evaluation. The pilot work addressed these dimensions within the proposed site.

#### **4.2.2.1 Context description**

The pilot work was conducted in the adult oncology ward at a referral hospital in the northern part of Jordan (The hospital name was anonymised due to ethical consideration). It is a tertiary care unit, which includes well-established, and high technology surgical, medical, oncology, intensive care, intermediate care, paediatric, obstetric, coronary care and emergency units, about 60 outpatient clinics and 21 operating theatres. Oncology patients are treated in a 16-bed oncology ward and outpatient clinic for short chemotherapy regimens. This hospital

is considered one of the best hospitals in the country. The administration of the hospital aspires to be one of the hospitals that apply international standards of high quality medical care.

### **Oncology Unit**

The Oncology Unit was chosen as the physical place for this case study. This unit is a mixed adult oncology ward (see pictures 4.1 and 4.2). It has 16 beds in single rooms, all of which are equipped with oxygen and suction ports. There is one isolation room for patients treated with radiation or radioactive iodine. In general, the unit has basic machines such as portable suction, ECG, ice maker, refrigerator, and emergency trolley. There is a medication room where medications are prepared and stored, and a treatment room where certain procedures (bone marrow aspiration, central line insertion and lumbar puncture) are conducted. Intravenous preparations of morphine, pethidine and tramadol are kept in a locked cupboard to be used when needed and to save staff time. It is the responsibility of the head nurse to check and refill the stock.

The nurse to patient ratio is 1:4, and a primary nursing care model is employed whereby each nurse is assigned four patients and he/she is responsible for the patients' total care. The hospital uses traditional paper records to document the patients' nursing and medical information. English is the language used in the unit and the entire hospital as well. In this unit the numbers of health professionals are as follows:

- 1- Physicians: eight medical and surgical oncologists and two gynaecologists (n = 10).
- 2- Nurses: 13 registered nurses, including the Unit Manager (UM) and one support worker.

Average admission rates per month are 100 patients, with an average length of stay of seven days. This admission rate would enable the researcher to recruit adequate patient numbers for the study. Patients are admitted to the unit to receive chemotherapy, treat chemotherapy complications, pain management, treatment evaluation, and for palliative care in some situations.

**Picture 4.1 Oncology Unit entrance**



**Picture 4.2 Typical patients' room**



#### **4.2.2.2 Culture**

The culture is about how processes, events, procedures and total patient care are provided in the hospital, and in the oncology unit in particular. In this case, culture includes nurse culture in the unit, current practice in pain assessment and management and pain education in the hospital.

##### **4.2.2.2 .1 Nurses in the unit**

All of the nurses working in the unit have a Bachelor's degree in nursing, and a few of them have Master's degrees. On average, the nurses have approximately three

years clinical experience. Thus, they are considered a young group of nurses, the majority of whom are male. The researcher had the chance to talk with seven nurses and the head nurse. The researcher introduced himself to the workers as a PhD student who would like to carry out his PhD research in their hospital. The aim of the study was presented for them and was described as a study to implement a PMP into oncology nurse's daily practice.

#### **4.2.2.2.2 Current practice in pain assessment and management**

Discussions on cancer pain assessment and management practice with the CNO, head nurse, and registered nurses revealed that the hospital had recently started to use a pain assessment tool (Numerical Rating Scale) as a requirement for the Joint Commission International (JCI). The JCI is an internationally recognised accreditation body, established in 1994, which works with health institutes and ministries and hospital administrations all over the world (Joint Commission International, 2009). The JCI mission is "to continuously improve the safety and quality of care in the international community through the provision of education and consultation services and international accreditation and certification" (Joint Commission International, 2009). It was initially thought that because a pain assessment tool was in place, it may have been necessary to find another site to conduct the main study. However, it was still necessary to complete the pilot work.

After talking with nurses, the CNO and HN, and reading the policy documents, it was found that on admission, all patients are usually asked whether they have pain. If a patient has pain, a detailed form should be used to assess pain (see figure 5). Since this form was for use throughout the whole hospital, it contains different scales, which are numerical rating scales(NRS), face pain scale and FLACC (face, legs, activity, cry and consolability); these scales are suitable for adults (NRS), paediatrics (face pain scale) and the unconscious or less than three years old patient (FLACC). The NRS was the tool chosen for use in the oncology unit; it comprised a three-step care plan that starts with assessment, and follows with action and re-assessment. Additionally, it contains information such as pain location, diagnosis, side-effects of pain medication and the worst pain level that the patient experienced. It should be completed once a shift. However, checking of the nursing documentation revealed that the tool was not being used.

It was seen that pain reporting mainly depended on the patient, and most of the nurses tended to wait for the patient to ring the nursing bell and tell them about pain. Although the NRS is available, it was rarely used this may indicate the passive resistance of nurses to the autocratic administration style. Nurses told the

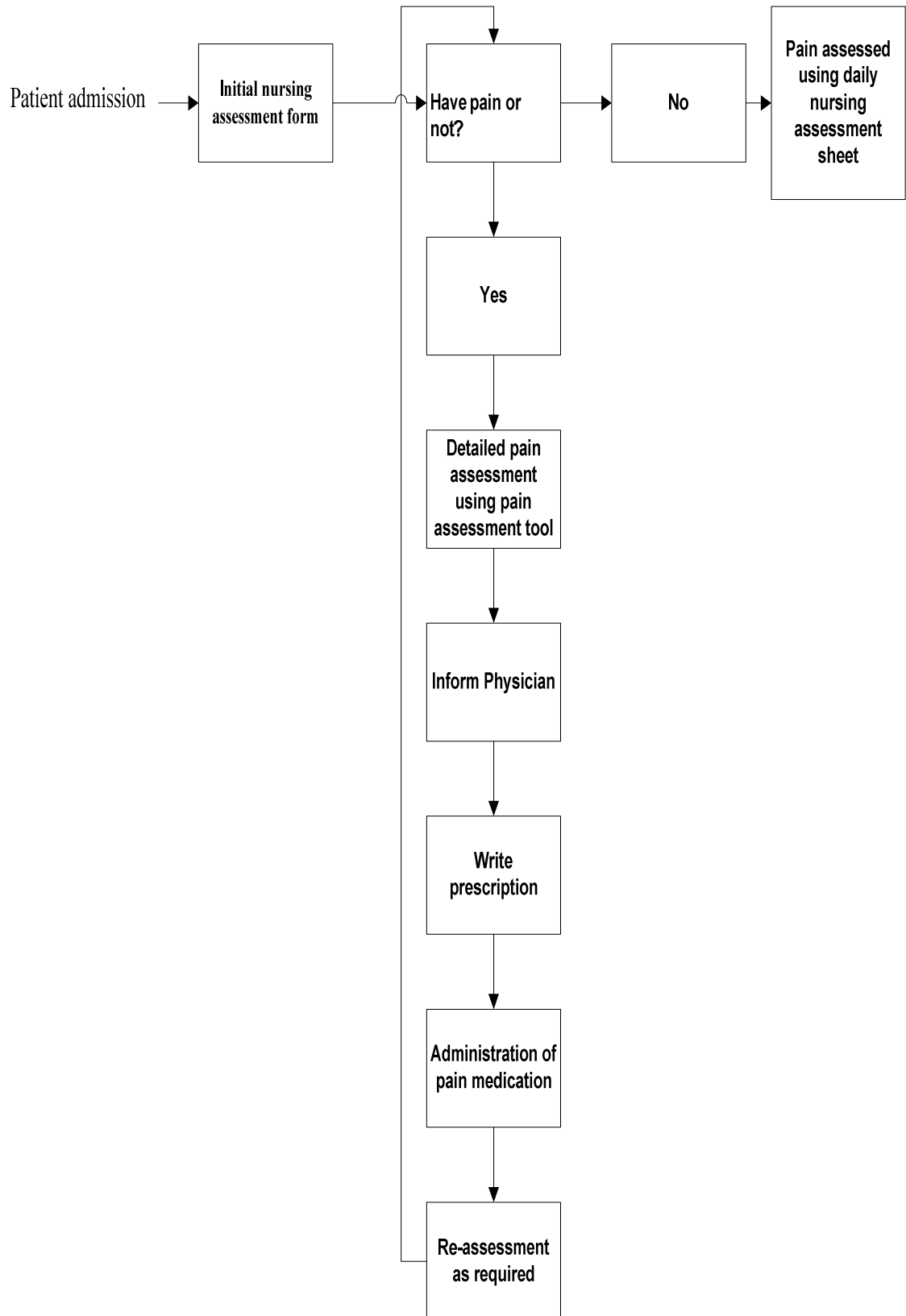
researcher that they felt that the tool was not suitable to assess cancer pain. For example, N10 said:

*It is silly just asking the patient how much is your pain? We should give them other options to express pain.*

In the oncology unit there seemed to be a lack of awareness about the importance of pain assessment and management. Patients sometimes waited a considerable time to receive appropriate pain medication. The sequence was that the patient calls the nurse, and then nurse calls the resident physician who would come and assess the patients' pain. Only then would pain medication be prescribed. Thereafter, the nurse administers the drug if it is available (if not they would have to order it from pharmacy). The time from reporting pain to administration of the medicine can be about one hour. It was found that most patients were not prescribed regular pain medication, with the majority given a single (stat) dose which often left the patient suffering. In the four cases nurses responded to the patient's pain once called, but pain re-assessment was not performed after pain relief had been given. Common practice was to give patients treatment once pain became severe and intolerable. Generally it seemed, communication between patients and nurses in regard to pain was poor, and the newly introduced pain management policy in the hospital was not being used in the oncology unit. This had the effect of suggesting that pain was treated randomly rather than systematically. These findings were in accord with what have been explored in the previous literature (chapter two) in regard to cancer pain practice.



**Figure 4.1 Pain assessment and management steps in the Oncology Unit**



#### **4.2.2.2.3 Hospital policy of pain management**

There was a pain management policy in place within the hospital. The policy was intended to standardize pain assessment and management across all hospital departments. The policy listed the steps and procedures that should be followed when treating pain. However, on examination, the policy appeared to be less than comprehensive, and some gaps were identified, which included:

- 1- The main focus of the policy was to identify pain levels above 5 on a 10 point scale. There was no provision for mild pain.
- 2- Using scores such as the NRS ignores the multidimensional pain experience.
- 3- Although the WHO guidelines on analgesic treatment are attached to the policy, nothing is mentioned about how and when to use them.
- 4- As this policy is general in purpose to all hospital departments, it should clearly define the roles of healthcare provider (nurses and physician) and should establish accountability. The policy misses this essential element.

This policy lags behind the current evidence-based practice and needs revision to fill these present gaps.

#### **4.2.2.2.4 Pain education and resources**

The hospital had no formal or informal education programmes about cancer pain assessment and management; however, some of the nurses had received post-graduate pain education before joining the hospital. Nurses reported that they had also received limited explanation for the new policy on pain management when it was introduced in 2009. Generally, it appeared that the ward nurses were receptive to the idea of an education programme to help improve patient care in this important area. At the same time other nurses such as unit manager who was not eager to the idea of the education course. The researcher therefore introduced himself to the staff of the continuing education department in the hospital. They showed a willingness to provide the researcher with support (data projector, laptop and classroom).

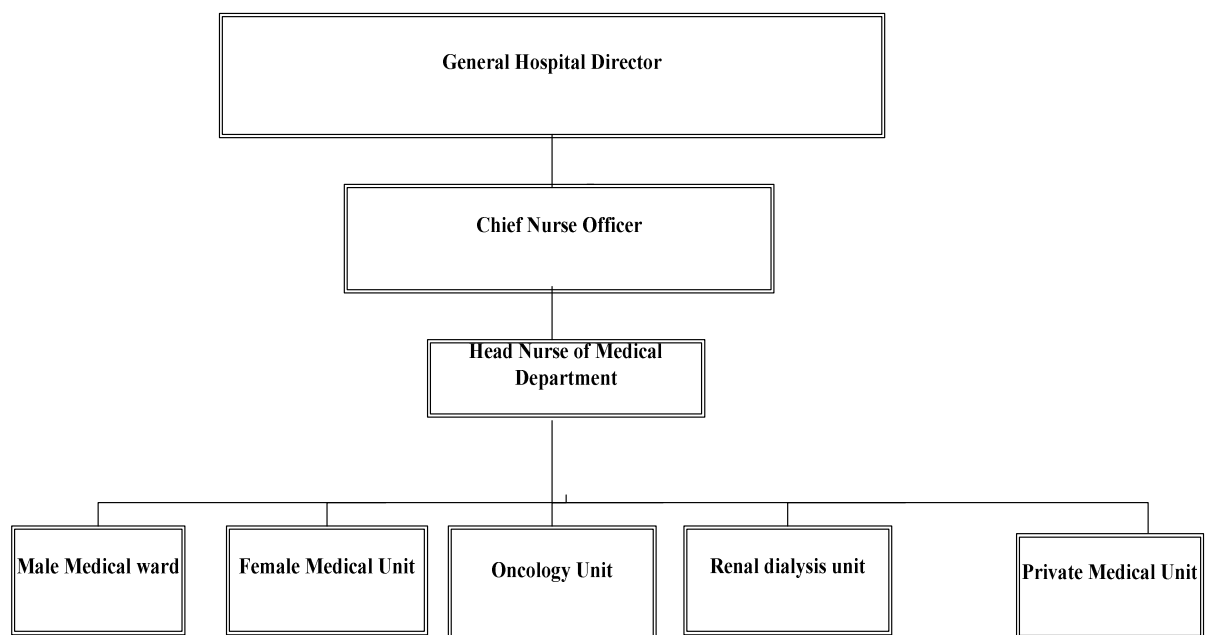
In summary, the pilot work identified that pain may be undertreated and poorly assessed. In addition, the hospital lacks the educational support for nurses, which in turn affects the total pain management services.

### 4.2.2.3 Leadership

In a life situation and healthcare practice, any individual may lead others. However, in this case our aims are to identify the organizational flow chart and leadership style that influences the capabilities to change.

Firstly, the unit is considered a division of the medical department, with the Head Nurse reporting to the Head of the Nursing Department, who reports directly to the CNO (see figure 4.2).

**Figure 4.2 Nursing department structure and reporting**



Secondly, the leadership style utilised in the hospital is a top-down structure; orders and instructions come from higher administration levels, and are disseminated down. This style disempowers the nurses, who feel that they have no authority and are not part of the decision-making process. The CNO tends to be democratic rather than autocratic in decision making, but the dominant trend is the command and control management pattern which increases the difficulty of initiating and making changes in this organization. This top-down approach could be clearly seen in methods used to implement the current pain tool. The general hospital director wanted to gain exceptional accreditation from the JCI, so the process of change started with little consultation. As part of this change, a pain assessment tool was implemented alongside a lot of other paperwork. No change model or education was employed to execute this policy change. As a result, the

NRS tool was not used and the process failed despite the original good intentions of improving patient care.

The researcher will therefore try to bring a balance between the autocratic and democratic trends; this can be achieved through giving the nurses the chance to choose the methods they prefer to receive the education programme and suggest some of its content, choose the day they want to attend, and consider their feedback in regard to the tool to be implemented. At the same time, the interest shown in the study from the CNO helped the researcher to negotiate with the management teams and help to facilitate the active participation of nurses in decision making related to the implementation process.

#### **4.2.2.4 Evaluation**

An evaluation or feedback system is not currently available at the study site, although there are some quality assurance indicators that are usually measured by the quality assurance department. The researcher was not able to use the hospital feedback system, because there was no such method to evaluate any implemented change, and there was no strategy to evaluate the quality of the pain management process in the unit. The lack of such an evaluation method may compromise the chance that changes made in practice are effective. In order therefore to measure the effect of change, it was necessary to implement an evaluation strategy. Using examples from the literature, the following outcomes were employed to evaluate the PMP effects in the main study:

- a) The Pain Management Index (PMI), which is an approach that was suggested by the literature to evaluate the adequacy of pain management. However, to construct the PMI two things were needed: pain severity scores and type of administered analgesic. It was found to be possible to use the PMI in the study, since the pilot work indicated that the needed information is available in patients' medical charts.
- b) The percentage of patients where the pain tool was used. This was identified in the pilot work using medical records.
- c) The researcher remained open for any other evaluation strategy that might emerge during the pre-implementation phase of the main study.

#### **4.2.3 Facilitation**

According to PARIHS, facilitation aims to accomplish the desired goals and develop and maintain teamwork. Facilitators can be external (from outside of the institution) or internal. In this study the researcher is the external facilitator (but

internal champions would be used) who will facilitate the use of the pain assessment tool through providing nurses with an educational programme, and instructing nurses how to use the tool and act as resource for nurses. External facilitators are equivalent to change agents (a term used in change theory). In addition, the purpose of facilitation is holistic in terms of improving cancer pain management in the unit.

## **Champions**

According to Change Theory, the champion should be knowledgeable and a role model for other staff. Two champions were identified during the pilot work. The study aims, protocol and the role of change agent assistants in the study were explained to this influential group of nurses. First the charge nurse and another nurse were recruited. Both had at least five years working experience and one of them has a Master's degree. They both agreed to take part in the study as champions because they believed there was a need to improve the care that cancer patients received. Moreover, one medical consultant was seriously considering becoming a champion for the physicians. Unfortunately, he travelled to Canada to attend a one year fellowship programme.

Although the best time to identify the champions and give them the information is near to the time the study will commence, it was decided that in this case it would be beneficial to recruit them early during the pilot work. Contact was maintained with them through emails and electronic social network sites and they were kept informed of all stages of the development of the study. It was thought that this might help the nurses to see the researcher as a colleague rather than an intruder, thus reducing any resistance to the proposed change and enhancing the partnership. In addition, it was thought that it may aid the process whereby the nurses feel valued rather than as customers or recipients of an imposed change.

The PARIHS model was used as a framework during the pilot work. It is clear that the site was in a moderate state of readiness and appropriateness for change. However, an in-depth analysis of driving forces (facilitators) and restraining forces based on the proposed change was needed. This enabled the researcher to benefit from facilitators' contributions and developing strategies to overcome the restraints, which was conducted in the light of change theory.

## **4.3 Driving versus restraining forces**

Based on the pilot work in the unit, it became obvious that the context (at individual and administration levels) was ready to change not least because of the future JCI accreditation visit, but resistance was anticipated.

It was expected that the study would be fostered by many facilitating factors, including: firstly, the vision of the CNO, who recognised the need for change in oncology nursing practice. The CNO guided the service reform through the whole hospital toward improving the quality of nursing care. In addition, the hospital currently was in the final stage of implementing the JCI standards to improve the quality of health care services provided for patients. A requirement of this was that the hospital is obligated to improve pain assessment and management. As a result, an acceptable (as the original was not being used) pain assessment tool and management protocol needed to be established.

Secondly, the champions were motivated and willing to help by taking an active part in the implementation process. The champions were two nurses, and it was agreed to maintain contact with them to facilitate merging the researcher with the team and reducing any resistance.

On the other hand, some nurses (including the head nurse) believed that using a pain tool was pointless and had no beneficial effects on the overall adequacy of pain management which may lead to passive resistance (such as not using the tool) or even take action to resist the study, for example one nurse said:

*The hospital is in shortage of machines that usually used in cancer pain treatment like epidural and PCA, so we should bring such machines and then talk about the assessment tools. (N05 Registered Nurse)*

*And the unit manager confirmed:*

*Yes using pain tool may sound scientific but clinically I do not see it has that importance. Cancer causes pain then we should treat the cause and the symptom will disappear (HN Unit Manger)<sup>1</sup>*

In addition, the policy on pain management needed to be modified, which was challenging and difficult to achieve. However, providing education sessions, involving all healthcare workers in the process, and support from the CNO were anticipated to result in an important impact on balancing the resistance and enhancing the active participation of all healthcare workers.

Finally, physicians may stand in opposition to the planned study as a result of perceiving the researcher as an intruder and subordinate invading their area of authority. Thus, the researcher was compelled to use some strategies to involve physicians to avoid their resistance. These strategies included involving physicians

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<sup>1</sup> Quotes were taken from researcher discussion with nurses that was carried out in the unit. Notes were taken at the time and translated to English later.

in the change process by sending them an information sheet about the study before embarking upon the implementation, and inviting them to attend a meeting to explain the study. In addition, physicians were asked permission to include their patients in the study. Furthermore, they were invited to the educational programme and encouraged to express their suggestions to improve the whole implementation process.

In summary, the readiness of the context for the main study was assessed and the main features of the pain management process in the oncology unit were identified. As a pain assessment tool was found to be already in place on the ward, it was necessary to consider whether the study was applicable in this setting.

#### **4.4 Was this study site applicable?**

Based on the aforementioned factors, the decision of whether or not to conduct the study in the selected site was undertaken. Although the use of a pain assessment tool had already begun, the study site was still deemed applicable and valuable for a number of reasons. Firstly, the pain assessment tool already in place in the site is general in purpose and cannot completely assess the multidimensional aspects of the pain experience of cancer patients. In addition, it appeared that the motivation behind the use of this tool is to get JCI certification, without realising the importance of pain assessment. Nurses believe that they will not use the tool after gaining the accreditation, as per discussion with five nurses, and this was stated explicitly by N1 Charge Nurses:

*I believe nobody will use the tool in the near future, I mean after JCI certificate being granted. We will back as we were, what comes quickly will go quickly.*

Moreover, this tool was introduced into practice without prior education and most of the nurses did not understand how to use it correctly. Nurses felt overwhelmed by this tool since they were forced to use it without acceptable justification. One nurse said:

*They (administration people) brought this tool and forced us to use it without telling us how to use it; they think that we are machines and we have to obey orders.*

Finally, the CNO showed an interest in using a tool that is specific for cancer patients and utilising change theory principles. Hence, this might be a good opportunity for the study site to improve the quality of pain management that they provide. In addition, the CNO was committed to the idea of the researcher conducting the study and gave a promise to stop the use of the current pain

assessment tool. This endorsement provided the opportunity to conduct the implementation study in the hope that it would provide an important insight about cancer pain, its management process, and enlightenment on the implementation process of the PMP.

## **4.5 Instrument testing**

The second part of this pilot work was conducted in part to test and confirm the use of the study questionnaires in a real life situation and evaluate the adequacy of translation. The literature review suggested the possible tools that could be used namely (more theoretical details about these tools are available in chapter 6):

- The BPI
- Demographic data sheet
- Data extraction sheet
- The BQ

### **4.5.1 BPI and data extraction sheet**

Some minor alterations were made to the data extraction sheet including the addition of enquires about diagnosis, date of data extraction, and frequency of prescribed pain medication, and changing the font and some spelling errors. No changes were made to the BPI which had been previously translated into Arabic and used on Arabic populations, and it was used by four nurses with no major difficulties. However, nurses suggested that they needed a brief introduction to the BPI and its use.

### **4.5.2 Barriers questionnaire**

The barriers questionnaire was completed by four patients, one family caregiver, and five nurses. The BQ was translated using back translation approach. The translation appeared adequate as all participants required no explanation of items in the BQ. It took them ten minutes, on average, to complete the questionnaire. They stated it was easy to comprehend and to use. Some minor changes were required, such as adding the serial number to match it with the participants and other questionnaires. It was suggested that the introductory paragraph be in bold font.

One open question was added to the barrier questionnaire to elicit any barriers not mentioned on the BQ and allows participants to report any barriers related to the specific setting and culture. Participants were asked to list anything they perceived



as a barrier to optimal cancer pain management. Four out of 10 participants (one patient and three nurses) answered the question. It elicited new answers which are not covered in the main questionnaire, thus the use of such category was useful to our study and the researcher decided to continue its use in the main study as it was thought to make a valuable contribution to the overall understanding of barriers in this newly examined culture and region of practice.

It was believed that this pilot work did not contaminate the main study results (test re-test effect) as, only the BQ was completed by the participants (nurses, patients and family caregivers) and they would not be asked to complete the BQ again. This pilot work was to check the appropriateness of the site to the main study; it was not about conducting part of the main study.

## **4.6 Summary**

The pilot work showed that the site was suitable to the proposed implementation study. Although a pain assessment tool was previously introduced, it was not used as it should be. The use of BPI, BQ, and data extraction sheet in the main study was confirmed and they were found feasible to be used in the study. In addition, the PARIHS model was useful as a tool to assess the readiness of the hospital for change. It highlighted the complexity of the implementation process. For example, areas that are potentially problematic, such as convincing nurses to buy into the change (using the tool), were figured out, and steps were put in place to work with staff in the oncology unit. Hence, it was believed that such a complex topic may optimally be explored using case study design which may offer a better opportunity of understanding cancer pain management in a culture that little is known about. The next chapter discusses the case study design used in the study.

## **5. Chapter Five: Research Method**

## **5.1 Introduction**

This chapter presents the aims of the study and an overview of the study design including the description of case study as a research design and its usability in this study. Then the units of analysis are defined and the theoretical propositions underpinning the case are listed. Finally, generalization within the case study design is discussed.

## **5.2 Case study aims**

In light of the literature review, there is a need for more data about cancer pain management among Jordanian adult cancer patients and Arab-Islamic culture in particular. However, the available evidence about Pain Monitoring Programme (PMP) implementation process is rather limited and weak. This in part was because of the use of pure quantitative research methods such as survey and Quasi-experiments as main designs in the implementation studies.

Detailed description of the implementation process is needed. Most of the previous studies reported quantitative results only without indicating how such outcomes were reached. In addition, cancer pain management, implementing and evaluating PMP are not well known subjects in Jordan. This area of interest is considered to be relatively new in Jordan (this study is the second study in Jordan on cancer pain management improvement). Therefore, there was a need for a thorough investigation and detailed description of a complex process using more than one method, data source and analytical technique. Hence, producing a complete picture that reflects the current situation and deepening our understanding of the PMP implementation process within the Arab-Islamic culture is important. Thus, this case study sought to provide an understanding of how a PMP can be implemented in everyday nursing practice and evaluated. Conducting the case study in an Arabic cultural context is novel.

### **Aims of this study were:**

- **To explore how a pain monitoring programme (PMP) could be implemented into nurses' daily practice in a cancer unit.**
- **To explain how the introduction of a PMP would affect the process of pain management.**
- **To describe the experience of changing nurses' practice toward evidence based practice within the Islamic-Arab culture.**

## **5.3 Study design**

### **5.3.1 The case study**

Case study is a research strategy that is becoming increasingly popular among healthcare organisations and healthcare-related research (Huberman and Miles, 2002; Yin, 2009). The term 'case study' refers to and represents a research strategy that often enables the researcher to obtain a holistic and meaningful description of a particular phenomenon (Gerring, 2004). Using case study seems to be an appropriate and effective research strategy in providing a clearer understanding of individual, community, social and political phenomena, hence it is becoming more popular in fields such as psychology, sociology, politics and business (Yin, 2009).

The increasing popularity of case study design has been linked to the flexibility that the case study provides the researcher in relation to data collection techniques (Yin, 2009). Thus, flexibility enables the researcher to utilize more than one methodological approach to investigate the same subject but from different angles (methodological triangulation), and also offers the advantage of using various sources of evidence through different data collection techniques (triangulation of data) (Merriam, 1998) and thus it is consistent with the main aim behind this study which seeks a thorough understanding of the process of changing practice and evaluating the change effects on the process of cancer pain management in the oncology unit.

Case study design was used in this study, although it could have been conducted using other purely quantitative methods. The case study design allows thorough exploration and description of the implementation processes. In addition, by utilising quantitative and qualitative data collection and analysis methods, richer information can be yielded (Yin, 2009). This design helped to explore different aspects of how a pain assessment tool can be implemented into nursing practice. Hence, the barriers to cancer pain management, nurses' knowledge on cancer pain assessment and management and the effects of using such a tool on the overall cancer pain management and nursing practice are all taken into account, increasing the likelihood that the change is crystallised into practice.

Finally, the case study design was selected in favour of a clinical Randomised Control Trial (RCT); latter design is well-known and acceptable within the academic and clinical environment. The RCT is able to predict causal relationships and examine whether the tested intervention was effective or not (Bowling, 2009; Shadish et al., 2002). However, The case study design can offer additional

explanation of how the intervention works or why it does not work, which is not possible with an RCT (Yin, 2009). In addition, preceding an RCT with a case study is acceptable because it provides in-depth information that can inform the design of an RCT or the choice of instruments since little is known about the topic in Jordan in particular.

Implementation research can be seen as the study of means (techniques) that might be effective in increasing the utilization of research findings into healthcare providers' daily practice. Thus, improving the quality of care and eliminate inappropriate practice (Walker et al., 2003). However, this study is an implementation study that aimed to implement an intervention (pain assessment tool and education) into daily practice of nurses'. This study utilised a before and after design (Bowling, 2009) but this use can be only seen as an approach to research (a tool to introduce the change into practice) rather than as a research design. Baseline information was collected about the context before introducing the PMP (Walker et al., 2003) because little is known about cancer pain management in Jordan (Finley et al., 2008) and to aid in selecting the best way to deliver the change (Kitson et al.,1998; Roger 2003). Then after the PMP had been introduced, researcher evaluated the interaction of PMP with the context (nurses, daily routine) and its impact on cancer pain management process in the unit. This study used both quantitative and qualitative data collection methods to gather a set of comprehensive information. Hence this study provided a thorough picture about implementation and cancer pain management processes that were not possible to be gained through only using a simple quantitative before and after designs (Yin, 2009). In addition, this study aimed to change nurses' practice toward using pain assessment tool through introducing the BPI combined with education. Thus the main intention of this case study was changing and improving in nurses' practice in the hope of improving the adequacy of cancer pain management which made it an implementation research study according to the literature in the research implementation field (Backer, 1991; Kitson et al., 1998; Roger, 2003; Walker et al., 2003).

### **5.3.2 Types of case study:**

Yin's school of thought, represented by his book published in 2009, has been followed. This is because Yin's work was more oriented toward case study using the mixed approach, and provided a step by step plan for doing case study research. Yin (2009) identified two main types of case study, single and multiple-case study design. A single or multiple case studies can also be categorized as holistic (one unit of analysis) or embedded (more than one unit of analysis).

### **Single-case study designs**

Yin (2009) reported five justifications for the use of a single-case design. One justification is to examine a critical case with a well-defined set of theoretical assumptions. Single-case enables the researcher to test theoretical assumptions with the results that in order to support or refute a theory. A second rationale for a single-case design is when there is a rare or unique case. For example, in medicine a study of a rare case of disease can document and list all the related characteristics, which will be a valuable contribution to knowledge. Third, the single-case design can be used when it represents a distinctive case such as a specific school in a certain city. Fourth, single-case design is appropriate when the researcher intends to study a case over time (longitudinal), such as describing the implementation of a new innovation. Fifth, the single-case can be justified when the researcher gains access to investigate and describe a case that was previously inaccessible or difficult to access (Yin, 2009).

### **Multiple-case studies design**

The use of multiple-case design has increased dramatically in the last few years (Yin, 2009). One advantage of the use of this design is its capability to produce robust and convincing evidence. However, multiple-case design requires more resources and time, which are usually unavailable to individual researchers. Another advantage is that multiple-case design allows the researcher cross-case comparison, which empowers the reporting of case study results (Yin, 2009).

Regardless of whether the researcher decides to adopt a single- or multiple-case study design, cases should be carefully chosen so as to produce literal or theoretical replication (Yin, 2009). While the concept of literal replication implies that choosing similar cases would lead to similar results, in the case of theoretical replication, the researcher chooses different cases in order to generate contrasting results, but for anticipated reasons (Yin, 2009).

While some social researchers such as Shavelson and Townes (2002) argued that case studies are only appropriate for exploratory studies, Yin (2009) suggested that case study could be used as an exploratory, descriptive or explanatory method, and that some factors such as the type of research question, and the researcher's aims could determine or influence which case study strategy to use. Questions that ask 'what' could be linked with exploratory case study design, and in this situation often aim to generate a hypothesis for further investigation or study. However, researchers should be aware of situations where the 'what question' might represent 'how many' or 'how much', in which case, the case study would be inappropriate, and a survey method could be a more beneficial strategy (Yin,

2009). On other situations, where the researcher aims to answer questions starting with 'how' and 'why' have been linked to explanatory case study. In this situation the researcher tries to establish causal relationships and to explain how an event occurs (Yin, 2009). The descriptive case study tries to provide a comprehensive description of a phenomenon and is rarely used to comprehensively describe an environment prior to starting a project. In the context of this study, although the main design was exploratory, other elements of the explanatory case study design, as suggested by Yin (2009), also were used.

### **5.3.3 The case and its units of analysis**

Defining the case and its unit of analysis is advantageous in helping to determine what type of data is to be collected and when to start and end the case study (Yin, 2009). This study used the single embedded case study design. The study was single because it was conducted in one setting and one oncology unit in Jordan. Thus, the main case was **the implementation process of a pain monitoring programme into nurses' daily practice**. The single case was chosen because of the nature of the inquiry. It could be argued that it would have been advantageous to conduct multiple case studies, but because of a lack of resources this was not possible. This project was restricted by the duration of the PhD scholarship, which required the candidate to finish within three years. The case was embedded because it contained more than one unit of analysis, namely:

**Patients, family caregivers, healthcare providers, pain management process indicators, and the implementation process.**

However, the physical place of the case was an oncology unit within a tertiary healthcare setting in the northern part of Jordan. Complete description of the context of the case is available in chapter four (pilot work).

### **5.3.4 Theoretical propositions**

Yin (2009) urged case study researchers to identify the propositions underpinning the case study. This is helpful in guiding the study in terms of data collection and analysis. In addition, proposition can help in determining where the case starts and where it ends up. However, Yin (2009) also reported that researchers might have a justifiable basis for not having extensive theoretical propositions, such as in an experiment, surveys and to some extent exploratory case studies. However, exploratory cases still need to set purposes and a battery of measures to evaluate their findings (Yin, 2009). Conversely, Stake (1995) reported no such recommendations about propositions, and placed emphasis on the fact that case study seeks a deep understanding of case and its entrenched components. Thus,

holding prior thoughts or ideas might result in limited understanding of the case of interest. And this was taken into consideration to reduce the impact of the researcher's pre-conceived ideas and strategies to enhance the trustworthiness of the results were deployed (see chapter six).

In the context of this research, three theoretical propositions were in mind while developing and conducting the study. These propositions were considered during the design of the study, selection of the conceptual framework, data collection, and interpreting the findings. These propositions came from the personal working experience of the researcher as an oncology nurse, the customized research utilization model (see figure 3.1) and the knowledge gaps identified by the literature review. Therefore, the propositions underpinning this study were:

- The use of a PMP in daily nursing practice would have a positive impact on the pain management process.
- The use of the PARIHS model and change theory was expected to guide the implementation process and the interpretation of results.
- An implementation process that closes the gap between managers and clinical staff would have a better chance of success in terms of adoption of the pain assessment tool.

### **5.3.5 Generalization and the case study**

It has been suggested (Stake 1995; Yin 2009) that no generalization can be sought from a single case study. However, the findings can be added in the results of previous or upcoming case studies, therefore generalizations can be extrapolated. Findings might confirm or refute a theory and may even lead to building a new theory (Eisenhardt, 1989). Thus, accumulation of knowledge along with providing a thorough understanding of a real life situation could be the ultimate advantages of case studies (Stake, 1995; Yin, 2009).

This case study was carried out to understand the process of implementing a PMP into nursing practice and to investigate the process of cancer pain management within a selected oncology unit. Thus, as the aim of this case was to broaden the understanding of implementation and pain management processes, the sample size and its impact on the study findings became less important to this case. However, the researcher tried to collect data from as many of participants as possible within the time frame of the study. Although, this case study is not about number of participants, a number of 50 participants was deemed to be both suitable and feasible. This number of participants would allow the use of descriptive and



inferential statistics such as Confidence Intervals (CI) of the mean, t-tests, and Analysis of Variance (ANOVA) (Campbell et al., 2007; DS Moore and GP McCabe, 1993; Field, 2009). These participants were recruited only to complete the survey part in the case study. All nurses and doctors working in the study ward were invited to participate. Recruiting healthcare providers from outside the unit would not contribute to this case.

## **5.4 Summary**

The case study is a flexible and comprehensive research method suited to implementation research. In this study, the single embedded-case study design was chosen to answer study questions and it was exploratory in nature. The case study method has the potential to reveal the aspects of a change process in and cancer pain management in the Arab-Islamic culture. Since this case study is the first to be conducted in Jordan on adult cancer patients, there was a need to gather baseline information about cancer pain management in the unit. Therefore the next chapter presents the pre-implementation work in this study.

## **6. Chapter Six: Pre-Implementation Work**

## **6.1 Introduction**

This chapter describes the pre-implementation work which was conducted prior the introduction of the pain monitoring programme (PMP). This stage aimed to gather baseline information about cancer pain management and prepare the setting (oncology unit) for the upcoming change. This chapter provides an overview of the processes of obtaining access, administration support, and champions' selection. Additionally, data collection and rigour are also discussed.

## **6.2 Aims**

This phase comes as one of the consequent stages undertaken to implement the BPI into practice. The pre-implementation work was intended to:

- Identify how cancer pain is currently being assessed in the unit.
- Identify how cancer pain is currently being managed in the unit.
- Explore cancer pain status in the unit in regard to: pain prevalence, severity, and interference with life aspects.
- Explore the barriers to cancer pain management from patients, family caregivers and healthcare providers' point of views.
- Explore factors that may lead to inadequate pain management in the unit.
- Set the final plan for implementing the pain monitoring programme (education sessions and the use of Brief Pain Inventory (BPI)).

To carry out the pre-implementation work in the oncology unit, authorization from the hospital administration was required and steps were carried out to obtain full access to the unit and participants, as discussed in the following section.

## **6.3 Access to setting and approaching participants**

Accessing the case setting was a continuous process that was a pre-requisite of the pilot work (described in Chapter four), preparation, changing and evaluation phases. It was found that gaining the Ethics' Committee approval was the easiest part of this process.

According to the hospital rules, Ethics Committee approval to conduct the project in the unit was required. It took the researcher one month to get approval, and two meetings were required to obtain the final committee approval to conduct the study. However, when commencing the actual study, many hidden facets appeared not to be guaranteed by the approval (see appendix 6). Theoretically, the ethics committee decision was the only authorization necessary to approach the setting, doctors, nurses, patients and family caregivers, which would cover the whole study

duration. However, in the fieldwork, three levels of access were recognized (see figure 6.1). These three levels included:

### **6.3.1 Level one: higher administrative levels**

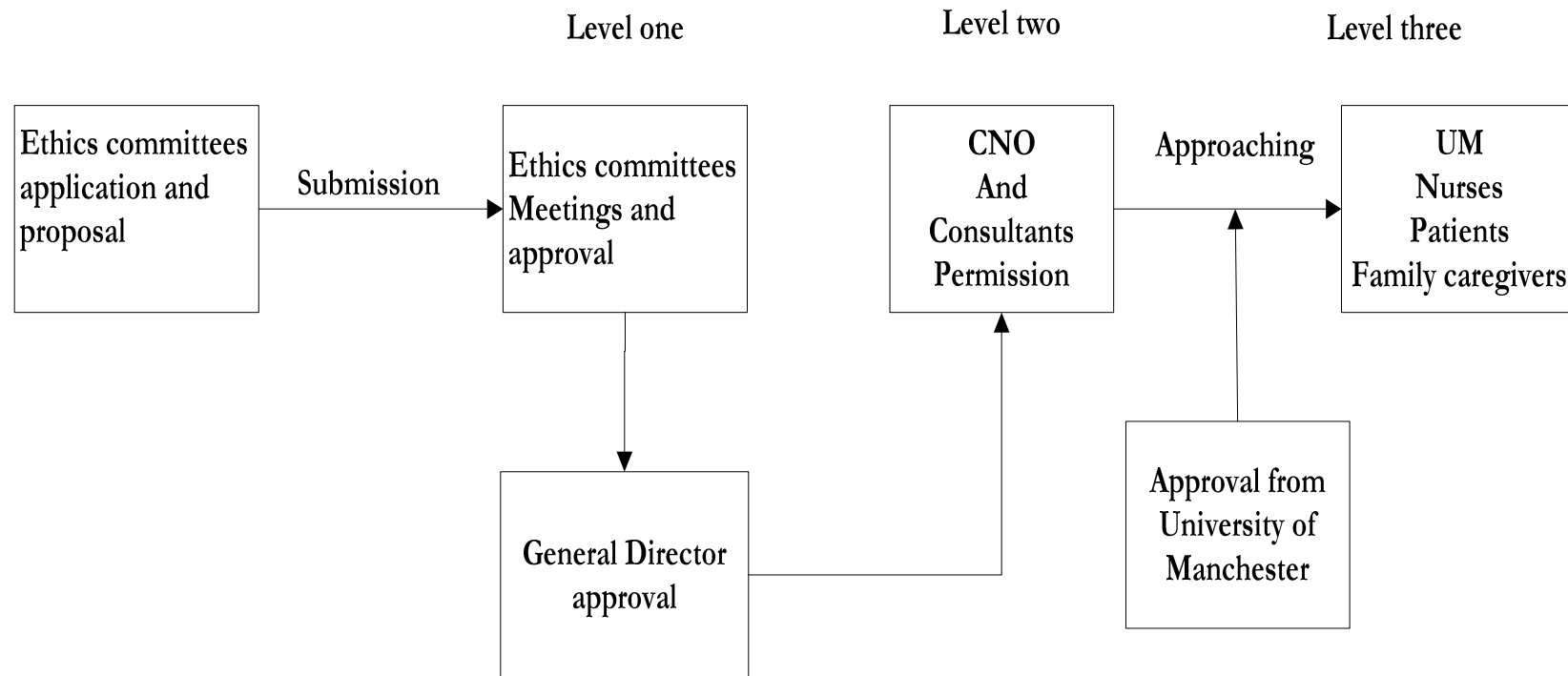
Level one represents the general or initial step that should be taken to allow access to the research setting and all of this was carried out before embarking on the pilot work. For this study, two kinds of approval were required: the first one was ethics committee approval. The hospital ethics committee convened twice, comprising two consultants (from the internal medicine department), the CNO assistant, and a social worker. The researcher completed an application prior to the meeting, which included a detailed proposal, and then presented the study briefly at the beginning of the meeting. Many questions were asked, and the main two ethical concerns of the committee were assuring the safety of patients who participated in the study, as shown in the chairman's question:

*So, we can understand that you are not going to test any drug or instrument on our patients, as you know this issue is problematic and we would not make our patients an experimental field for researchers.*

The oncologist also said:

*we are changing the rules governing the researchers in the hospital, we want to make sure that any amendment to your study is informed and approved by the ethics committee before implementing it, we have seen researchers who was given the approval to do something but they actually did something else.*

**Figure 6.1 Levels of access**



During the meeting the researcher confirmed that he would be (ethically) obligated to avoid doing harm to participants in terms of physical and emotional harm. In addition, it was indicated to the committee members that talking to patients about cancer, pain, and barriers might distress the patients' emotional status and mood. Therefore, the researcher included, in the study, only patients who know their diagnosis, and who showed willingness to participate in the study after reading the information sheet. Further, participants were encouraged to contact the researcher for any question or concern. To our knowledge no harm occurred to any participant in the study.

The second ethical concern was the need to obtain informed consent from participants, and particularly patients. The Ethics committee required that a copy of informed consent to be placed in patients' medical records, and to provide the committee with a list of patients who took part in the study. Hence, the researcher confirmed, to the committee, that each participant would be given at least 48 hours to decide whether to participate or not. If a participant was willing to participate, a written consent form was signed by the participant and the researcher (see appendix 7). It was indicated to the committee that an information sheet explaining study purposes and protocols to be provided for all participants (see appendix 8). This information sheet explains the study aims, procedures and participants' role in the study. In addition, oral explanation of the information sheet was provided where needed.

Further, assurances were given to patients that refusal to participate will not adversely affect their treatment. All participants were reminded that they had the right to withdraw from the study at any time they wished. Given all these requirements were met, the ethical approval was given (see appendix 6).

The second approval was required from the General Director (GD) of the hospital. The Ethics Committee decision along with the proposal was forwarded to the GD office, and then after ten days it was returned with acceptance. Then the University of Manchester ethics committee application also was submitted. In that meeting, there were no major concerns and the most important one was to explain how interviews would be conducted and where they would take place. All required amendments were made and ethical approval was granted (see appendix 9). This ethical approval was obtained prior to the main study but after the feasibility work.

Finally, the identities of participants were not revealed; only aggregate data were reported, and responses remained confidential. In this context, the hospital name and some role names were changed to maintain confidentiality. Thus, the context

name was not revealed; instead, the setting was called a 'tertiary care hospital in the northern part of Jordan'. In addition, all documents containing information that can be linked to the context were anonymised.

In summary, level one required the completion of two ethics committee applications, providing presentations and attending three meetings. This process took one month in Jordan and another one in the UK, and did not guarantee the conduct of the study at the hospital premises, and thus level two was hidden, but mandatory.

### **6.3.2 Level two: intermediate managerial level**

This level required good communication skills, and previous knowledge of the people in the setting was helpful. The main players at this level were the CNO and consultants working in the unit. They were contacted to obtain permission to approach nurses and patients. Without their permission the study would not be possible, despite obtaining ethical approval.

Maintaining good relations with the CNO and three consultants resulted in their acceptance of the study, and allowing the researcher to approach nurses and patients. The other seven consultants were contacted and asked to give the researcher permission to recruit their patients and complete the Barriers Questionnaire (BQ). Five of them gave permission to recruit their patients, and two refused to allow the researcher to include their patients in the study. They did not give an explanation for this decision.

Research projects with aims that are in accord with an organizational agenda have a better chance of acceptance, and improve the likelihood of success. This study was seen as a part of the hospital's movement to toward improving patients care, and this was clearly stated by the CNO in the first study day meeting:

*Again you are welcome in our hospital premises, the hospital recently has received the JCI certificate and we are committed to provide high standard care and provide our staffs with appropriate skills and knowledge, your study serves our optimal goal and I am happy to host it. It is my great pleasure to have you here; you will give us a hand in taking nursing practice at the hospital a step forward.*

The CNO subsequently confirmed:

*The world is moving toward evidence base practice which need more research results to be used in nurses' practice. In addition,*

*nurses must do their own research. Our next step in this hospital is to use evidence based practice through using, communicating and integrating research results into practice.*

Level two was important step in the process of obtaining access. The key people supported the decision, and it was quickly disseminated through the top-down managerial hierarchy. Though it was essential to gain the acquiescence of this level, personal permission from participants and the Unit Manager (UM) was crucial to the study.

### **6.3.3 Level three**

At this level the researcher sought permission from each participant to participate in the study. Informed consent is essential. It depends partially on the communication skills of the researchers and the way they introduce themselves to the participants. The researcher explicitly stated that his aim was to work *with* rather than work *on* participants. This was appreciated by participants, especially nurses. The two champions (champion section was discussed in chapter four and in the next heading) helped in merging the researcher with other nurses and being perceived as a normal colleague in the context rather than as a stranger. Only the UM took an adverse position at the beginning of the study, despite giving permission to work in the unit. In conclusion, getting access is a necessary and a complicated process. Although the researcher considered the issue of access prior to embarking upon the core study, obtaining access in itself did not guarantee the smooth progress of the study, and champions were essential.

## **6.4 Administration support**

One of the main study facilitators was the nursing administration support. The CNO had been contacted before embarking on the study to establish initial permission and support. The study was considered to be consistent with the hospital ultimate mission and timely, therefore it received complete support.

It was believed that the study could serve the hospital in the following aspects:

- 1- Putting a pain assessment tool into practice, because the previous one failed to become embedded. The JCI required the use of a pain assessment tool, and this study had the potential to assist the hospital in this regard.
- 2- Teaching the hospital staff: the study included teaching sessions on cancer pain management, which was also facilitative of the JCI and hospital mission. And this was said by the CNO:



*We are strongly interested in generalizing this course to all nurses over the hospital and I think I will be there on the first day. I recommend that we can meet from time to time just to keep me update with your study progresses.*

- 3- Hosting a PhD project was considered to be a privilege by the hospital, and beneficial to the institution's reputation.

These three points are believed to have increased the likelihood of the hospital hosting and supporting the project. Key people's support and involvement in the study enabled the researcher to access the study site freely. The support was maintained throughout the study stages, although some challenges were experienced. As the hospital adopted the top-down management style, the support from the CNO disseminated to lower levels for the assistants, education department and staff in the unit. However, it did not guarantee complete cooperation from participants. Each group of participants needed the researcher to approach them separately to get their ultimate support. At the same time, the reader should be reminded that the study would not be possible without the higher administration's support.

## **6.5 Champions**

As previously mentioned, during the pilot work, two champions were identified. Unfortunately, one of them left the hospital unexpectedly. Therefore, there was a need to recruit a second champion.

The target champions were the three charge nurses (there were four charge nurses in the unit, one of whom was already a champion), but not one of them showed an interest in being a champion. Then, the need for a second volunteer among nurses in the unit was announced. Thereafter, one of the nurses showed an interest. The champion discussed with the candidate his concerns and the required information, and this was done in the form of informal chatting and socialization. Finally, the second champion who agreed to take part of the study was recruited.

Champion one was a charge nurse in the unit, currently enrolled in a Master's degree programme. She was the most experienced nurse in the unit (8 years) and replaced the unit manager in case of absence. She was self-confident and motivated to change. On the other hand, the second champion was male and had three years' working experience. Though his experience was short, he was active and had good social relations in the unit and in the hospital overall.

The researcher tried to narrow the gap between the administration and nurses. Thus, nurses were involved and given a voice in the study. The champions were encouraged to discuss the project with nurses then with the principal investigator, to ascertain nurses' input into the study. The researcher met the champions and, based on their suggestion, changes were implemented. Table 6.1 details the main nurses' representative (champions') suggestions. Nurses in the unit seemed to appreciate their involvement in the project, and this motivated them to bring success to the project through their active participation in the study.

**Table 6.1 Champions' suggestions**

<b>Suggestion</b>	<b>Researcher Action</b>
Starting the education courses at 9 am instead of 8 am to increase the attendance rate.	Accepted and implemented
The education session dates to be on the 7 <sup>th</sup> , 8 <sup>th</sup> , and 10 <sup>th</sup> of march according the nurses' preference and agreement.	Accepted and implemented
Giving certificates of attendance to nurses to improve the credibility of the courses.	Accepted and implemented
Using open group discussion teaching style instead of classic lecture style to increase staff attention and improve staff understanding of the presented issues.	Accepted and implemented
Covering all types of pharmacological and non-pharmacological pain management interventions deeply in the course.	Not implemented because of time limit, and it is beyond the course's aims, but it could be followed-up by the continuous education department.

Overall in this study champions helped in:

- 1- Transforming the researcher from being a complete outsider to an insider for the unit workers.
- 2- Selecting the best way to deliver the education session and ensure the attendance of all nurses in the unit.
- 3- Arranging the study events and getting the nurses involved in the study.
- 4- Acting as role model during the implementation phase and thereafter.

5- Taking over the researcher's role after withdrawal from the context.

Most of the time, the researcher maintained communication with the champions via phone calls.

## **6.6 Sample and recruitment**

This case study was conducted in one oncology care unit that was chosen purposively and not randomly. All workers in the unit were eligible for participation in the study. In the pre-implementation stage, the following participants were recruited as follows:

### **6.6.1 Healthcare providers**

The researcher was looking to involve nurses and consultants in the unit by completing the BQ, interviews and involvement in the implementation process. All 12 nurses in the unit took an active role in the study, but only six (out of 10) consultants completed the BQ, which was the only contribution by consultants in the study.

All nurses working in the unit (12) were invited to participate in the study. Nurses completed the BQ, and attended semi-structured interviews. In addition, they used the tool (Brief Pain Inventory BPI) and facilitate the tool implementation.

The usual recruitment procedure for consultants (10) was that the researcher called on the phone and provided them with information about the study. Consultants who agreed to participate were sent an information sheet, consent form, and BQ to their offices. The researcher reminded them after two and four weeks, then collected the completed questionnaires combined with signed consent forms.

Nurses were approached directly by the researcher. The study purpose and procedures were presented for all nurses in a short presentation between shifts. Each nurse was then given a package that included all the questionnaires to be taken home and completed. Nurses who agreed to be interviewed were scheduled based on their preference. They were also given the chance to choose the best place to do the interview. Therefore, interviews were carried out in the hospital canteen or restaurant (away from the hospital). Also, the CNO, CNO assistant and the UM (Head Nurse) were recruited and participated in the study.

### **6.6.2 Patients and their family caregivers**

The patients in the oncology unit and their family caregivers were targeted. Seventy five dyads of patients and their family caregivers were invited to complete

the Arabic version of the BQ and the BPI for patients only. Fifty dyads agreed to take part in the study. The researcher recruited only cancer patients who were:

- 18 years or older
- Agreed to participate in the study and signed a written consent form
- Had been admitted in the unit for at least 24 hours
- Knew their cancer diagnosis
- For the family caregivers, only those 18 years old or older, and who were named by the patient as their primary informal caregiver, were involved.

The usual recruitment procedure was that a healthcare worker approached the patient or the family carer to ask if the researcher could speak to them about the study. If they agreed, the researcher reviewed the study with the patient and carer, provided written information about the study, asked if they would like any other information, asked if they had any questions and then, if they verbally agreed to participate, provided the consent form. It was usual for participants to have a minimum of 48 hours to decide if they would like to participate, after which they were given the BQ for completion. For each patient the medical chart was checked to see whether they had completed the old pain assessment tool or not, then they were asked to complete the BPI in order to collect baseline information about pain in the unit.

### **6.6.3 Medical records**

The medical records for the 50 patients who completed the BQ were checked to assess the pain severity, pain assessment tool use, medication used in cancer pain treatment and therefore the adequacy of pain management in the unit.

### **6.6.4 Others**

During the pre-implementation phase other people were recruited opportunistically such as one resident doctor and one family caregiver who were seen in the unit and showed a willingness to participate in the study and to be interviewed. In addition, two Islamic scholars were asked about the Islamic opinion on the use of pain medications (since it was found from nurses' interviews that there was a need to clarify Islam opinion on narcotics use). The researcher called them on the telephone and asked to meet up with them. They agreed and the meetings were at the scholars' homes. Consent forms were signed before starting the interviews.

## 6.7 Data collection techniques

In keeping with a multi-method case study data were collected from a variety of sources and this not only enables a deep understanding of the case, but also allows the triangulation of data. This provides the researcher with various and diverse evidence from different sources, thus researchers can look at their area of enquiry from different angles (Creswell, 2003; Stake, 1995; Yin, 2009). Therefore, in this case, various approaches were used in collecting the pertinent data, including the following:

- Questionnaire survey was used to collect information from patients, family caregivers, and healthcare providers about the barriers to cancer pain management. In addition, the BPI was used to gather information about pain and its management in the oncology unit. Then, the pain management index (PMI) based on the above information was constructed.
- Semi-structured interviews for CNO, CNO assistant, unit manager, nurses, resident doctor, family caregiver and Islamic scholars.
- Observation of relevant nurses' practice, such as pain assessment, responding to pain complains, pain management, giving pain medications, and pain re-assessment.
- Documents that included pain management policy in the hospital, selected nursing courses and pain management lectures in four nurses' schools.
- Archival records that included patient medical charts to collect the data about cancer pain and its management in the unit. In addition, information about the use of new pain assessment tool was extracted.

Each data collection method is discussed in more detailed in the following pages. However, table 6.2 summarises what data was collected and how it was collected.

**Table 6.2 Data Collection in pre-implementation stage**

<b>Data source</b>	<b>Role in Pre-implementation (duration: 6 weeks )</b>
<b>Nurses</b>	They completed the BQ (N=15). In a semi-structured interview, they were asked to answer questions about current pain assessment and management practice and the perception of the use of pain assessment tool into practice (N = 11) and the UM.
<b>Physicians</b>	Completed the BQ (N = 6).
<b>Patients</b>	Completed the BPI (self-report) and BQ (N = 50).
<b>Family caregivers</b>	Complete the BQ (N = 50).
<b>Medical records</b>	Prescribed pain medications were extracted. Nurses' notes checked. Pain assessment tool was checked for availability (N = 50).

### 6.7.1 Questionnaires survey

Survey is commonly used to collect data in health care research. There are various types of surveys, including self-administered questionnaires, mail survey, interview survey, telephone and online surveys (Rubin and Babbie, 2009). Surveys are commonly used where data about attitudes, opinions and beliefs are needed. In addition, questionnaires may also be used to anticipate outcomes of certain events (Bowling, 2009; Clifford, 1997). In this study, the self-administered questionnaire was used. Because this study was conducted in a hospital, there was no need for mail or other types of surveys. In addition, the physical presence of the researcher to collect the completed questionnaires was linked to a higher completion rate, and enabled the researcher to reduce missing data (Rubin and Babbie, 2009), the researcher waited for the nurses to render the completed questionnaires. While a questionnaire survey can be viewed as an economical way of obtaining a wide range of data and information (Fowler, 2002), questions should be clear, simple and unambiguous (Fowler, 2002). The use of self-administered questionnaires is considered to be suitable for researchers with limited funds and time, such as student researchers (Rubin and Babbie, 2009). However, its limited ability to establish causality and the high likelihood of giving biased generalization because of bad sampling are the main shortcomings of survey method (Rubin and Babbie, 2009). Brace (2008) stressed that researchers should not use questionnaire survey just to collect data, as the most important thing is the accuracy of data. Thus, in order to obtain accurate information that represents the respondents' level of knowledge, participants were asked to answer all the questions to the best of their knowledge and not to use textbooks or to seek help and advice from anyone else. In this case the following questionnaires were used:

### **The Demographic Data Sheet (DDS)**

The DDS included questions designed to elicit information about participants' (nurses, physicians, patients and family caregivers) demographic characteristics such as sex, age, marital status, and education (see appendix 10). In addition, the DDS contains information about the patients' general health status and includes questions related to cancer diagnosis and other chronic medical conditions. It was developed by the researcher and was attached to the questionnaires completed by the participants.

### **Barriers Questionnaire II (BQ)**

The BQ was developed by Ward et al. (1993), and was revised and renamed as the Barriers Questionnaire II (Gunnarsdottir, 2008) (see appendix 11). It was generated to measure the barriers that hinder optimal pain management, and it can be used by patients, family caregivers and healthcare providers. The BQ II consists of 27 questions with four sub-scales: physiological effects, fatalism, communication and harmful effects (Ward et al., 1993b). Each item can be given a score ranged from 0 (no barriers) to 5 (high barriers level). The internal consistency of the BQ II is 0.89, and the Cronbach's alpha for its sub-scales ranged from 0.75 to 0.85. Permission to use this tool was obtained from the author (see appendix 12). It was translated into Arabic and verified using the back-translation approach, and a linguistic expert was consulted to ensure that the translation is adequate (see appendix 13). It was completed by 50 dyads of patients and their primary family caregivers, 15 nurses, and six consultants (see table 6.2). Based on the pilot work results, one open question was added to the barrier questionnaire to elicit any barriers not mentioned on the BQ, and to allow participants to report any barriers related to the specific setting and culture.

### **Brief Pain Inventory – short form (BPI)**

This instrument is used to assess the severity and impact of pain on daily functions (Cleeland, 1994). It is appropriate for patients with cancer pain and pain from other chronic diseases (Mendoza et al., 2006); it also identifies the location of pain, medications, and the amount of pain relief in the past 24 hours or the past week. The BPI can be completed by patients or at interview, and the short form requires 5 minutes to complete. Permission to use the BPI in this study was obtained from the author (see appendix 14). The BPI has been validated in different languages by examining the consistency of its two-factor structure (factors: severity of pain and impact of pain). Although, the Arabic version (see appendix 15) was not validated, but it was provided to the researcher by the tool's author. The internal consistency reliability for BPI is good (Cronbach's alpha reliability ranges from .88 to .91)

(Mendoza et al., 2006). This is the tool that was implemented into daily nursing practice. It was not only used to collect data about cancer pain in the unit for the study purposes, but also as the main tool to assess pain daily clinical practice within the oncology unit. It was used in its original text and no changes were made to the BPI.

### **6.7.2 Semi-structured interviews**

Interviews can vary from completely structured to in-depth and fully unstructured (Clifford, 1997; Creswell, 2008). This technique has been widely associated with qualitative research. An interview can be viewed as an active and interactive process that requires the interviewer to listen to the interviewee, to maintain and exchange eye contact, and to provide encouragement to the interviewee; furthermore, the interviewer should aim to link between the research aims, objectives and the interview questions and newly emergent issues without missing important information in order to plan sequential questions (Creswell, 2008; Yin, 2009)

Semi-structured interviews, when compared to the structured interview, are considered as a flexible approach in presenting questions to the interviewee; although the interviewer has a set of questions prepared prior to the interview, the flexibility of this approach allows the researcher to address emergent issues, rather than adhering to a set of structured questions (Becker and Bryman, 2004).

In this context, the semi-structured interview was adopted due to the degree of flexibility this approach offers to both the interviewer and the interviewee, consequently facilitating a progressive focus that could enhance the quality of the collected data (Flick, 2009). Semi-structured interviews allow the researcher to ask specific questions, but this should not prevent addressing new and emerging topics (Yin, 2009).

Interview questions were pre-written and prepared prior to the interview (see Table 6.3). All nurses signed consent forms before the interview, and they were given the choice to choose the preferred place for the interview. Six of them were interviewed in the hospital canteen, and the rest were interviewed in a restaurant in the nearby city. The CNO, his assistant and the unit manager, were interviewed in their offices, but the Islamic scholars were interviewed at home. In addition, the resident doctor and the family caregiver were interviewed in the teaching room in the unit. The interviews' duration ranged between 20 to 35 minutes, with majority of interviews taking approximately 25 minutes.



**Table 6.3 Interview guide**

<p><b>Semi-structured interview guide</b></p> <p>Once the interviewee is ready to the interviewee the researcher asked:</p> <p><b><u>Part one:</u></b></p> <ul style="list-style-type: none"><li>❖ <b>General questions</b></li><li>▪ How many years you have been working as qualified nurse?</li><li>▪ How many years worked in this hospital?</li><li>▪ Have you attended any education related to the cancer pain management? And if yes when was that, and what it was about?</li><li>❖ <b>Cancer pain management in the unit</b></li><li>▪ Please could you describe steps of treating patient with pain in your ward?</li><li>▪ From your point of view: do patients receive adequate pain management?</li><li>▪ Why patient are usually under medicated for cancer pain?</li><li>▪ How we can improve the use of pain assessment tool?</li></ul> <p><b><u>Part two:</u></b></p> <p><b>For the following question please chooses the most appropriate items that represent your daily practice of <u>pain assessment</u>:</b></p> <p><b><u>A) I usually:</u></b></p> <ul style="list-style-type: none"><li>▪ Ask the patient if he/she has pain</li><li>▪ Ask the patient to rate his/her pain on a 10 points scale verbally</li><li>▪ Use the pain assessment tool adopted by the hospital</li><li>▪ Never ask patient about pain, because if they have pain they will call me.</li></ul> <p><b><u>B) For pain assessment documentation I usually:</u></b></p> <ul style="list-style-type: none"><li>▪ Fill the pain sheet in patient medical record as proof of documentation.</li><li>▪ Include all pain related information in nursing note sheet.</li><li>▪ Consider it is enough to administer the pain medication and no need for further documentation.</li></ul> <p><b><u>C) In regard to the use of a pain assessment tool in nursing daily practice, I think it is (you can choose more than one):</u></b></p> <ol style="list-style-type: none"><li>1- Extra paper work.</li><li>2- Good to use a pain assessment tool, but no one will look at it.</li><li>3- An important pre-requisite to optimal pain management.</li><li>4- It is important and should be use in daily manner.</li></ol>
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The researcher wrote notes during the interviews and audio recordings were not made. There are many reasons behind not recording the interviews. First, in Jordan, recording someone's voice is not well-accepted culturally, since usually it is

perceived as evidence to be used against the speakers. If recording was insisted upon, it would lead to a lower response rate.

Second, Stake (1995) and Yin (2009) argued that using tape recording is rather costly, and its benefit to the final case study report is of little importance.

*For many researchers, the tape is of little value unless ultimately an audio presentation is intended. Getting the exact words of the respondents is usually not very important; it is what they mean that is important (Stake, 1995, p. 66).*

Third, open-ended questions on problem-specific topics were used; it was not overwhelming to catch most of what the participants covered in their answers by writing notes. Therefore, the overall interview quality was not as it should be. Nurses were asked to answer these questions in English. In addition, some nurses preferred to answer in Arabic, and then researcher translated the text into English on the same day of the interview. During the field work the researcher was required to meet with other interviewees such as CNO, CNOA, and Resident doctor. The Reasons behind these interviews are explained table 6.4.

**Table 6.4 Interview personnel**

<b>Interviewee role</b>	<b>Frequency</b>	<b>Purposes</b>
<b>CNO</b>	5	Establish access to the unit and allow the study Discuss cancer pain managements Discuss study progress Regain access for the second follow-up
<b>CNO assistant</b>	3	Coordinate the study events Take a information about the unit Regain access for the second follow-up
<b>Resident doctor</b>	1	To ask about cancer pain assessment and management in the oncology unit (same nurses questions with some minor differences)
<b>Family caregiver</b>	1	To ask about his experience of treating cancer pain for his father the unit
<b>Islamic scholars</b>	2	To ask about the Islamic opinion on the use of narcotics in cancer pain treatment.

At the beginning of the study, the researcher intended to use the NVivo software, but it was found that the interview transcription was small and manageable manually. Creswell (2007) suggested that the optimum benefits of computer software in analysis occur when the researcher has more than 500 pages of interview transcriptions or field notes. Therefore, the researcher transcribed all of the interviews immediately after ending the interview. All interviews were typed in Microsoft Office Word 2003 on the day the interview took place, and then the transcriptions were stored in a password-protected laptop computer.

### 6.7.3 Observation

Observation is considered to be one of the main data collection methods in qualitative research, especially in a case study (Creswell, 2007; Yin, 2009; Stake 1995). According to Yin (2009), observation, as a data collection method, varies from a formal observation, which follows a pre-designed observational protocol to look at particular issues in meetings or class rooms, to a less formal observation, which often takes place during the process of collecting other evidence such as interviews. Gold (1958) identified four different types of observations that represent the degree of the researcher's involvement in the field (Holloway and Wheeler, 2002). The first type is the **complete participant**, in which the researcher takes an insider role that also involves covert observation; the second type is the **participant as observer**, in which the observer can be a member of the workforce who has an interest in exploring or investigating an area of practice, hence he/she also adopts an observer role. However, this is normally done after negotiating and obtaining access to the research site, as well as obtaining ethical approval prior to commencing research. The third type is the **observer as participant**, in which the observer is not a member of the workforce and this role comprise more observation rather than active participation (Baker, 2006). Finally, the **complete observer** has no involvement in the research settings and often conducts their observation through a one-way mirror (Holloway and Wheeler, 2002).

In this case study, the researcher was external to the workforce, and could be described as an **observer as participant**, collecting the data about nurses' practice in relation to cancer pain management. The researcher observed wherever nurses assessed pain, responded to patient pain complaints, pain management, administration of pain medication and pain re-assessment after intervention. No specific tools were used to record observation; it was undertaken by note-taking, describing some situations and reflecting on the observations which is the most commonly used approached to collect data through observation (Baker, 2006). The researcher kept these observations as field notes (example of observation text can be found in appendix 16). All observation notes were written while the researcher was in the unit, then they were typed in Microsoft Office Word 2003. The observations were conducted formally over six occasions during the pre-implementation phase. The observations each lasted for 3 hours in the morning (8-11 am) and 3 hours in the afternoon (3-6 pm) on different days. A total of 18 hours were spent in observation during the pre-implementation. The researcher sat on the nursing station and watched nurses, and sometimes the researcher responded

to some patients' complaints, especially when nurses were busy during peak hours. Finally, all observation notes were kept as field notes and subjected to analysis.

### **Insider verses outsider**

The researcher approach followed in this study, in observing nurses, can be called as 'moderate role' (Baker, 2006). The researcher tried to balance between being insider and outsider at the same time. From one side, the researcher can be considered as 'insider' because he had worked for two years in the medical unit as registered nurses and one year in the oncology unit as head nurses (prior to leaving the hospital in 2006). And he knew most of the nursing administration personal in the hospital. On the other side, researcher was an 'outsider' to most of nurses in the unit because they were newly employed. In addition, the researcher has not been to the hospital since three years ago, many producers and unit routines have been changed.

In this case study, being insider was beneficial in terms of easy access through shortening the time needed to wait for ethics committee meeting and less time was needed to know administration people (Asselin, 2003). On other hand, one pitfall of insider observer is risking the validity of the case study results and threatening its trustworthiness. In the context of this study, the researcher described the data collection in details, kept record of all data collected and filed notes to enhance the researcher objectivity and findings reliability (see rigour in page 130). It is known that being outsider observing people may make them uncomfortable (Creswell, 2003). Therefore, all actions to minimise this effect were taken into consideration. The researcher allocated one week to familiarise himself with ward staff. In addition, the pilot work was conducted in the same unit and the researcher at that time introduced himself to staff as a PhD student who would like to examine the process of pain assessment tool implementation into daily practice, and who would like to work with nurses for a while for research purposes. The champions were kept in contact with the researcher throughout the study, and they helped the researcher to merge in with the context and being perceived as non-threatening.

Reflecting on this issue, the researcher if were given a second chance to do the same case, he would chose to conduct the study in a setting where nobody know him, though gaining access might be difficult. It was difficult for the researcher to ignore what he knew already about the practice and listen instead to participants describing their new practices. One measure taken to reduce this impact was triangulation of data sources and collection method. For example, the researcher decided to observe pain management encounters and ask all nurses about how they assessed and managed cancer pain to ensure that the researcher's pre-

conceptions were not incorporated in the findings. Therefore, the pain management practice was described in detail by nurses and also observed to validate responses and avoid incorporating the researcher's ideas.

#### 6.7.4 Document review

Documents are considered a valuable data source in qualitative research, particularly case studies (Creswell, 2003; Yin, 2009). They can be classified into two categories: public (policies, official reports, and minutes of meeting) or private (personal diary or email). One advantage of using documents is that they are accessible at any time convenient to the researcher, and could save time, money and effort (Creswell, 2003). They may also bring explicit confirmation of evidence from other sources. However, they may also be considered an imprecise and biased source of data (Yin, 2009). Reviewing relevant documents is another method of data collection that could provide vital information for case study research (Yin, 2009). Therefore, in this case study, the documents were used in order to examine the hospital pain management policy and to formulate a picture about what pain education is given for nurses back in nursing schools, through looking at course syllabuses and lecture content in the biggest and oldest of the four nursing schools. This was because of the lack of information related to pain education in Jordan in the literature. Accessing these documents was not difficult (see table 6.6), but it took time, especially for the lecture content. All documents were examined against the literature and international guidelines for treating pain (Raphael et al., 2010a; Raphael et al., 2010b). However, these are secondary resource which may be not reliable but in this study they were additive to the multi-data sources that were consulted.

**Table 6.5 Reviewed documents**

<b>Document Name</b>	<b>Type</b>	<b>Notes</b>
Hospital Pain Management Policy	Policy	–
Fundamentals of Nursing Theory and Clinical	Course Syllabus	For 4 nursing schools
Medical and Surgical Nursing Care (Level One) Theory and Clinical	Course Syllabus	For 4 nursing schools
Medical and Surgical Nursing Care (Level One) Theory and Clinical	Course Syllabus	For 4 nursing schools
Pain Management Teaching Content	Lectures (power point presentations)	For 4 nursing schools

### **6.7.5 Archival records**

Archival records are the last source of data used in this case study. For some case studies records may be considered essential, but for others it may be of little value. This depends on the nature of case inquiry, for example in quantitative-oriented case study, extracting data from the records may turn into data that allow the use of statistical analysis that in part may improve the external validity of the case (Yin, 2009).

Patients' medical charts were used to extract some pain-related information. Although medical records contain important and objective clinical information, they are usually inaccurate and errors on data extraction might occur because they are simply not written for research purposes (Aaronson and Burman, 1994; Krieger, 1992; Melton, 1997; Yawn et al., 1998). Some clinical information that is usually kept in the medical records (e.g. nursing notes, pain assessment and medication sheets) was used, such as pain assessment, prescribed pain medication, and percentage of tool use. One justification for the use of such records is that they are the only available source for such information. Data were extracted using a pre-prepared data extraction sheet (see appendix 17). Based on these data pain prevalence was calculated, along with the percentage of tool use, type of the given pain medications and pain severity. The adequacy of pain management in the unit was estimated using type of medication and worst pain score. This is known as the Pain Management Index (PMI).

#### **Pain Management Index (PMI)**

Pain level was compared with the most potent analgesic prescribed for each participant. The potent analgesic level for each participant was determined as follows: 0, no analgesic drug; 1, non-opioid; 2, weak opioid; and 3, strong opioid, based on the WHO ladder. The worst pain score was determined for each participant from the BPI: level 0, no pain (score 0); 1 mild pain (score 1 to 4); 2 moderate pain (score 5 to 6); and level 3, severe pain (score 7 to 10) (Serlin et al, 1995). The PMI was calculated by subtracting the pain level from the analgesic level, and ranges from -3 (patient with severe pain receiving no analgesic) to +3 (patient receive strong a strong opioid and reporting no pain). Therefore, a negative score is an indicator of insufficient pain management. On the other hand, a score of  $\geq 0$  indicates the adequacy of pain treatment (Cleeland, 1994; Lin, 2000). There are three methods to assess the adequacy of pain management, including: pain prevalence, PMI and time to pain control. The PMI is the only available numerical mean to evaluate the adequacy of pain management. However, it is criticized for assessing the adequacy of treatment at a single point in time

(Russell et al., 2006) which may not reflect the changing nature of pain (frequent increase or decrease). In addition, PMI may result in giving misleading results. For example a patient can still be in pain and the PMI score indicate that pain management is adequate.

## **6.8 Rigour**

Research quality continues to be of central interest (Creswell, 2003; Stake, 1995; Yin, 2009). Quality is conceptualized in different terms like rigour or trustworthiness, both of which are about research results' validity and credibility. According to Bowling (2009), the concept of rigour is relevant in relation to the reliability and validity of the data and reduction of bias (Bowling, 2009). In addition, it can be achieved through being systematic in data collection, analysis and interpretation, using more than one method, and complete description of how the study was conducted (Bowling, 2009; Mays and Pope, 1995). Furthermore, Creswell (2003,p.196) listed eight approaches to validate study results: triangulation, use-member checking, use of rich and thick description, clarify the bias, presenting the negative results, spending a long time in the field, use of peer reviewing, and external auditor. In the context of this study, four strategies were almost used to enhance the trustworthiness of the study. These strategies were:

- Triangulation
- Checking with participants
- Rich description
- Working in the field for long time

### **Triangulation**

The term 'triangulation', which is often equated with combining different methodological approaches, could be seen as a way of enhancing the confidence of the findings, particularly when the researcher uses a diverse and sufficient amount of data, or follows an explicit data analysis technique (Yin, 2009; Stake, 1995)

Although triangulation often indicates methodological triangulation, Patton (2002) discussed four different types of triangulation:

- Triangulation of data: this form represents a way of combining data from various sources, individuals, or places and times. In this study, various individuals and sources were used, for example the researcher looked at barriers to cancer pain management from patients', family caregivers', and healthcare providers' perspectives, as indicated in the results chapter.

- Triangulation of theories: this concept of triangulation offers the researcher the choice of approaching the data from different theoretical dimensions, utilised side-by-side in order to assess the level of their usefulness. Therefore, to guide the current case study, two models (PARIHS and Lewin's Change Theory) were used. Then they were used to construct the results chapter and explain study results.
- Investigator triangulation: where more than one interviewer or observer is introduced in order to minimize the subjective influences of individuals. It does not apply to this study.
- Methodological triangulation: can be described as the most common form of triangulation, particularly in social research, which involves combining more than one method, such as qualitative and quantitative, in one research. This form of triangulation consists of a combination of both qualitative and quantitative evidence from questionnaires, interviews, documentary review and observations was used in this study.

### **Checking with participants**

Yin (2009) and Stake (1995) suggested that case study reports should be shared with the case informants to check their content. This may provide the researcher with valuable suggestions, but may delay the final report. It also may improve the likelihood of reporting precise information. Due to the large number of participants and complexity of the case report (PhD thesis), it was neither possible nor feasible to follow this. However, seven nurses agreed to check the text of their interviews and agreed on the content. Other questionnaires were checked for unreasonable answers, and the researcher contacted the participants concerned for more clarification.

### **Rich description**

Providing a thorough description for the case study actors, context, findings and research process illuminates the heart of the case to the reader. Thus, in this case a complete detailed description of the case actors (without compromising the confidentiality of their identity) has been provided. In addition, a description of the context of the case was given, along with photos to acquaint the reader with the physical place and its layout.

Finally, the research process was described step by step to the reader. This is to provide a clear picture of the research process. For example, the process of getting access to the context, current pain management practice, and the implementation



process were described. Also field notes, thoughts, reflections and the text of interviews and completed questionnaires were kept throughout the process.

### **Working in the field for a considerable time**

A prolonged engagement in the study field has been considered as an important element in research, as it allows the researcher to have a better understanding of the contextual environment, culture and practice (Lincoln and Guba, 1985). In this study, achieving this was facilitated by spending about 160 hours in the field; this enabled the researcher to merge in the context and achieve a deep understanding of its actors, policies and procedures. In addition, it helped to rule out any changes in the unit (procedures, policies, documentation etc.) that might threaten the validity of the study or lead to false positive or negative conclusions.

## **6.9 Summary**

Conducting the single site case study was challenging and every attempt was made to involve all actors in the cancer pain management process in the unit in this study, although ultimately this was not possible. Nurses and their administration were the main active players in this case but not the oncologist. In addition, efforts were made to enhance the study's trustworthiness and improve its transparency. However, to validate the participants' responses and enhance our understanding of both implementation and cancer pain management processes, various data sources and collection techniques were used. Therefore, the next step was to analyze the data which needed the use of both statistical and thematic analysis to distil the results in a readable and sound form. Thus, the next chapter discusses the approaches to analysis used in this case study.

## **7. Chapter Seven: Data Analysis**

## **7.1 Introduction**

This chapter provides an account of the data analysis approaches that were used in this study, including the preparation of both quantitative and qualitative data for analysis. In addition it presents the statistical and thematic analyses used in the study.

## **7.2 Analysis in case study**

Case study analysis is not a straightforward process; indeed, it is the most challenging part of doing a case study. Having a general analysis strategy can help to deal with data equally, excluding rival irrelevant explanations and reaching valid conclusions (Yin, 2009). Yin (2009) suggested four main strategies, namely: relying on theoretical propositions, developing a case description, using qualitative and quantitative data, and rival explanations. The current case has utilised data mixing, because this case contained both qualitative and quantitative data. According to Yin (2009), using such a strategy is a good choice for postgraduate students or researchers who are using the case study approach for the first time.

This strategy would be of importance where the case contains a considerable portion of quantitative along with qualitative data. Using the statistical analysis can improve the internal and external validity of the case (Creswell, 2003; Yin, 2009). Researchers can use this approach if the case contains data about attitudes and behaviours embedded in the unit of analysis, or if the case was evaluative (Yin, 2009). The current case was evaluative, and substantial amounts of quantitative data were collected. The qualitative part also was used to verify, expand and add new knowledge to the quantitative part.

## **7.3 Preparing the data for analysis**

### **7.3.1 Quantitative data**

Various steps were taken to prepare the data for analysis, including data checking, coding, entry, and transforming.

#### **Data checking**

The completed questionnaires from patients, family caregivers, and healthcare providers were checked for missed answers, mistakenly filled sections and any unclear answers, for example, participants who selected two answers where only one was required, or writing in answer to an open question.

There were two types of missing data; the first was skipped data (Bowling, 2009), such as average, lowest pain scores and current pain scores and pain interference sub-scales. The second type of missing data was 'inadequate responses' (Bowling, 2009), which were mainly related to medical records and healthcare workers' documentation practices. This type of missing data is common when collecting data from medical records (Aaronson and Burman, 1994; Yawn et al., 1998). For example, it was not possible to extract information on cancer stage, education level, and type of cancer treatment from all of the records. The researcher asked the nurse responsible for patients and frequently they provided imprecise information, but the records were considered as the only source for these data. No corrections were made for this kind of missing data, and they were excluded from the analysis.

### **Data coding**

Coding is the process of sorting and categorizing collected data into a meaningful and structured form (Bowling, 2009). Coding is used for quantitative and qualitative data. Data from the questionnaires (Barriers Questionnaire (BQ), Brief Pain Inventory (BPI), data extraction sheet) were given numbers to represent the category they belong to, for example male participants were assigned the code 1, and females assigned 0. The coding sheets were prepared before starting data collection and used as a standard to maintain consistency through all data sets.

### **Data entry**

Questionnaire-generated data entry can be a repetitive and tedious task (Silman and Macfarlane, 2002). Senior researchers as well as beginners can make errors during the entry process (Silman and Macfarlane, 2002). Data were entered as soon as possible after being received into a pre-prepared SPSS (release 17) data file. The entered data were double checked line by line, in SPSS, against the original questionnaires. Thirty nine questionnaires (30%) were also checked randomly against the original questionnaires, and a few mistakes were found. Most of the mistakes were incorrect numbers entered due to pressing more than one key during data entry, and some missing values (13 mistakes), which were subsequently corrected. In addition, frequency and range were computed using SPSS and checked for all variables. Unreasonable values were corrected, for example three participants were identified with gender code '3', which is not used in the coding system, so the researcher returned to the original questionnaire and entered the right value.

## **Data transformation**

Some data needed to be converted into different formats or recoded as new variables. For example, some participants wrote their date of birth for their age, therefore the researcher calculated their age in years. Education level was recoded, using transform option in SPSS, into two categories: highly (diploma or above), and lowly (secondary school or lower) educated, and type of cancer treatment (chemotherapy or combination treatment). On the barrier questionnaire, three questions were positively worded, and therefore scoring was reversed to be consistent with other items, as instructed by the questionnaire author.

## **7.4 Statistical analysis**

Quantitative analysis was carried out using SPSS (Release 17). Statistical analysis for each study stage (pre- and post-implementation) was conducted in two stages. The first was descriptive analysis, wherein the participants (patients, family caregivers and healthcare workers) in the study were described in terms of demographics, and answers on BPI and BQ. The second stage was the test of associations between predictors and outcomes variables. A statistician was consulted, and verified the appropriateness of the tests. The tests used were: paired and unpaired t-tests, the Mann-Whitney U test, the Kruskal-Wallis test, Pearson's Chi-squared test, and Spearman's correlation coefficient.

### **Normality and homogeneity of variance assumptions**

Many statistical tests for continuous variables require them to be normally distributed (Field, 2009). The normality assumption was assessed through generating histograms for the variables of interest. Skewed or non-normal results were concluded based on an eyeball test, which means looking for any evidence of non symmetrical bell shape distribution or departure from hypothetical normal distribution curve, then confirming any conclusion using the Shapiro-Wilk test. The null hypothesis for this test is that the variable has a normal distribution; a non-significant result indicates normality. Also, where the sample size was  $\geq 40$ , the t-test was conducted regardless of how the variable behaved, based on the Central Limit Theorem, which states that the sampling distribution of the sample mean should be normal when the samples are large (McCabe and Moore, 1993). However, Levene's test of equality of variance was used to compare the variance in two groups. The null hypothesis here is that the population variance is the same in the two groups; a p value  $\leq 0.05$  indicates that the homogeneity assumption has been violated, and equal variance cannot be assumed (Field, 2009). The statistical software (SPSS) runs two versions of the t-test for equal variance and the other

assumed non-equal variance, therefore for the former case the result of where the non-equal variance was taken.

### **7.4.1 Descriptive statistics**

In this study, three types of participants were recruited and mutual demographics and participants' group specific information were collected. For the three groups (patients, family caregivers and healthcare workers) the following data were collected: age, gender, education level, and place of living.

Descriptive statistics, including frequencies, percentages, mean, standard deviation (SD) and confidence interval (CI) for the mean were calculated. The mean and its CI were reported for continuous normally distributed variables, but for the non-normally distributed variables the median and inter-quartile range (the difference between the 25<sup>th</sup> and 75<sup>th</sup> quartiles) were reported (Field, 2009).

#### *Barriers Questionnaire*

This questionnaire was completed by the patients, family caregivers and healthcare providers and the main outcomes of interest were the total scores for the BQ and its subscales (normally distributed). Therefore, mean, SD and CI for the mean were calculated. There was a secondary interest in looking at participants' responses on individual scale items to see how participant answered each item of the BQ, thus mean and SD were also calculated.

#### *Brief Pain Inventory*

Descriptive statistics including mean, SD, median, and interquartile range were calculated for each sub-item for the first 50 patients because of the intention to gather comprehensive baseline information, but not for other stages. For the rest of patients, in the two follow-ups, the BPI inventory was completed (as it become the daily tool for pain assessment) but the worst pain score was only extracted and this because the worst pain score is the only item needed to calculate the Pain Management Index (PMI), so other measures were skipped to save patients and the researcher time and effort.

### **7.4.2 Bivariate analysis**

Bivariate analysis includes the test of the differences between two groups, and correlation or association testing (Bowling, 2009; Field, 2009).

### **7.4.2.1 Comparison between groups**

#### *Comparing the BQ total scores between groups*

The variables that permitted comparisons of BQ total scores between groups were gender and educational level of the groups of participants. This comparison was conducted with the pre-implementation patients, family caregivers, and healthcare workers groups from which the baseline data were gathered. In the patient participants other variables could be compared. These were whether they had pain, chronic disease or leukaemia and lymphoma or solid tumours. These comparisons were conducted using the independent t-test.

Other comparisons were made between patients' and family caregivers' scores, and between these and healthcare providers' scores. These were carried out using the paired and unpaired t-test. One justification for this is that the patient group is related to the family caregiver group, but not to the healthcare provider group. Thus, using one-way ANOVA was not acceptable because of the violation of independence assumption. To avoid inflating type-one error the Bonferroni correction was used, and so all effects were interpreted at the 0.025 level of significance (Field, 2009).

#### *Comparing the BPI items scores between groups*

The BPI comprises many items. For the worst pain scores, the comparisons included the data of 130 patients (all patients in the study stages), but for the other items only the data of the first 50 patients (pre-implementation stage) were included (only worst pain score was collected in the follow-up stages because it is the only needed element to construct the PMI). The variables of interest that allowed the two group comparisons included gender, education level, diagnosis, type of cancer treatment, and whether they have chronic disease or not. These comparisons were conducted using the Mann-Whitney Test (due the violation of the normality assumption).

#### *Comparing the PMI between groups*

The PMI was calculated and compared between study stages (pre- and post-implementation) using the Mann-Whitney U Test. The two groups of patients (pre- and post-implementation) were independent. However, the Kruskal-Wallis Test (non-parametric ANOVA equivalent) was used to compare the PMI between three stages (baseline data, first follow-up and second follow-up). It is a non-parametric test that should be used where it is difficult to justify the use of ANOVA (Field, 2009). In case of significant results, multiple comparisons were conducted using the Mann-Whitney U Test to locate where the significant differences lay. To avoid

inflating type-one error the Bonferroni correction was used, and so all effects were interpreted at the 0.0167 level of significance (Field, 2009).

#### **7.4.2.2 Correlations**

##### *Relationship between the BQ total scores and continuous variables*

Spearman's correlation coefficient was used to assess the correlation between BQ scores and age, and worst, lowest and average pain, because these two variables were not normally distributed (Field, 2009). The researcher looked at the correlation coefficient value ( $r$ ), whose value range between -1 (negatively correlated) through zero (where there is no relation) and +1 (positively correlated). A  $p$  value  $\leq 0.05$  was considered a significant correlation (Field, 2009).

##### *Relationship between BQ and binary variables*

The relationship between worst pain score and age, gender, education level, cancer stage, and type of cancer were examined using Spearman's correlation coefficient, because of variable not being normally distributed (Field, 2009).

### **7.5 Qualitative data and analysis**

#### **Data preparation**

Interview texts (notes) were translated into English and typed into Microsoft Word on the same day of the interview. Back-translation technique was used; the researcher firstly translated the transcripts into English then translated the English version into Arabic and the same meaning and content were maintained. An Arabic linguistic specialist was consulted to check the translated version of the transcript against the Arabic version, and 17 changes were detected related to inappropriate translation from Arabic into English (semantic issues). Thus changes were applied to sentences that did not reflect the exact meaning of the original Arabic sentences.

Interviews with nurses and the field notes were written while the researcher was in the research setting, and the interview guide was followed to assure that all desired questions were asked. The interview texts were checked for content and clarity immediately after the interview sessions and in case more information was needed, and participants were asked again to explain or add the needed piece of information. Some difficulties in reading the written answers were faced, in which case participants were asked to clarify the answers until the right meaning was assured.



### 7.5.1 Analysis

Data included the following: semi-structured interview transcripts, field notes and open-ended questions. Thematic analysis was used to analyse all of these data forms. Thematic analysis can be an iterative and a back and forward process (Braun and Clarke, 2006; Creswell, 2007). All data were subjected to thematic analysis, which is a commonly used analysis technique in qualitative contexts (Braun and Clarke, 2006; Creswell, 2007). The six steps suggested by Braun and Clarke (2006) were adopted, as shown in table 7.1

**Table 7.1 Thematic Analysis Process**

Phase	Description of the process
1- Familiarizing yourself with your data:	Transcribing data, reading and re-reading the data, noting down initial ideas.
2- Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3- Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4- Reviewing themes:	Checking if the themes work in relation to coded extracts and the entire data set, generating thematic map of the analysis.
5- Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells. Generating a clear definition and name of each theme.
6- Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature. Producing a scholarly report of the analysis.

Taken from Braun and Clarke (2006), 'Using thematic analysis in psychology' (*Qualitative Research in Psychology*, p. 88).

For example, in the pre-implementation stage, the nurses were interviewed and one question was asked about what factors they thought may cause patients to not receive adequate pain management. The first step was that the researcher read through the interviews text and writes some notes using coloured pen. Then researcher started to determine the codes (see table 7.2), then re-read the text, resulting either in new codes or removing unrelated ones, then the initial sub-themes were established (see table 7.2). After that, the initial themes were re-read again and worked out to conclude the final themes that were used in writing the

first draft of the results chapter, then themes quality were enhanced through reflecting on and revising these chapters.

**Table 7.2 Thematic analysis example**

Interview Coding		Possible sub-themes	Final theme
Code	Data extract		
Low priority	"I think here in Jordan we are different from other part of the world, pain medications are prescribed depending on the physician mood. Patient are suffering inadequate pain treatment, it is really messy and complicated here. I knew patient who was crying from severe pain, I swear we called the physician at night and he was very angry and order 500 mg paracetamol, Then he turned his phone off."	<ul style="list-style-type: none"> <li>➤ Negative attitudes toward cancer and cancer patient.</li> <li>➤ Lack of knowledge and training</li> <li>➤ Appreciate clinical experience learning and ignoring research</li> </ul>	<ul style="list-style-type: none"> <li>➤ Healthcare providers-related barriers to cancer pain management</li> </ul>
Lack of knowledge	"We as nurse don't have knowledge, authority and respect. We try to be helpful but at the end the doctor has the pain medication in his pen. Sometime we act and argue with the physicians to give the patient the adequate dose; it did not work all the time."	<ul style="list-style-type: none"> <li>➤ Lack of authority and power</li> </ul>	
Misconception	"Physicians pretend that daily use of pain medication will result in addiction and these believe have been disseminated among all healthcare providers and patients as well."		

## **7.6 Summary**

Analysing the collected data in this case study required the use of both quantitative and qualitative analysis approaches. Statistical analysis ranging from simple tests such as descriptive statistics to more complex inferential statistics such as the Kurskal-Wallis Test was used in this case study. In addition, thematic analysis was used to analyse the qualitative data such as interview texts, field notes and open-ended questions. It was anticipated that analysing case study data would be a challenging task. Thus it was carried out over two stages; the pre-implementation work and the post-implementation phase. The following chapter presents the results of the first analysis stage.

## **8. Chapter Eight: Cancer Pain Management: Results of Pre-Implementation Work**

## **8.1 Introduction**

This chapter presents the results of the assessment of cancer pain management status in the oncology unit. This included the description and demographics of the participants in the study, presenting the data related to cancer pain management in the unit such as pain prevalence, severity, and adequacy of pain treatment, and the factors influencing cancer pain management in the unit. Additionally, nurses' perceptions of using the pain assessment tool are presented. All of these results represent the state of cancer pain management in the unit before introducing the Pain Monitoring Programme (PMP). The reader should be reminded that the following instruments were used in data collection during this phase:

- The Arabic barrier questionnaire (BQ)(see appendix 13)
- The Arabic brief pain Inventory (BPI)(see appendix 15)
- Demographical data sheet (see appendix 10)
- Semi-structured interview questions (see table 6.4)
- Data extraction sheet (see appendix 17)

## **8.2 Description of the main units of analysis**

As previously stated, this is a single-case study with embedded units of analysis that included:

- ❖ Patients and their family caregivers.
- ❖ Healthcare providers (nurses and physicians).
- ❖ Implementation process of the PMP.

These units of analysis are described in detail in the following sections in terms of demographics for the pre-implementation stage.

### **8.2.1 Patients**

#### **8.2.1.1 Demographics**

Seventy five Jordanian cancer patients and their primary family caregivers were invited, 50 (the response rate was about 66%) dyads agreed to take part in the study. In this section patients' data are presented. There was a slightly higher number of females ( $n = 27$ ) than male participants. The mean age of patients was 41.9 years (SD 15.4), and the range was from 18 to 77 years.

Education levels were divided into two categories: highly educated (having a diploma or higher qualification) and less educated (having secondary school education or less). Table 8.1 presents the frequency and percentages for demographic characteristics

**Table 8.1 Patients' demographics**

<b>Characteristics</b>	<b>Frequency</b>	<b>Percentage</b>
<b>Gender</b>		
Male	23	46
Female	27	54
<b>Marital status:</b>		
Married	34	68
Single	14	28
Widowed	2	4
<b>Education category:</b>		
Highly educated	22	44
Less educated	28	56
<b>Place of living:</b>		
City	29	58
Village	21	42
<b>Do you work?</b>		
Yes	19	38
No	31	62

The results show that most patients (n = 34) were married. In addition, 28 had secondary school education as their highest level of education. Most were living in cities (n = 29) and not working (n = 31).

### **8.2.1.2 Disease-related characteristics**

The following features were extracted for the patients. They included having chronic disease or not, type of cancer, stage of cancer, and type of cancer treatment (see table 8.2). Chronic disease means any disease lasting more than six months, such as diabetes mellitus or heart diseases. Information only about cancer stages was not always available in the medical records.

**Table 8.2 Disease-related patients' characteristics**

Characteristic	Frequency	Percentage
<b>Having chronic diseases?</b>		
Yes	9	18
No	41	82
<b>Type of cancer:</b>		
Leukaemias and lymphomas	17	34
Solid tumours	33	66
<b>Cancer stage:</b>		
Early stages	17	34
Advance stages	19	38
Missing	14	28
<b>Type of cancer treatment:</b>		
Chemotherapy	33	66
Combination	17	34

Table 8.2 shows that most patients (n = 41) were free of chronic diseases other than cancer. Thirty three patients had solid tumour cancer, 19 of them were in late cancer stages, and 33 were treated with chemotherapy.

### 8.2.2 Family caregivers

A total of 50 family caregivers completed the BQ. All were one of the patient's first degree relatives (husband, wife, son, daughter, father or mother). There were 28 female caregivers. Participants' ages were grouped into three categories. Table 8.3 summarises the main characteristics collected about family caregivers.

**Table 8.3 Family caregivers' demographics**

Characteristic	Frequency	Percentage
<b>Age:</b>		
18 to 35 years	24	48
36 to 55 years	20	40
≥ 56 years	6	12
<b>Gender:</b>		
Male	23	46
Female	28	54
<b>Education level:</b>		
Highly educated	21	42
less educated	29	58
<b>Living with patient in the same house?</b>		
Yes	36	82
No	14	28
<b>Are you working?</b>		
Yes	22	44
No	28	56

A considerable number of family caregivers (n = 44) were under the age of 55. Most of them (n = 36) were living in the same house with patients, and 28 were not working. Finally, 29 of them only received secondary school education or less.



### **8.2.3 Healthcare workers**

All nurses and consultants who were working in the oncology unit were invited to participate in the study.

Fifteen nurses (all nurses in the unit), including the UM, participated in the study. Two of them only completed the BQ and then they were transferred to another unit. The head nurse, aged 51, with 28 years of experience, was excluded only from the statistical analysis for the mean, standard deviation (SD), and the range, because both values were identified as outliers and this may affect the results interpretations.

Nurses' mean age was 26 years (SD 1.9), ranging from 23 to 29 years. The majority of nurses were male (12 out of 15). They had on average 3.8 (SD 2.0) years of working experience. Thirteen nurses had a Bachelor's degree, and two had a Master's degree. All nurses reported that they had not received pain education in the last five years.

Ten consultants were invited to participate in the study, six of whom agreed to complete the BQ, but eight allowed the researcher to approach and collect data from patients. Consultants' mean age was 46.3 years (SD 4.6), ranging from 40 to 51 years. They had been qualified for a mean of 10.8 years (SD 4.1). Four consultants were males, and two were females. All of them had a Master's degree and had received no education about pain management in the last five years.

## **8.3 Cancer pain prevalence, severity and interference with daily living life**

In order to make a baseline comparison, it was necessary to conduct some survey work on cancer pain in the unit before implementing the PMP. Because information about cancer pain in Jordan is anecdotal, no data were available about cancer pain at the study location. The patients who were admitted to the unit over a three-week period were recruited and surveyed for pain using the BPI.

### **8.3.1 Pain prevalence**

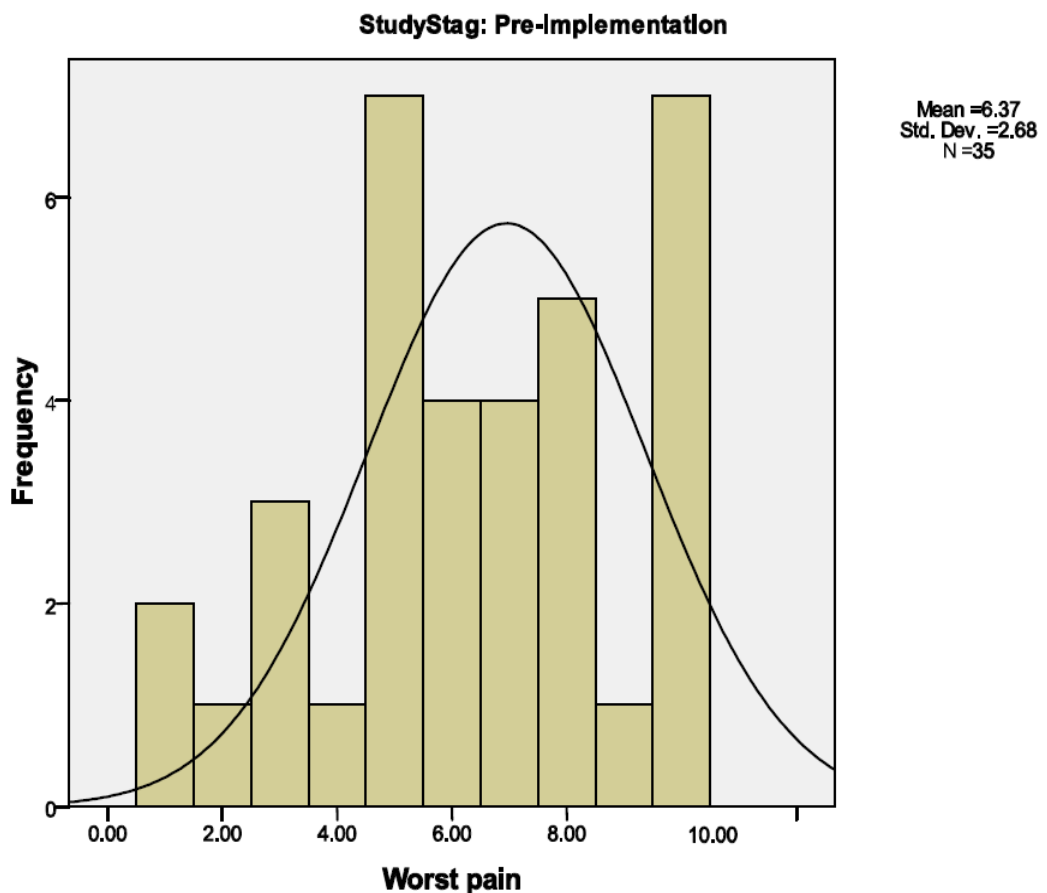
The patients were asked (using the BPI) whether they had pain at the time of survey or not. The results indicated a high percentage of patients with some pain, 35 out of 50 patients had pain (70%).

### 8.3.2 Pain severity

Patients with pain were asked (using the BPI) to rate their pain now and estimate level for worst, lowest, and average pain in the preceding 24 hours.

The worst pain scores were not normally distributed, and the Shapiro-Wilk test was significant ( $W = 0.94$ ,  $p = 0.045$ ). Kurtosis was  $-0.72$  and skewness was  $-0.30$ , which confirms that worst pain score is not a form of normal distribution, as in normal distribution both values should be zero (Field, 2009, p. 138). The worst pain scores distribution is shown in figure 8.1. The mean of worst pain scores in the last 24 hours was high at 6.37 out of 10 (maximum score), and the median was 6 (interquartile range from 5 to 8). The mean of the average pain intensity felt by participants in the previous 24 hours was relatively high 4.3. In addition, the mean of pain now was slightly worse at 4.8 than average pain, and the mean score of lowest pain level experienced by participants in the last 24 hours was 3.1. Descriptive statistics for pain intensity measures are presented in table 8.4.

**Figure 8.1 Distribution of worst pain score**



**Table 8.4 Descriptive statistics for pain intensity measures**

<b>Pain measures</b>	<b>Mean (SD)</b>	<b>Median (interquartile range)</b>
Pain now	4.3 (3.3)	4 (1 to 8)
Average pain in the last 24 hours	4.8 (2.5)	4 (3 to 8)
Lowest pain in the last 24 hours	3.1 (2.6)	2 (1 to 5)

### 8.3.2.1 Comparing pain indicators

Pain indicators were compared to test if there was a difference in pain indicators score in regard to gender, education level, type of cancer, cancer stage, type of cancer treatment, and having chronic disease or not. The Mann-Whitney U Test was used to compare the distribution of pain indicator scores by category. Results for each indicator are detailed in the tables in appendix 18. No significant differences in distribution were found in pain severity indicators between any of the groups.

### 8.3.3 Pain interference with life aspects

The second part (sub-scale) of the BPI is designed to evaluate pain interference domain, thus participants were asked (using the BPI) to rate how much their pain was interfering with aspects of daily life in the last 24 hours. These aspects included general activity, mood, walking ability, normal work (inside and outside home), relationships with others, sleep and enjoyment of life. Descriptive statistics are shown in table 8.5.

**Table 8.5 Pain interference**

<b>Interference with:</b>	<b>N</b>	<b>Minimum</b>	<b>Maximum</b>	<b>Mean</b>	<b>SD</b>
General activity	35	0	10	4.6	3.4
Mood	35	0	10	4.8	3.2
Walking Ability	35	0	10	4.4	3.3
Normal work	35	0	10	5.5	3.0
Relation with others	35	0	10	4.3	3.1
Sleep	35	0	10	6.0	3.3
Life enjoyment	35	0	10	5.8	3.2

It was found that pain in general interfered in a major way with the selected daily life aspects. It was found that the means for the eight sub-scales scores were above four, which may be considered to be a high level of interference. The highest interference average scores was with sleep (Mean= 6.0 SD 3.3), normal work (Mean= 5.5 SD 3.1) and mood (Mean= 4.8 SD 3.2). Those three vital aspects of life have been found to be affected by feeling pain in cancer patient.

### 8.3.3.1 Relationship between age and pain interference

Spearman's correlation coefficient was estimated between age and pain interference indicators. Table 8.6 presents the output of Spearman's Test. The results show that there were no significant relationships between any of pain interference indicators and patient age. This implies that age did not affect the amount of interference caused by pain.

**Table 8.6 Relationship between patients' age and pain interference indicators**

<b>Correlation between age and:</b>	<b>n</b>	<b>Spearman's rho</b>	<b>p</b>
Pain interference with general activity	35	0.13	0.463
Pain interference with mood	35	-0.28	0.112
Pain interference with normal walking	35	-0.11	0.531
Pain interference with normal work	35	-0.09	0.628
Pain interference with relation with others	35	-0.19	0.284
Pain interference with sleeping	35	0.15	0.388
Pain interference with life enjoyment	35	0.06	0.715

### 8.3.3.2 Comparing pain interference scores between two groups

The following variables were compared with pain interference: gender, education level, type of cancer, cancer stage, type of cancer treatment, and having chronic disease or not. The Mann-Whitney U Test was conducted. None of the test results showed a significant difference except for walking (U = 88.0, p = 0.024) when compared by type of cancer. This result indicated that pain in patients with blood cancers (Leukaemias and lymphomas) compromised ability to walk (mean rank = 23.0) compared to patients with solid tumours (mean rank = 15.0).

Overall, pain prevalence was found to be high among cancer patients. In addition, the participants' worst pain scores on average were high and severe. Furthermore, pain affected participants' life activities. Thus, pain seems to be prevalent in the oncology care unit. This led to asking the following question: How is pain currently assessed in the unit? This is discussed in the following section.

## 8.4 Pain assessment and management in the oncology unit

Pain assessment practice in the unit was covered by the pilot work in chapter four (see page 90). Complementary data are presented here to help to complete the picture about current practice in the unit.

### 8.4.1 Nurses' pain assessment practice

During the interviews, nurses were requested to choose statements that represented how they usually assess pain in the unit. Nurses were given four sentences and were asked to choose one or more statement which represented their practice (see table 8.7).

**Table 8.7 Nurses' pain assessment practice**

Number	Sentence
One	I (nurse) ask the patient if he/she has pain.
Two	I ask the patient to rate his/her pain on a 10 points scale verbally.
Three	I use the pain assessment tool adopted by the hospital
Four	I never ask patient about pain, because if they have pain they will call me.

Surprisingly, not one nurse chose sentence three, which was thought to be the most obvious and best practice answer; six nurses chose sentence one, two chose number two, and only three nurses chose sentence one and two at the same time. Interestingly, four nurses never asked patients about pain. This also suggested that nurses tended to wait until patients complained rather than regularly assessing their pain. Almost half of the nurses at the unit (six) said that they usually asked patients to rate their pain, but this was not evident in the observation of the unit. Most of nurses tended to behave in different ways than they previously claimed. This highlights the discrepancy between nurses' beliefs and actions.

### 8.4.2 Disparities between what nurses said and what they actually do

A gap between what nurses usually said to the researcher and what they practised was identified. The researcher compared what was found in this stage to what was concluded in the pilot work (see figure 4.1) regarding the pain management steps in the unit. The source of information in pilot work was some informal discussion with nurses and what was written in the policy, which it was believed might reflect current daily practice. However, interviewing nurses, observing nurses, and reviewing patients' medical files revealed that there was no regular pain assessment on patient admission to the unit or for inpatients. In addition, it seems that it was the responsibility of the patients to report and complain about pain. It

was evident from patients' medical records that the pain section was usually left blank. In addition, it was observed that the patient was the initiator and nurses reacted to patients' pain complaints. Patients' complaints were treated as any other regular complaints, and feeling pain was not taken as a serious complaint which needs quick and effective action. Furthermore, patients waited some time until they received the treatment (15 to 45 minutes).

The discrepancy between what nurses reported and what they actually did is apparent, and this could contribute to the problem of insufficient pain assessment. This may suggest that nurses tend to report that they treat patients' pain adequately, while in fact they did not.

### 8.4.3 Perception of the pain assessment tool

The nurses' perception of the use of pain assessment tool in practice was investigated. They were asked, in the interview, to choose how they perceived the use of the pain assessment tool in general, and table 8.8 summarizes nurses' choices.

**Table 8.8 Nurses' perception of pain assessment tool**

<b>I (nurse) think that the use of pain tool is:</b>		<b>Number of Nurses</b>
<b>Negative</b>	Extra paper work.	1
	Good to use a pain assessment tool, but no one will look at it.	4
<b>Positive</b>	An important pre-requisite to optimal pain management.	2*
	It is important and should be use in daily manner.	7

\* Nurses chose the third and fourth choice at the same time.

It was found that seven nurses positively perceived the use of the pain assessment tool in daily practice. On the other hand, five nurses held a negative perception toward the use of pain assessment tool. However, the majority of the nurses had a positive perception of the pain assessment tool; although it was found that the tool was not used as it should be.

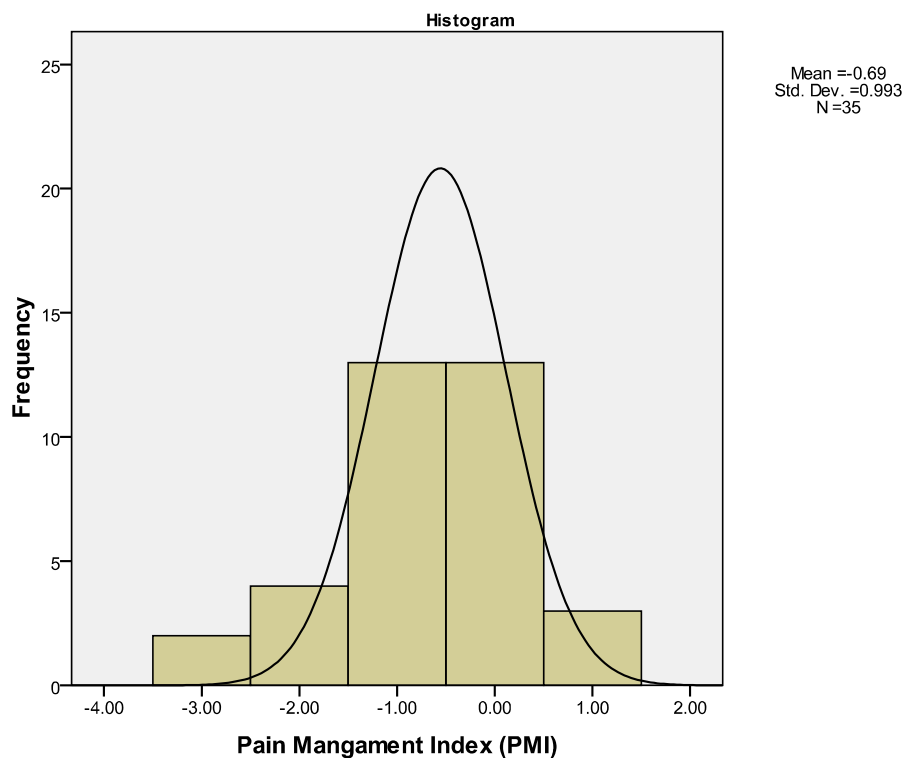
The audit of 50 medical files found that the pain assessment tool was used only in 16 files. In addition, pain was documented in nursing notes in only one file, and pain medications were given and signed without any other documentation for 12 patients. In 21 medical files, nothing was found about pain. This highlights the fact that perceiving the tool use positively does not necessarily mean that it is used in the daily practice. The results indicated that even if nurses had faith in the tool,

they were reluctant to use it in their daily practice. Therefore, this suggested other factors that might result in a low percentage of pain assessment tool use in the oncology unit. Furthermore, pain assessment was not as it should be, and it was expected that pain management might also be compromised, which would logically result from the impaired pain assessment process.

### 8.5 Pain management adequacy in the Oncology Unit

The adequacy of pain management in the unit was assessed. The PMI was calculated for the 35 patients found in pain. The mean of PMI was -0.69 (SD 1.0) and range from - 3 to 1 see figure 8.2.

**Figure 8.2 The distribution of patient PMI scores**



The results (negative mean scores of PMI) showed that most patients with pain received inadequate pain management. This meant that either patient received low doses of pain medication, which were not effective for the pain severity, or they were not given any treatment for pain (this more frequently happened when the pain level was less than 3). It was found that 10 patients with pain had not been treated for their pain, and the majority of those treated received weak opioids such as Tramal (tramadol). The least-used drugs were the NSAIDs and paracetamol. Nine patients have been prescribed strong opioids. On other hand, these doses were given once (stat orders) or as needed doses (PRN). It was found that most patients (n = 15) were given stat doses or PRN. The remaining 10 patients were on regular pain medication. In addition, it was found that only five patients were

treated with more than one pain medication, and single drug treatment was the common practice (20 patients). The most commonly used route for drug administration was the intravenous route (n = 20), followed by the oral route (n = 14; see table 8.9).

**Table 8.9 Indicators of pain management in the unit**

	<b>Count</b>	<b>Percentage</b>
<b>Type of prescription:</b>		
<b>Stat or PRN</b>	15	60
<b>Regular</b>	10	40
<b>Combination treatment:</b>		
<b>Yes</b>	5	20
<b>No</b>	20	80
<b>Rout of administration:</b>		
<b>Intravenous</b>	20	80
<b>Oral</b>	4	16
<b>Others</b>	1	4

The results above support the fact that lack of or inadequately conducted pain assessment may result in inadequate pain management.

It was observed that most pain medications were ordered over the phone without seeing the patient. Hence, medication orders were given without seeing and without physician assessing the patient, for example one nurse said:

*Once I called a doctor at night shift and asked him to come to see a patient who had pain. The doctor asks me if the patient can wait for one hour because he was tired and he wants to take a nap. I said no then the doctors become angry, finally he came after one hour and a half. N08 Registered Nurse*

In two observed situation (whereas pain was to be managed) the patients' pain was either ignored or treated inadequately. For example, two nurses were reluctant to give narcotics, as revealed in this conversation:

*RN03 said: did you see this patient he is always doing this (seeking his medication dose on time), do you think he is telling the truth.*

*RN04: for me, I think he is seeking attention nothing more. He wants the medication to feel the happiness not the relief. If his claim is right, how he can manage to walk to the nursing station? We usually delay his dose.*



Re-assessment either was lacking or seemed to be conducted inappropriately; in one situation, the nurse found the patient still to be in pain, but undertook no further intervention to treat it. This leads to the conclusion that pain was not a priority for nurses or physicians. The results presented in the previous sections highlighted the problem of inadequate pain management at the oncology unit. Many of the issues faced indicated some barriers and lack of knowledge regarding pain management.

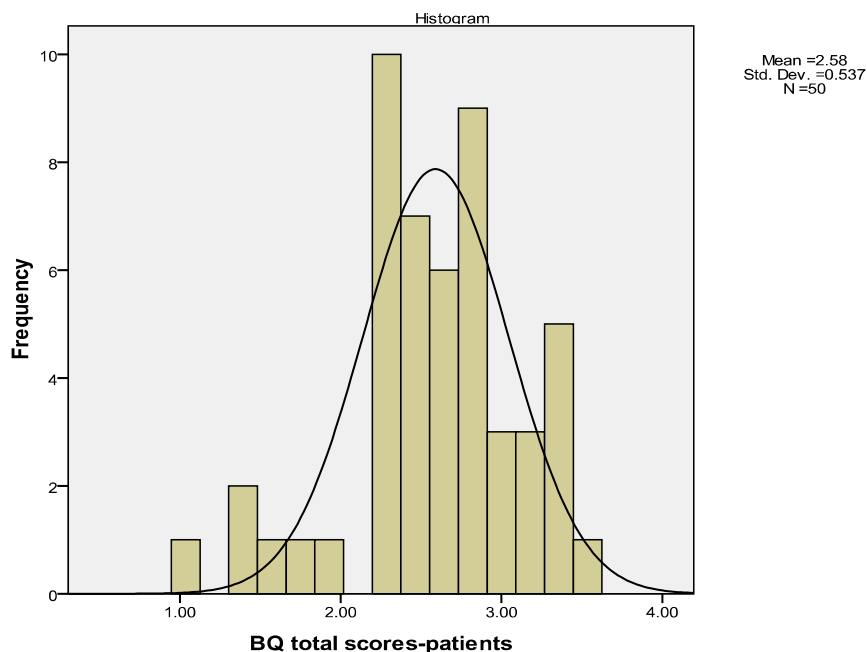
## 8.6 Barriers to cancer pain management

The researcher surveyed 50 dyads of patients and their caregivers and 21 healthcare providers working in the unit during the pre-implementation phase. Although 75 dyads of patients and family caregivers were approached, 25 refused to participate in the study. The reasons behind the refusal were: feeling fatigue (10 patients), not willing to talk about cancer (5 patients), patients did not know that they had cancer (8 patients) and three patients gave no reason. All nurses completed the BQ (15 nurses), and six out of ten consultants agreed to complete the questionnaire. The total BQ mean score ranged from 0 (no barriers) to 5 (high barriers level). The higher the score the higher the barriers level to cancer pain management.

### 8.6.1 Patient barriers to cancer pain management

The mean score of total barrier questionnaire scores was 2.6 (SD = 0.5) and 95% confidence interval (CI) for the mean ranged from 2.43 to 2.83. Figure 8.3 shows the distribution of total BQ scores.

**Figure 8.3 The distribution of the total score of BQ – patients**



The total BQ scores were normally distributed, and the Shapiro-Wilk Test was not significant ( $W=0.96$ ,  $P = 0.095$ ). The mean score for patients was high, which means that patients hold a considerable number of barriers. Patients mean scores and CI for the mean of BQ sub-scales are shown in table 8.10.

**Table 8.10 Means and CI of BQ sub-scales**

<b>Sub-scale</b>	<b>Mean (SD)</b>	<b>95% CI</b>	<b>N</b>
<b>Physiological Effects</b>	2.8 (0.8)	2.49 – 2.97	50
<b>Fatalism</b>	1.8 (1.0)	1.45 – 1.99	50
<b>Communication</b>	2.5 (1.0)	2.23 – 2.78	50
<b>Harmful Effects</b>	2.8 (0.5)	2.43 – 3.03	50

The physiological effects of pain medications and its harmful effects were the major barriers with the highest mean score. The highest concern within the harmful effects subscale was the addictive nature of pain medicine; the mean was 3.2 (SD 1.8) for this item. The means of other sub-scales were also high, indicating the high levels of barriers that patients hold. This perhaps affects the treatment of their pain. Each patient exhibited barriers to some degree. Patients deemed that pain medications can intercept the feeling of new pain 3.4 (SD 3.2), prevent it from working for stronger pain in future 3.2 (SD 1.5), and may mask the change in body health status 3.1 (SD 1.8). Most items got a mean score  $> 1.5$ , and this also indicated the large magnitude of patient concerns; see table (see appendix 19). Addiction was an obvious concern for patients; all BQ items containing the word 'addiction' got high mean scores, usually  $> 2.5$ .

### **8.6.1.1 Comparing total BQ scores between two groups**

The following variables allowed the comparison of the BQ total scores between two groups: gender, educational level, type of cancer, stage of cancer, having pain and having chronic disease or not. Independent t-tests were estimated table, see 8.11.

All analysis assumed equality of variance, confirmed by Levene's Test (all  $p > 0.5$ ). Moreover, no significant difference in the mean BQ score was found between males and females, Leukaemia patients or solid tumours, highly or low educated patients, early or advanced stages, and with or without chronic disease. P values were  $> 0.05$ , and all 95% CIs of the difference contained zero, consistent with the t-test results.

**Table 8.11 Independent t-test results analysing the difference in mean total BQ score between two groups**

Variable	t	df	p	95% CI of the difference	Mean (SD)
<b>Gender</b> Male Female	1.55	48	0.128	-0.1 to 0.5	2.5 (0.6) 2.7 (0.5)
<b>Education level</b> Low educated Highly educated	0.890	48	0.386	-0.4 to 0.2	2.5 (0.5) 2.7 (0.5)
<b>Diagnosis</b> Leukaemias and lymphomas Solid tumours	-0.92	48	0.362	- 0.5 to 0.2	2.5 (0.6) 2.6 (0.5)
<b>Cancer stage</b> Early stages Advanced	0.30	34	0.862	-0.3 to 0.4	2.6 (0.6) 2.6 (0.5)
<b>Chronic disease</b> Yes No	1.95	48	0.058	-0.1 to 0.9	2.2 (0.4) 2.6 (0.5)

### 8.6.1.2 Correlation between total BQ score and age and pain indicators

Spearman's Correlation Test was conducted between total BQ score and age, pain now, worst, lowest, and average pain. There were no significant correlations found between total BQ scores and age or any pain indicators (see table 8.12).

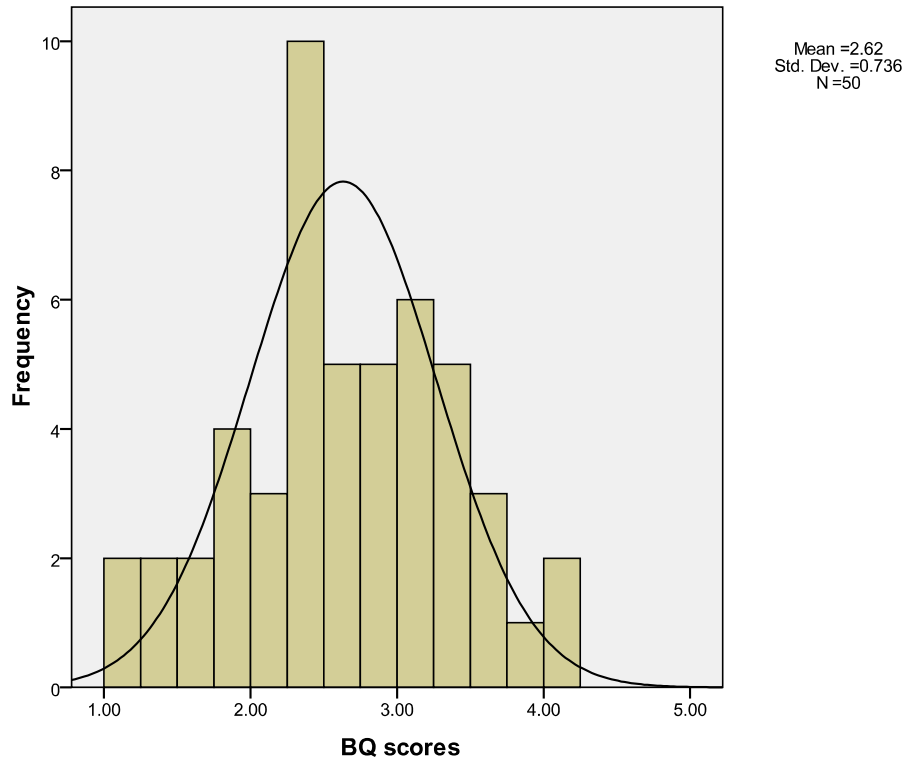
**Table 8.12 Spearman's correlation coefficient analysing the relationship between total BQ score and age, and pain severity indicators**

Variable	Spearman's rho	P
<b>Age</b>	0.08	0.575
<b>Pain now</b>	-0.08	0.692
<b>Worst pain</b>	0.02	0.929
<b>Lowest pain</b>	0.13	0.465
<b>Average pain</b>	-0.03	0.884

### 8.6.2 Family caregivers' barriers to cancer pain management

The mean score of total barrier questionnaire score was 2.6 (0.8) and 95% CI for the mean ranged from 2.41 to 2.83. The Shapiro-Wilk test was not significant ( $w = 0.99$ ,  $p = 0.878$ ), which indicated that total BQ scores had a normal distribution (see figure 8.4). The mean scores of the BQ sub-scales are presented in table 8.13.

**Figure 8.4 The distribution of total BQ for family caregivers**



**Table 8.13 The mean scores for the BQ subscales**

Sub-scale	Mean (SD)	95% CI	n
<b>Physiological Effects</b>	2.8(0.9)	2.45 - 2.97	50
<b>Fatalism</b>	2.0 (1.1)	1.68 - 2.29	50
<b>Communication</b>	2.4 (1.8)	2.12 - 2.73	50
<b>Harmful Effects</b>	2.9 (1.0)	2.66 - 3.20	50

The mean scores of BQ sub-scales were high and the physiological effects and harmful sub-scales got the highest score again. Interestingly, the mean score for fatalism was higher than for patients' scores (M = 1.8). The mean score of the BQ items are presented in appendix 20.

It was found that all the family caregiver participants have at least some degree of concern, and all means of BQ items were higher than 1.8. Similar to the patients, family caregivers believe that pain medication use can either prevent its effect for stronger pain 3.1 (SD 1.8), or prevent patients from knowing what is going inside their body 3.2 (SD 1.6). Family caregivers believe in the limited ability of pain medication to relieve pain 2.3 (1.5). All items containing the word 'addiction' got high mean scores (3.3, 3.0, and 3.2 respectively).

The results show that family caregivers have almost the same barriers as the patients, and even more for specific items.

### 8.6.2.2 Comparing the total BQ score between two groups

Variables which enabled comparison of the mean total BQ score between two groups were gender, education level, work status, and living with patient in the same house or not. All analysis assumed equality of variance confirmed by Levene's test (all  $p > 0.5$ ) except for working status ( $p = 0.048$ ), therefore non-equal variance was assumed. The independent t-test was used, and the results showed that there were no significant differences in the mean of total BQ score between the mentioned groups except for age group ( $t = 2.50$ ,  $df = 48$ ,  $p = 0.016$ ) and the 95% CI of the difference did not contain zero, consistent with the t-test result, thus the null hypotheses of no difference in the total BQ mean score between age groups should be rejected. It was found that younger family caregivers have higher concerns than older caregivers (mean = 2.88 and 2.38 respectively; see table 8.14).

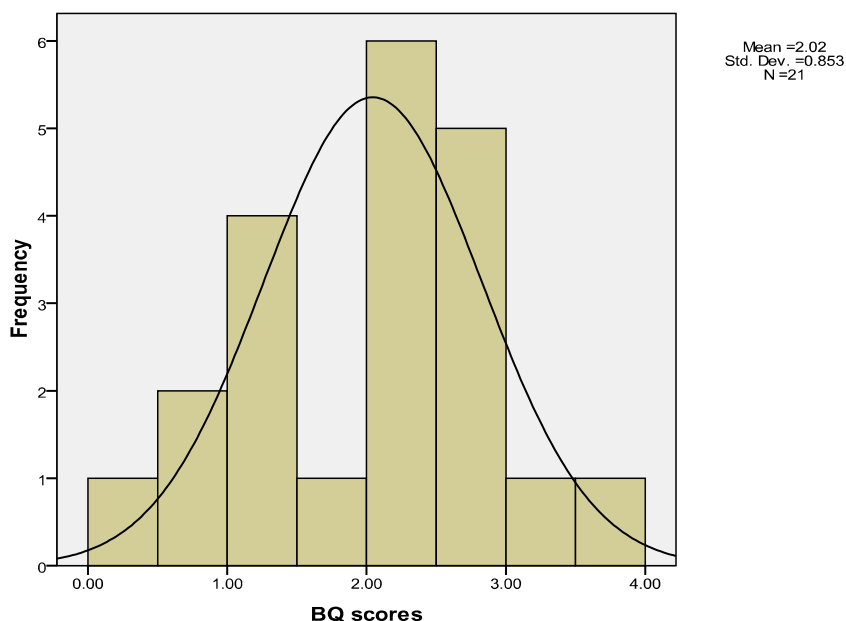
**Table 8.14 Independent t-test results analysing the difference in mean total BQ score between two groups**

Variable	t	df	p	95% CI of the difference	Mean (SD)
<b>Gender</b> Male Female	-0.03	48	0.978	-0.43 to 0.42	2.6 (0.7) 2.6 (0.8)
<b>Education level</b> Low educated Highly educated	0.25	48	0.803	-0.38 to 0.48	2.6 (0.7) 2.6 (0.8)
<b>Working status</b> Yes No	1.88	48	0.083	- 0.05 to 0.84	2.4 (0.5) 2.8 (0.8)
<b>Living with patient in the same house</b> Yes No	1.91	48	0.062	- 0.88 to 0.95	2.5 (0.7) 2.9 (0.8)
<b>Age groups</b> 18 to 55 years ≥56	2.50	48	0.016	0.01 to 0.89	2.9 (0.8) 2.4 (0.6)

### 8.6.3 Healthcare providers

All nurses who worked in the unit (15) and six consultants completed the BQ. The mean for the total BQ scores was 2.0 (SD 0.9). The total BQ scores for healthcare providers were normally distributed ( $W = 0.95$ ,  $P = 0.386$ ), as shown in figure 8.5. The 95% CI for the mean ranged from 1.6 to 2.4. The mean score and CI for the mean of BQ sub-scales are shown in table 8.15.

**Figure 8.5 The distribution of BQ scores for healthcare provider participants**



**Table 8.15 Mean scores and CI for BQ sub-scales.**

Sub-scale	Mean (SD)	95% CI	N
<b>Physiological Effects</b>	2.3 (0.8)	1.91 – 2.64	21
<b>Fatalism</b>	1.4 (1.0)	0.99 – 1.89	21
<b>Communication</b>	1.8 (1.2)	1.09 – 2.20	21
<b>Harmful Effects</b>	2.2 (1.0)	1.68 – 2.66	21

Healthcare providers hold their own concerns, but lower than those of patients and family caregivers. However, despite their clinical knowledge and training, the concerns of healthcare providers were still relatively abundant. The fatalism sub-scale mean score of 1.4 (1.0) was the lowest, indicating that healthcare providers may believe more in the ability of pain medications to effectively treat pain. The physiological effects and harmful effects of pain medications were foremost in the healthcare providers' concerns (2.3 SD 0.8, 2.2 SD 1.0, respectively). The healthcare providers' response on BQ items is presented in appendix 21. Healthcare providers believed that pain medications can block the ability to distinguish the subsequent pain, and the mean score for this item was extremely high at 3.9 (SD 1.4). Also, they thought that taking pain medicine may mask changes in the patient's health status, with a score of 3.0 (SD 1.3). In addition, addiction concerns were high; the three items asking about addiction were highly rated as concerns (3.2, 3.3, and 2.9 respectively).

The independent t-test results show that there were no significant difference in the mean total BQ total score between nurses (Mean = 2.2 SD 0.9) and physicians (Mean =

1.6 SD 0.7)( $t = 1.48$ ,  $df = 19$ ,  $p = 0.154$ ). All analysis assumed equality of variance confirmed by Levene's test (all  $p > 0.5$ ). Spearman's correlation coefficient indicated that there were no significant correlations between the BQ total score and healthcare provider age ( $r = -0.36$ ,  $p = 0.114$ ) or years of experience ( $r = -0.32$ ,  $p = 0.16$ ).

### 8.6.3.1 Comparing the total BQ score among participants

To compare the mean score of total BQ among the three participants groups, one way ANOVA could be used, but these groups are not independent. Therefore, the paired and un-paired t-tests were used instead. Tables 8.16 and 8.17 detail the results of paired and un-paired t-tests. To avoid inflating type-one error the Bonferroni correction was used, and so all effects were interpreted at the 0.025 level of significance (Field, 2009).

**Table 8.16 Independent t-test results analysing the difference in mean total BQ score between two groups**

Variable	T	df	p	95% CI of difference
<b>Patients and healthcare providers</b>	2.77	69	0.001	0.15 to 0.98
<b>Family caregivers and healthcare providers</b>	2.97	69	0.004	0.19 to 0.99

The analysis assumed equality of variance, confirmed by Levene's test ( $p > 0.5$ ) for the second comparisons, but not for the first one. It was found that the mean total BQ for healthcare providers significantly different from patients' and their family caregivers' mean score ( $p < 0.025$ ). This was consistent with the interpretation of the 95% CI of the difference, which did not contain zero for both comparisons. This means that patients (Mean = 2.58, SD = 0.5) and their family caregivers (Mean = 2.62, SD = 0.8) have higher concern levels than healthcare providers (Mean = 2.0, SD = 0.9)

To test the difference in the mean total BQ score between the patients and their family caregivers, paired t-test was used because they were two related samples (see table 8.17)

**Table 8.17 Dependent t-test results analysing the difference in mean total BQ score between two groups**

Variable	T	df	p	95% CI of difference
<b>Patients and Family caregivers</b>	-0.30	49	0.767	-0.30 to 0.23

Table 8.17 shows that there was no significant difference in the total BQ means score between the two groups, which was consistent with interpretation of the 95% CI, which contained 0. Therefore, patients and their family caregivers held the same levels of concern regarding pain management.

#### **8.6.4 Additional comments**

The participants were asked to write anything they considered as a barrier which was not covered by the BQ. Twelve patients, eight family caregivers and four nurses wrote additional comments, and they were analysed using thematic content analysis. Five areas (themes) were identified in patient responses. Table 8.18 presents themes and their related patient responses. Family caregiver response contained no new themes, and most of what they mentioned in the responses were covered by the BQ or were not related to pain management. For example one family caregiver wrote:

*It is very common that family members refused the treatment using chemotherapy or radiation and that because they think its drawbacks are more than the benefits.*

And other one wrote:

*We have low knowledge regarding the disease and it is related consequences so, we need a purposeful education through lectures and leaflets on the national level.*

It was decided only to take the BQ answers into consideration. Although the four nurses commented on additional barriers options, these were included in semi-structured interview transcripts and analysed within that context.



**Table 8.18 Patients' response on additional comment made according to their category**

Theme	Response
<b>God's will</b>	<p><i>Cancer is affliction from Allah (God) to us, we have to live with this disease and bear the pain and Allah will reward us in the afterlife. I do believe and many others that cancer pain only can be relieved by Allah mercy but not by these pain killers that destroy the human body.</i></p> <p><i>... but we believe that all bad or good things are a gift from Allah and we should be happy for the good gifts and be patient when deal with the bad things, in all cases we should thank Allah</i></p> <p><i>The medication might be the only thing that can relieve the pain, but we only can complain our pain to Allah the only one who can remove it from our bodies and sometimes we should rely on him not medications that contaminate our body and spirit, personally, I preferred to suffer pain to gain the reward from Allah and his forgiveness.</i></p> <p><i>Allah rewards the steadfast not losers, I have refused narcotics for many times and hop that Allah will reward me and will forgive me in the next life. I endure pain for the good sake; it is worship.</i></p> <p><i>... And Allah will change our sins to rewards and avoid us the hell.</i></p> <p><i>I feel shame to take the narcotics from Allah. Allah will reward us for each pain we felt in this life and will overcome ours sins, I only need his forgiveness.</i></p>
<b>Psychological pain</b>	<p><i>... more concern should be given to the patient psychological status which is the most important thing for cancer patient. Having the cancer is the big problem by its own and the psychological pain is the worst, I ask Allah to alleviate all cancer patient pain.</i></p> <p><i>I believe the psychological aspect is the most important and this should be given attention by doctors and nurses, they should work to make the patient feel that he is controlling his disease so he can enjoy his last days.</i></p> <p><i>Cancer make me feel pain in my sprit which is greater and worst than physical pain, having cancer mean slow death and you should live with this fact for long or short time depend on how much you are lucky</i></p> <p><i>Physicians should improve patients' sprit because it is equal to the drug treatment with narcotics and physicians should lie to patient, though it is not acceptable but really it is a big relief to us</i></p>
<b>Physical environment</b>	<p><i>..., sometime smell of the hospital causes pain.</i></p> <p><i>The smell of hospital, bad ventilation, and being in the hospital make me feel pain compared to out of the hospital (we feel cured by 80%) therefore, health care providers should take this in consideration</i></p>

<p><b>Harmful effects of pain medication</b></p>	<p><i>I hate these medications, I have heard that many patients were given such medications and then slept; they had brain bleeding while sleeping. Physicians and nurses thought that patient was sleeping but actually he was dead. I do not want to sleep for ever, so I prefer pain to keep me awake</i></p> <p><i>I might become addict and that it is prohibited by my religion</i></p>
<p><b>Need for non-pharmacological intervention</b></p>	<p><i>I think that narcotics can relieve part of cancer pain, but the major part can be relieved by reading Quran, prayer and patient instead of medications.</i></p>

## **8.7 Factors contributing to inadequate cancer pain management**

Analysing nurses' interview texts, observations, and field notes identified many factors that may result in ineffective cancer pain management in the unit, including the following:

### **8.7.1 Belief in God's Will**

One of the main barriers to adequate cancer pain treatment was belief that taking pain medications was against the Will of God. One of the basic Islamic principles is to submit to the Will of God. Therefore, the patients endure pain for the sake of God. One example of this occurred during the interview with the unit manager:

*I knew a patient with colon cancer (stage IV) and he was in severe pain and terminally ill, but he refused the medications despite the severe pain. When we asked him why, he said Allah will reward me by reducing my sin and give me heaven. My pain is from Allah and he is the only one able to diminish it not anyone else. I will endure it for the Allah sake. HN Unit Manger*

Other nurses within the unit also identified the same case, for example N09 said:

*Some religious people refused the medications, because they believe that tolerating pain will be rewarded in the next life. They argue that pain is a test from Allah and they can pass by tolerating and not complaining of pain as the company of Prophet Muhammad did. N09 Registered Nurses*

N12 also confirmed:

*Unexpectedly patient doesn't want pain medications (narcotics) because this might violate his religious beliefs. N12 Registered Nurses*

Nurses reported that for many patients enduring pain was perceived as a source of God's reward in the afterlife; to be rewarded one must tolerate pain, as observed by nurses:

*Did you know that also patient sometimes refuse the pain medication because they believe it is against the religious rules?*

*Yes it is real, there is misunderstanding to Islamic rules and they want to suffer to get the heaven. N06 Registered Nurse*

*Also I have seen patients refuse the drugs because of religious beliefs. Someone said 'I am not taking the pain because I want the reward of God'. They feel it is normal to have pain and they tolerate it. N01 Charge Nurses*

Many nurses deemed this belief to be a result of misunderstanding Islamic rules, and confusing narcotics and street drugs. Due to the identification of this issue, two Islamic scholars were interviewed to identify the position that they would take in these cases. It was found that Islam allows the use of narcotics for medical purposes, and does not require followers to suffer when treatment is available treatment. On the contrary, Islam deems it a sin to forego treatment if the treatment is available and accessible. One Islamic scholar, when asked about the Islamic ruling on using narcotics for pain treatment, said:

*The basic principle is that the use of narcotic is prohibited by Islam rules, with the exception of medical purpose. Islam has recognized two uses for narcotics; the medical use under the medical professional supervision and the use for pleasure or escaping from real life. Regarding the medical use, Islam aims to preserve human lives, body and mind, thus Islam allows the use of narcotics to save human lives. For example, in heart surgery and other surgeries and in treating pain from chronic diseases. And patients are not required to endure intolerable pain. IS1, Representative of Ministry of Islamic Affairs*

The other scholar confirmed the prior opinion, saying:

*Yes we have seen through the history of Islam, people who combined the Prophet Mohammad and they chose to tolerate pain for the sake of Allah, but we should not take this as way of life because people abilities to tolerate pain are not the same and Allah allows us to seek treatment not killing ourselves. Those people are rare cases and should not be taken as role model ... IS2 scholar and member of Islamic Action Front Party*

### **8.7.2 Doctor verses nurse**

There was a hidden tension between healthcare providers, in particular between nurses and physicians. This tension was found to have an impact on the quality and quantity of cancer pain treatment. This tension took two forms, that different status

between nurses and doctors, and the general assumption that physicians are more powerful and important.

Both physicians and nurses tried to assert their superiority. For example the unit manager said:

*I might assess the patient and end up with pain score of 9 out of 10, and then I should call the physician, but he might assess again and say I will give him paracetamol. He is the superior and I should obey his order. What is the point of bothering ourselves with these things? HN Unit Manger*

According to hospital norms and rules, physicians take a higher position, which may put nurses in a defensive position all the time. Physicians may utilise hospital rules in a negative way to assert their superiority. This may negatively affect the total care patient receive in general, and in cancer pain treatment in particular. For example, physicians may delay prescribing pain medication just because the nurse asked them to write a prescription, or if nurses suggest a type of pain medication to be prescribed, physicians usually prescribe none or lower doses. Therefore, delay in medication dose is common, and low, inadequate pain medications are normal. Nurses in the interview reported that physicians may oppose nurses' suggestions without considering patients' pain.

*We as nurse do not have knowledge, authority and respect. We try to be helpful but at the end the doctor has the pain medication in his pen. Sometime we act and argue with the physicians to give the patient the adequate dose; it does not work all the time. N08 Registered Nurse*

*N5: I think morphine would be better for such pain score. I (Researcher) saw that RD face scowl and say why do you think that? N5: This is what books said not me and you can check that. RD: Okay, let try this and then we can give him morphine. Observation notes.*

The belief that physicians are very knowledgeable is reflected in lay people's appreciation of physicians because of their knowledge and this may enhanced the clash between the two professions. This may be increased if the physician is over confident and displays superiority. This may result in physicians ignoring nurses' suggestions and challenging them by prescribing other medicines (or nothing). Nurses in the unit reported the need for policy that clarifies the roles. They

expressed the need for a policy that enabled them to intervene and empowered their role as patient advocates:

*Sometimes physician do not prescribed pain medication just because nurses asked him to write a specific drug. I believe that nurse have very limited role in pain management in hospital. We are receptive to doctor orders only. If we argue with them, they will say: I am the doctor not you. N04 Charge Nurse*

*Let suppose we have a policy that says pain score of seven should be treated with narcotics, in this case I can argue physician if he did something against the policy and the issue no longer personal. N11 Registered Nurse*

The clashes between healthcare workers were considered to have negatively impacted the total pain management in the unit.

### **8.7.3 Institutional characteristics**

Participants' interviews and observation revealed a number of institution-related characteristics that might also negatively impact upon cancer pain management. Four main issues attributed to the institution were found, including difficult access to pain medication, low priority to cancer pain management, absence of pain policy, and the hospital was interested in building reputation rather the content of the provided services:

First, access to pain medications was difficult and complicated for healthcare providers, patients and their family caregivers. The process to get pain medication and narcotics in particular was long and bureaucratic. It can take from 15 to 45 minutes until patients receive pain medicine. A prescription is required for each single dose of narcotic, although it was prescribed regularly. The prescription needs to be signed by two nurses, a physician and the pharmacist. Another form has to be filled by nurses in the case of narcotics dispensed from the unit cabinet. Therefore, nurses may tend to avoid giving narcotics, as N8 said:

*Nurses and doctors feel lazy to give pain killers, because it needs them to follow some procedure that they felt it is overwhelming so the delay the required dose. N08 Registered Nurse*

There is an even more complex and longer process for patients or family caregivers who want to take medication at home after discharge. They are allowed to carry a dose that is enough only for three days. An identification card and witnesses are required at the time of dispensing, as per national regulations to control narcotics

abuse. Both nurses and family caregivers complained of the strictness of regulations. For example, a family caregiver said:

*There is a very complex procedure that I should follow to get narcotics. I have to prove that patient is my first degree relative, and then sign pledge to not misuse the medication. FC1 Family Caregiver*

Two nurses also confirmed this:

*We have a complicated procedure that we should go through until the patient got the pain killers; sometimes it takes 30 minutes or longer until the drug given to the patient. N12 Registered Nurse*

*We should first reduce the steps that should be followed before administering the drug dose. Currently, this process might take 30 minutes or longer I think this should be reduced to less than 5 minutes. N10 Registered Nurse*

In addition, pain medications, and narcotics in particular, were not available all the time in the hospital pharmacy stores:

*Frequently, patient faced problem of drugs unavailability for long time, we can say that pain medications are not always available in hospital pharmacy and narcotics are governed by strict rules, physician might feel threaten if he wrote many prescriptions. N10 Registered Nurse*

*... and some medications might be not available. N04 Charge Nurse*

Therefore, patients taking narcotics for example may be given NSAIDs instead of strong opioids. It was found that physicians tended to avoid prescribing narcotics in high doses or frequently, because they feared legal liability.

*Some physicians do not write the narcotics frequently because of legal liability. N01 Charge Nurse*

*The current regulations imposed a very complex and difficult procedure to get the prescribed narcotics and with limited dose allowed to be taken home. N04 Charge Nurse*

Secondly, cancer pain and its treatments were found to be given a low priority by administrative staff (CNO, UM). This creates a culture that devalues cancer pain and ignores its presence. As a result, the hospital lacked policies, treatment

guidelines, and awareness related to cancer pain, whereas these are available for other conditions such as decubitus (bed) ulcers. This leads to a state wherein pain is either not treated or under-treated, as can be seen in the following sample of nurses' quotes:

*Believe me the nurse and doctors do not take the pain seriously and consider it as something unnecessary or additional. Here in the unit they focus on the disease itself and consider pain is unavoidable, patient should tolerate it finally. N09 Registered Nurse*

*Prescribing the pain medication should be based on the best available guidelines not on the healthcare team mood and preference. N11 Registered Nurse*

*Physicians focus on treating the disease itself and less or no attention is being given to pain. They frequently perceived pain treatment as unnecessary option. N11 Registered Nurse*

*The problem that is the carelessness about patient pain, hospital administration always talking about pain relieve, sadly without action. N01 Charge Nurse*

Thirdly, nurses in the interviews acknowledged the absence of policies that control the process of pain management and outlined healthcare providers' responsibilities and liability. The unit manager spoke it clearly when he said:

*The hospital administration should establish a policy that explains the role of nurses and physicians and, of course, a protocol for pain management should be included within the policy. For example, if they adopt that one that you told me about (WHO ladder) then all the healthcare provider will abide and patient will not be under the healthcare provider mercy and kindness. HN Unit Manger*

Another nurse confirmed that the patient is the loser in this process:

*Pain is treated randomly without having any systemic process or pain team. This makes it even worse and patient is the only loser in this equation. N12 Registered Nurse*

Nurses reported that there were many violations of patient rights, ethics and treatment principles. About nine nurses urged the need for a policy to enforce optimal pain management rather a recommendation only. They considered policy as



back up for them, and it empowered them to advocate for patients. Nurses believed that this might balance physician superiority. Doctors deemed that such a policy would be useful:

*Such guideline should be adopted by the hospital and thus they can enforce physician to act accordingly. So the personal attitudes and beliefs govern the total process now. RD Resident Doctor*

*And here N08 said with frustration:*

*I think here we are different from other parts of the world, pain medications are prescribed depending on the physicians' mood. Patient are suffering inadequate pain treatment, it is really messy and complicated here. I knew patient who was crying from severe pain, I swear we called the physician at night and he was very angry and ordered 500 mg paracetamol, then he turned his phone off. N08 Registered Nurse*

*Now everybody in this hospital appreciates the policy and obeys it. For example if the general director of the hospital ask me to do something against the policy , I will never do that and no one will blame me, and the same if you violated something in the policy so you will be questioned and may be punished depend on what you did. N11 Registered Nurses*

Finally, nurses believed that hospital administration is interested in creating and building the institution's reputation rather improving the quality of healthcare services. This may move the focus from the content of the service to the external appearance. For example, theoretically the unit has its own pain assessment tool that was rarely used. Pain policy was available but not implemented or disseminated. Nurses thought that all new changes were implemented to satisfy JCI inspectors, not for improving patient care, as implied in the following:

*Nobody cares; they have the JCI accreditation now so it is done. N09 Registered Nurse*

*Since we've got the JCI, nobody use the tool and if used it no one ask about it. N10 Registered Nurse*

*Such tool needs time and training, we lack the time and the hospital provides no training except the orientation programme. HN Unit Manager*

## **8.7.4 Healthcare providers characteristics**

Interviews with participants highlighted two main characteristics that might adversely affect cancer pain management process:

### **8.7.4.1 Holding negative attitudes toward cancer and cancer pain**

Many of the nurses who work in the unit seemed to hold negative attitudes toward cancer and its treatment. Nurses also reported that physicians may have the same negative attitudes. Nurses acknowledged that this negative attitude may be because cancer is a progressive and aggressive disease that usually leads to patients' death. This resulted in more concentration on treating cancer itself and less care for symptoms management, including pain management. In addition, there was a tendency to view pain management as an accessory to, and not an essential part of cancer care. This may hinder patients from receiving the required treatment, as evident from unit nurses' observations:

*Healthcare workers consider cancer patient as hopeless cases and no need to pay more attention to their pain. Their pain can be treated by treating the cause which is the cancer. N04 Charge Nurse*

*We and other healthcare providers may have negative attitudes toward cancer pain and they do not show great interest in the whole issue. N06 Registered Nurse*

*Patients believe being in the hospital justifying the need for pain killers or any type of medication. Once patient received the first dose they started asking for another. So we try to reduce it by delaying the dose, using other drugs and sometimes prohibiting the patient from the dose. N01 Charge Nurse*

*Patients always seeks medication and attention, I can know when patient is really in pain, but I never believed patient claims, patients are rarely reliable. N06 Registered Nurse*

*Physicians focus on treating the disease itself and less or no attention is being given to pain. They frequently perceived pain treatment as unnecessary option. N06 Registered Nurse*

### **8.7.4.2 Lack of knowledge and training**

It was found that healthcare providers and nurses in particular, lacked the required knowledge to deliver adequate pain management. They lacked information

regarding pain definition, pathophysiology, assessment, and treatment. Most nurses expressed the need for education and training, since no education on pain management had been provided in the institution in the last five years, which explained their lack of information about pain management as an active process.

*Many doctors especially junior residents do not have the knowledge to prescribe pain medication, so they use the medical record to see what the patient has been given previously and then prescribe the same drug. N06 Registered Nurse*

*In many situations physicians are not able to discriminate between the patient inability to sleep (insomnia) and pain because they rarely assessed patient pain and find it enough to give some types of hypnotics' drugs. In addition, we all need teaching really; our knowledge is totally superficial. N06 Registered Nurse*

The lack of knowledge and training may explain the considerable number of non-evidence-based behaviours committed by nurses and physicians. For example, patients were given normal saline injections instead of narcotic dose, and regular doses of narcotics were delayed or reduced in administration time.

*Many physicians are reluctant to prescribe narcotics because pain policy required that narcotics drug orders to be renewed every 24 hours, so they feel lazy to do so. In general, I feel that patients are neglected. HN Unit Manger*

*Nurses frequently do not like to dispense narcotics because they need to refill the stock again and this needs them to go through procedure that they hate. The worst thing is also the mood of nurse govern process of drug administration, when the nurse do not like the patient he may procrastinate medicine dose for hours. Is this ethical, I do not think so, but this is the reality. N09 Registered Nurse*

*... neither physicians nor nurses assess the pain. It just their personal estimation and judgment, they gave medications without even seeing the patients. I have seen physician when he want to prescribe the medication, he just back the medical record and see what the other physicians have prescribed and then he wrote the same thing. N06 Registered Nurse*

*Also, we used to use normal saline injection instead of narcotic, I knew this is not ethical, but we do not want them get used to it. N12 Registered Nurse*

*The nurses delay reporting pain for two hours and then he called the physician. They gave him Tramal 100 mg i.v. Patient have received half of the written dose, just because the nurse believe that the patient is addict. N12 Registered Nurse*

### **8.7.5 Interference of surrounding community**

It was found that the social system surrounding patients has an effect on the type of pain management they receive. Jordanian community life is very close and interconnected. Families have a very active role in patient decisions. And as cancer is a chronic progressive disease, patients were frequently referred home for care, further entrenching family caregivers as the main decision makers for patients. This was found to have consequence which negatively impacted up on pain management. For example, the close-knit communities disseminate patients' private details quickly, reaching most patients' relatives. Once they know the patient is taking narcotics, the patient is at high risk of being ostracized. Investigations revealed that people have started to distinguish between people who are on drugs for medical reasons from street users, but this distinction remains unrecognized among villagers and people lacking in education.

*...person who is taking narcotics can be socially isolated. For example, if a man known to use narcotics, people may hesitate to propose to his daughters or sisters. N08 Registered Nurse*

*It is very sensitive issue in our very close society. Once people know that a person is taking narcotics they will isolate him. No mercy in this community. N12 Registered Nurse*

*... the family caregivers used to ask healthcare workers to not give the patient pain medication, because they do not want the patient to become addict. N06 Registered Nurse*

*Patients hesitate to ask for pain medication because of the fear of addiction and being stigmatised. N06 Registered Nurse*

### **8.7.6 Fear of addiction and misconceptions complex**

Most of interviewees associated prescribing and taking narcotics with addiction. It is a cultural fear that is prevalent among the wider community as well as healthcare

workers. This resulted in a state of narcotic phobia, whereby health professionals avoid prescribing narcotics, and patients avoid taking them, as stated by the HN:

*Well, pain and its treatment are difficult and complex issues for healthcare providers. I am working with all physicians here and I saw most of them hesitate to prescribe pain medications because they are afraid of patient addiction. HN Unit Manager*

Another nurse also said:

*.....patient and even family caregiver believe that narcotics use means addiction. And I do believe that, we shouldn't give patient much narcotics it is highly addictive as I knew. N02 Charge Nurse*

In the unit, narcotics are used as last choice medications, despite being recommended as the drug of choice for cancer pain. The general attitude in the hospital is to prescribe weak opioids, small doses and single doses. Healthcare providers collude in protecting patients from addiction. This attitude was seen in nurses' interviews:

*It is really complex and not easy here, I feel that all patients turn into addicts after two doses and start asking for narcotics only not other medication. So, I think nobody in hospital likes to prescribe or administer pain medication especially narcotics, we try to keep patients away from narcotics as much as we can. Sometimes we use placebo to distract patient, surprisingly it works and this show us that patient should not be trusted. N10 Registered Nurse*

*Oh, from my experience I can say that they (healthcare professional) want to protect patient from addiction. FC1 Family Caregiver*

*Most of us treat patient with the minimum opioid dose to protect patients from addiction. RD01 Resident Doctor*

Table 8.19 presents the most common misconceptions about pain and its treatment held by healthcare providers. These misconceptions have been seen to have negative effects on total pain management process in the unit.

**Table 8.19 Misconceptions and examples from nurses' responses**

	<b>Misconception</b>	<b>Response</b>
<b>1</b>	Regular pain medications cause addiction.	Physicians pretend that daily use of pain medication will result in addiction and these believe have been disseminated among all healthcare providers and patients as well. N08 Registered Nurses
<b>2</b>	Patient who asks for opioid dose is addict.	If the patient feels good after dose of drug and asks the healthcare team another same dose they start to suppose that patient is addict. In all cases and most of the time the healthcare workers believe that patients are lying when they tell about their pain. N09 Registered Nurses
<b>3</b>	Physiological indicators reliable in pain assessment.	We (nurses) do not believe patient pain report and we depend on own judgment that based on nurse mood and sometimes the physiological sings like high blood pressure and facial expression. N12 Registered Nurses
<b>4</b>	Reserve strong medication for later	Cancer patient need strong pain medications and for long time, but healthcare provider do not like that, they would prefer to reserve the strong medication as last choice, regular pain medications are not commonly used. HN Unit Manager

### **8.7.7 Devaluing patients pain report**

Nurses and physicians believe that patients may be lying or exaggerating when they report pain, as suggested by N10:

*Patients like pain medications. Rely on patients report for pain is risky practice from my opinion and many nurses agree with me.  
N10 Registered Nurse*

Additionally, nurses claimed to have the ability to distinguish patients with pain from others who pretended to have pain in order to get narcotics. They depended on clinical experience and physiological indicators of pain, such as high heart rate and blood pressure. Facial expression is highly appreciated, and patients who cry, moan, have a gloomy face, or are reticent and stay in their room tend to receive stronger medication and higher doses than patients who have pain but behave normally. This seems to be prevalent among nurses, and may affect their decision in administering narcotics:

*...patient should complain of pain and he should convince the nurse otherwise nobody will know about his pain. N06 Registered Nurse*

*We [nurses] do not believe patient pain report and we depend on our own judgment that based on nurse mood and sometimes the physiological signs like high blood pressure and facial expression. N12 Registered Nurse*

*... patients always complaining and if we listen to them we will give them all narcotic stock in one day. So we are balancing between what patients are asking and what they actually deserved. N11 Registered Nurses*

*When it comes to the pain we do not believe the patients. We believe in facial expression and physiological indicators rather than patient report. In our practice, patient with pain will express his pain, blood pressure and pulse rate can be good indicators. N08 Registered Nurses*

## **8.9 Summary**

The pre-implementation work was essential to understand the process of cancer pain management and increase the awareness of the need for change to the current practice of cancer pain management in the unit. This work highlights that pain was prevalent and severe among cancer patients. It was clear that nurses tend to not use the available pain assessment tool (the old tool), and pain treatment was not as it should be, leading to cancer patients suffering. Therefore, this result confirmed the need for implementing a new pain assessment tool in practice.

The pre-implementation recognized that many factors blocked optimal cancer pain management in Jordan that were related to patients, healthcare workers, family caregivers and the health institution (there were many structural/institutional disincentives to prescribing narcotics). The need for education session on cancer pain management was significant (as expressed by nurses). Thus, education sessions were provided for the nurses who worked in the oncology unit. The following chapter discusses the provision of the education course and the PMP evaluation working methods.

## **9. Chapter Nine: Nurses Education and Evaluation Work**



## **9.1 Introduction**

As it was found that the nurses in this study needed education on cancer pain management, education sessions were provided for unit nurses after the completion of the pre-implementation work. This chapter provides an overview of this education programme which was followed by an introduction of the Brief Pain Inventory (BPI) into practice. Education and BPI together comprised the pain monitoring programme (PMP). This chapter aims to give an overview of the evaluation work method, which was decided after the introduction of the PMP, in terms of data collection and follow-up procedures.

## **9.2 Education programme**

The education programme was provided to equip the nurses with a basic knowledge of cancer pain management and to familiarize them with the BPI, and provide a chance to try the tool themselves.

### **Course objectives**

By the end of the course nurses were expected to:

- a. Correctly demonstrate an understanding of pain as a multi-dimensional experience.
- b. Identify causative factors for cancer pain.
- c. Recognise the importance of pain assessment and management.
- d. Be informed about the barriers to optimal cancer pain management.
- e. Demonstrate competence in assessing cancer pain.
- f. Demonstrate competence in using the brief pain inventory.
- g. Comprehend the main available pharmacological and non-pharmacological interventions to treat pain.
- h. Understand the nursing role in cancer pain management.

### **Course content**

The course content was developed in consultation with supervisors, champions, and previous literature. The style of education in Jordan is usually didactic, and group work was also used. To satisfy the abovementioned objectives, nurses were provided with three teaching sessions, each of which was two hours long, on pain

assessment and management. The three sessions were given in one teaching day and covered the following topics:

A) Session one

- defining pain
- aetiology of pain in cancer
- prevalence of cancer pain
- importance of pain assessment

B) Session two

- myths and misconceptions about pain
- pain assessment
- how to use the brief pain inventory

C) Session three

- overview of pain management intervention
- nursing role in pain management
- barriers to cancer pain management

The first session gave an introduction about pain, including definitions and prevalence rates in cancer patients in the literature. Emphasis was placed on the importance of pain assessment as a prerequisite of effective pain management. Then, in the second session, more in-depth information was provided and discussed about myths of pain management and how to assess cancer pain effectively. At the end of the session, the nurses were instructed on how to use the BPI and they were given a chance to apply their understanding with colleagues in groups. In the final session the available pain treatment was presented and discussed (mainly pharmacological treatment mentioned in the literature). Patient-related, worker-related and family caregivers' barriers to cancer pain management were also addressed.

### **How it was conducted**

The teaching methods were eclectic and included Powerpoint presentation lectures and group discussion (both habitually used in Jordan as teaching methods) of case studies of commonly faced situations in pain management. English was used in presenting the lectures, but the discussion was conducted in both English and

Arabic (all participants were bilingual). All nurses and physicians in the unit were invited to attend the course, but only nurses were in attendance. The course was offered at three different times over a week to allow all 12 nurses to attend. However, the UM and one nurse were unable to attend (due to other commitments). During the course, coffee and lunch breaks were provided. As per discussion with the CNO, an additional day off was given to nurses who attended the course as compensation for their time. Nurses were given hard copies of all presentations and a copy of the BPI (see appendix 22).

The sessions were an opportunity for an open discussion about pain management. Three topics received extensive discussion: addiction, positive placebo effects and pain assessment procedures. At the end of the second teaching session, nurses were given the chance to use the BPI and were given feedback, followed by an open discussion about the tool and its use in daily practice. All questions about the tool were answered. These questions were mainly about small details in the tool, and its correct use. For example N04 nurses asked:

*Should we write patients' names by hand or put the available sticker (provided by hospital)?*

It was agreed to place the hospital sticker on top of the page. Another concern was the section in which the completed BPI is recorded. The paper medical record is divided into parts, designated: previous admissions, doctors' notes, and lab tests, interdisciplinary notes (where nurses, doctors, social workers can follow patients' progress and document their interventions) and finally the nursing section. Nurses suggested placing the BPI in the interdisciplinary section to be seen by professionals from all fields. Nurses were provided with a protocol for the use of this tool.

#### **Protocol for tool use:**

To facilitate easy use of the new pain assessment tool, some guidance was provided for nurses. This was important to ensure a smooth transition to the new tool. It consisted of the following steps:

- 1- The use of the pain assessment tool (BPI) will be twice a day (once per shift).
- 2- The exact time to use the tool is with the morning round of vital signs (10 am) and with the evening round (10 pm).

- 3- In case of a patient having been given pain medication, re-assessment should be conducted every 15 minutes until pain is relieved, as expressed by the patient (re-assessment part).
- 4- The nurse should ask patients about pain rather than waiting for them to report pain (nurses should act rather than react).
- 5- Determine the suitable pain medication type to administer according to pain severity and the WHO analgesic ladder.
- 6- Nurses should maintain patients' right to be pain-free during the hospitalization period and thereafter.

This protocol was followed during the early stage of implementation and it was amended as required in the subsequent follow-up period. After launching the use of the BPI, four short educational reminders of the protocol, basic assessment steps and the WHO ladder component were given. These sessions were provided in the education room in the unit between shifts for 15 minutes. Some minor issues were found and resolved. For example, it was the general consensus to not complete the medication section in the BPI, because patients' medication information could be found in the medication sheet. Also, as the BPI was printed out on two pages, nurses suggested doing it on one page instead. They thought that this would encourage nurses to complete it, because then it would not seem as tedious. All the BPIs were printed out using one page thereafter. The researcher subsequently withdrew from the context and started the evaluation.

The pre-implementation work has informed the education course content in term of the main point to address and to focus on. This work highlighted that nurses and patients believe that opioids are addictive and they should not be used frequently in cancer pain management. Thus, this was addressed and discussed in detail and the researcher provided nurses with reference which clarified the fact that addiction is unlikely when opioids are used for cancer pain. In addition, myths and misconceptions about cancer pain also were presented. For example, some patients and healthcare providers believed that taking pain medications would be an act against the God`s Will and Islamic instructions. Thus, two Islamic scholars were interviewed and their opinions which clarify this issue were presented to nurses in the course. The researcher showed them that `state of the art' practice in pain management is to believe patients `statements on pain.

It was found that hospital adopted top down (autocratic) management style. Therefore, it was thought that involving the nurses in the education may enhance their feeling of involvement in the education process. For example nurses chose the right time for the course and most of its contents. In addition, the open discussion was used to give the nurse chance to express their thoughts about the presented information rather than being a passive audience (e.g. in a classical lectures). Finally, the pre-implementation work identified the need for a protocol to instruct nurses how and when to use the tool (most nurses complained that the old tool was given to them without any guideline or instructions on its use). Hence, the researcher developed a protocol that was presented to nurses and then it was revised as study progressed according to the comments of nurses.

### **9.3 Evaluation**

The PMP was evaluated twice, at one and three months after its introduction into practice. Since there were no strategies available in the hospital system that could enable the researcher to evaluate the outcomes of programme implementation, he constructed a group of indicators that were recorded before and after implementation. The PMP was evaluated by calculating the Pain Management Index (PMI) scores, and determining the percentage of tool use. In addition, during the field work, another outcome of interest was identified and measured; this was the nurses' pain reporting percentage, which was measured using the medical charts audit. Hence, this evaluation stage was conducted to:

- To evaluate how the use of a PMP affected the pain management process in the oncology unit.
- To determine if the use of a pain assessment tool was maintained over time.
- To explore nurses' experience of using the BPI in daily practice to assess cancer pain.

### **9.4 Data collection techniques**

In the post-implementation phase, nurses were interviewed and medical charts were audited (see table 9.1).

**Table 9.1 Participants' role in the evaluation work**

<b>Data source</b>	<b>First follow-up (Duration: 3 weeks)</b>	<b>Second follow-up (Duration: 3 weeks)</b>
<b>Nurses</b>	They (N=11) were asked to describe their experience on the use of pain assessment tool.	--
<b>Physicians</b>	--	--
<b>Patients</b>	--	--
<b>Family caregivers</b>	--	--
<b>Medical records</b>	Prescribed pain medications, pain scores and percentage of BPI use was extracted (N=40)	Prescribed pain medications, pain scores and percentage of the BPI use was extracted (N=40)

### 9.4.1 Interviews

During the follow-up period informal discussions were conducted with nurses in the unit. During these discussions nurses working in the unit, excluding the UM (since he did not use the BPI), were asked about the experience of BPI use (see table 9.2). This was in the form of a brief interview that took approximately 5 to 10 minutes. Only one nurse could not participate due to sick leave (a total of 11 nurses were interviewed). During these short interviews, the researcher took notes (with no voice recording) and wrote the content after the completion of the interview. The notes were written in Arabic (since the nurses talked in Arabic), then translated into English and entered into Microsoft Word 2003. The interviews were conducted in the hospital canteen after arrangement with nurses (either in the morning after night shift or in the afternoon after the day shift).

**Table 9.2 Interview questions**

<b><u>Post-implementation interview</u></b>
<p><b>Nurse code:</b> -----</p> <p>1- What is best aspect of using the BPI?</p> <p>2- What is worst aspect of using the BPI?</p> <p>3- What are your suggestions to enhance the tool usability?</p>

### 9.4.2 Medical files

During the two follow-ups, 80 medical files were audited (40 for each follow-up). For medical charts, the researcher visited the unit once a week over three weeks in each follow-up. Then all the available medical charts were checked for the presence

of BPI, type of pain treatment, pain re-assessment and nurses' notes. This information was extracted using the data extraction sheet (see appendix 17).

### **9.4.3 Observation**

The researcher observed nurses practice in regard to pain assessment and management. For each follow-up the researcher visited the unit three times and spent one day from 7 am to 7 pm. In the two follow-ups, the observation occurred as three hourly sessions and two days for each follow-up (totally four days; two from 8 am to 11 am and two days from 3 pm to 6 pm). Therefore, the total observation time for each follow-up was six hours. The researcher wrote (in English) observation notes as field notes (no formal or structured observation form was used) (see appendix 16).

### **9.5 First follow-up**

One month after the introduction of the BPI, the researcher returned to the oncology unit to evaluate its use. The researcher maintained the contact with champions through phone after the withdrawal from the unit. The aim was to check all medical charts available in the unit on the day of observation. It was found that nurses were using the tool and most of the patients had the tool in their charts. However, it was also discovered that the re-assessment was either conducted improperly or not conducted at all. Thus, the re-assessment interval was increased from 15 minutes to 1.5 hours because the nurses had complained about the numerous re-assessments required by the protocol. In addition, many nurses suggested reducing the frequency of the tool use from twice a day to once a day. They deemed asking patients to answer several questions twice a day to be impractical. They also added that asking patients about pain once is enough, and by default patients with pain will be followed-up until they expresses no pain. Furthermore, nurses in the unit thought that conducting the pain assessment once rather than twice was more practical and feasible to accomplish in their busy unit.

Based on the evidence above, three brief education sessions on pain assessment and re-assessment were conducted. These sessions were intended to remind nurses of the most important steps of pain re-assessment and it was conducted in the education room within the unit premises. The protocol was subsequently amended, and it was arranged to use the BPI once per day.

### **9.6 Second follow-up**

This follow-up was conducted three months after starting the use of the BPI. The researcher was refused access during this time, despite having received ethical

approval and permission to conduct the work in the unit. The reason for the refusal, as stated by the nurses' administration, was that the hospital was to be inspected by the JCI surveyors, and the hospital administration had decided that the research project should not be held during that period. Therefore, nursing administration asked the researcher to renew the ethical approval because the hospital had changed the procedure for ethical approval. The researcher was required to go through a new process. This was questioned, since the original approval carried no time restriction, and was valid for one year according to the approval document. The researcher discussed this with the UM and CNO assistants, but they refused to compromise. The researcher met with the CNO and after this meeting the researcher was given an exception to complete the project within one month (before the next JCI inspection) and this result in cancelling the third and the fourth follow-up (it was originally planned to evaluate the tool after one, three, six months and one year). This resulted in shortening the follow-up to only three months follow-up. The project was near completion and fortunately this compromise meant that data collection was completed for the second follow up.

After regaining access, the researcher investigated the tool use and it was found that the tool had been slightly modified. The hospital logo was stamped on the top of the tool. The name of the tool had been removed and was now known as the 'hospital pain assessment sheet'. The researcher's recommendations on the policy had been implemented and the policy was activated starting August 2010. The tool BPI or 'the pain sheet' (as it is now called) has been assimilated into the hospital routine, each patient's file contains it and the ward clerk places it daily in the medical charts. Nurses do the pain assessment at 10 am and follow-up patients with pain as appropriate. In other words, the researcher's method was adopted, modified and presented as an innovation of the hospital staff and this might be interpreted as a successful outcome of this study.

## **9.7 Summary**

The education course provided nurses with basic information about cancer pain management that can be used in daily practice. A longer education course would be preferable, but limited resources and time did not allow such a course. Teaching was used to enhance the optimal pain assessment through the use of BPI into daily nurses' practice. Although the approval to conduct the study was granted, the researcher temporarily lost access to the study setting and this resulted in a shorter evaluation period than was intended (at least six months or one year). The results of evaluation work are presented in the next chapter.



## **10. Chapter Ten: Results of the Evaluation Work**

## 10.1 Introduction

This chapter presents the results of the Pain Monitoring Programme (PMP) evaluation work. It starts with a description of patients' characteristics, pain prevalence and severity. Then it provides an account of the possible effects of PMP on pain reporting, tool use and adequacy of pain management in the unit. In addition, this chapter presents nurses' experience on the use of the BPI in daily practice.

## 10.2 Patients' characteristics

In the post-implementation stage (two follow-ups), 80 medical charts pertaining to cancer patients were checked, 40 of which were male and the mean age was 41.6 years (SD 15.5); see table 10.1 for other characteristics.

**Table 10.1 Patients' characteristics**

Characteristic	Frequency	Percentage
<b>Having chronic diseases?</b>		
Yes	21	26.2
No	59	73.8
<b>Type of cancer:</b>		
Leukaemias and lymphomas	33	41.2
Solid tumours	47	58.8
<b>Cancer stage:</b>		
Early stages	13	16.3
Advance stages	34	42.5
Missing	33	41.3
<b>Type of cancer treatment:</b>		
Chemotherapy	51	63.8
Combination	29	36.2

For all of the patients in the study (including patients in the baseline data), there was slightly higher percentage of female (51.5%, n=67) than male (48.5%, n=63) participants. The mean age was 41.3 years (SD 15.4), ranging from 18 to 78 years. Since the comparisons between the baseline and the post-implementation conditions were essential, comparison of patients' characteristics pre- and post-implementation was also necessary to investigate whether the pre-implementation patients group was similar to the post-implementation group.

### Pre- and post-implementation patient groups

Comparisons were carried out between pain management aspects before and after the implementation of the PMP. These comparisons included comparing the adequacy of pain management as measured by the Pain Management index (PMI), the percentage of pain assessment tool use and pain reporting before and after the introduction of the PMP into practice. This was in accordance with the main study

aim, which was to examine the impact of the PMP on the adequacy of pain management in the oncology unit. Therefore, comparisons between two patients groups (pre- and post-implementation) were carried out in regard to gender, age, cancer type, stage, treatment, and having another chronic disease or not. The chi-squared test was conducted, and table 10.2 presents the results.

The results show that there were no significant differences between the pre- and post-implementation patient groups in regard to gender, age, having chronic disease, cancer type, and stage and type of cancer treatment. These results mean that these two groups were similar, which would support our interpretation of the results in the following section. This is because the results of comparisons between two groups in regard to selected outcomes can be enhanced if the two groups are similar (Field, 2009). In the context of this study, it helps to rule out the presence of some confounding variables that may invalidate the results when examining the impact of the implemented PMP on the adequacy of pain management.

**Table 10.2 Comparisons between patients in pre- and post-implementation**

<b>Variable</b>	<b>Chi<sup>2</sup></b>	<b>df</b>	<b>P</b>	<b>N</b>
<b>Gender :</b> <b>Male</b> <b>Female</b>	0.20	1	0.657	130
<b>Cancer type:</b> <b>Leukaemias and lymphomas</b> <b>Solid tumours</b>	0.68	1	0.408	130
<b>Cancer stage:</b> <b>Early</b> <b>Advanced</b>	3.38	1	0.066	83
<b>Cancer treatment:</b> <b>Chemotherapy alone</b> <b>Combination</b>	0.07	1	0.794	130
<b>Having chronic disease:</b> <b>Yes</b> <b>No</b>	1.18	1	0.277	130
<b>Age group:</b> <b>18 to 35 years</b> <b>36 to 55 years</b> <b>≥ 56 years</b>	1.05	2	0.794	130

### **10.3 Pain prevalence and severity**

In the two follow-ups, 80 medical charts belonging to cancer patients were checked for the occurrence of pain. Overall, it was found that 49 patients had pain (61. %) (25 in the first follow-up, and 24 in the second; see table 10.3). To investigate whether pain prevalence changed or not, pain prevalence was compared between the three main study stages (pre-implementation, first and second follow-up). Chi-

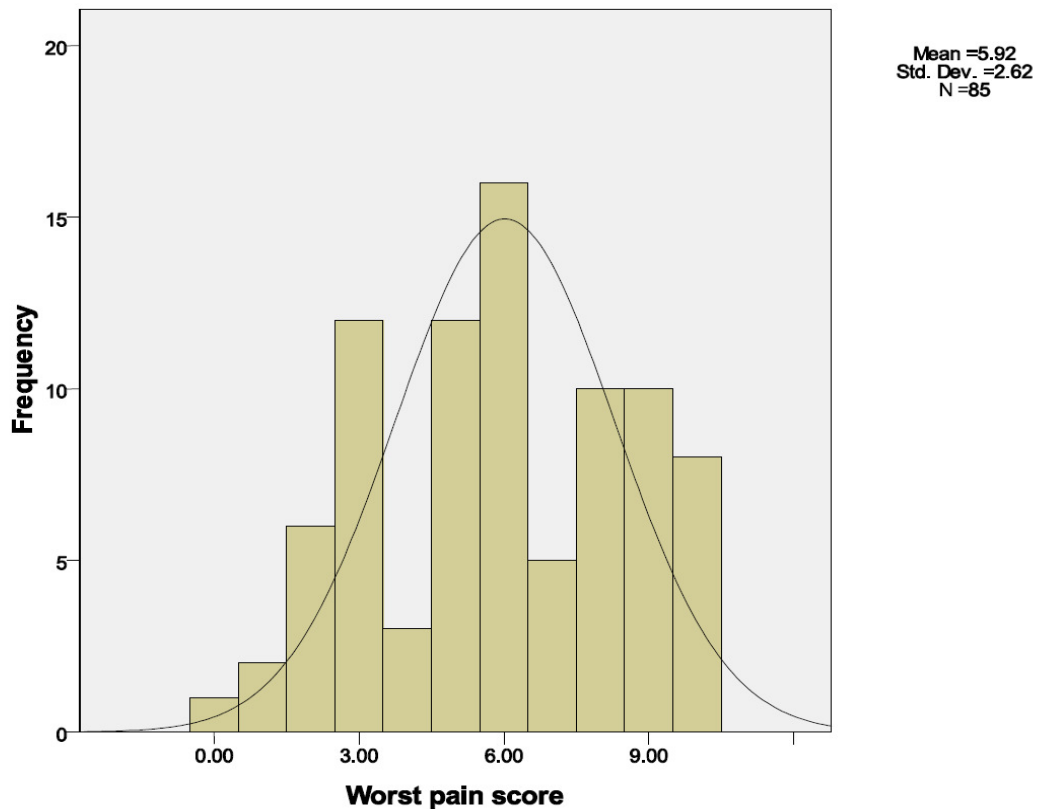
squared test show no significant difference in pain prevalence in the unit through the study stages ( $X^2=1.1.0$ ,  $df=2$ ,  $p=0.581$ ). In regard to pain severity, it was found that the mean worst pain score was high 5.6 (SD 2.6) in post-implementation (two follow-ups).

**Table 10.3 Pain prevalence through study stages**

Study Stage	Presence of pain	Frequency	Percent
<b>Pre-implementation</b>	No	15	30
	Yes	35	70
	<b>Total</b>	<b>50</b>	<b>100</b>
<b>First follow-up</b>	No	15	43
	Yes	25	57
	<b>Total</b>	<b>40</b>	<b>100</b>
<b>Second follow-up</b>	No	16	40
	Yes	24	60
	<b>Total</b>	<b>40</b>	<b>100</b>

For all patients who were included in the study (including patients from the pre-implementation stage), out of the total 130 patients, it was found that 84 patients (65%) had pain at the time of the survey. In regard to severity, the mean of worst pain scores in the last 24 hours was high at 5.9 (SD 2.6) out of 10 (maximum score), and it was not normally distributed. The Shapiro-Wilk test was significant ( $W= 0.95$ ,  $p < 0.003$ ) and Kurtosis was -0.93 and Skewness was -0.1. The worst pain score distribution is shown in figure 10.1. However, the median was 6 (interquartile range from 4 to 8).

**Figure 10.1 Distribution of worst pain score**



### **10.4 Pain reporting**

It was important to measure how often nurses reported pain. For this purpose the medical charts were checked and the percentage of the pain reported by nurses was calculated in the two follow-ups. For all medical charts that did not include anything pertaining to pain assessment (i.e. completed pain assessment tool, pain score in nursing note or physician’s note), the researcher conducted the pain assessment using BPI. These consisted of only two cases in the two follow-ups.

In pre-implementation stage, it was found that 38 (76%) patients experienced no pain, and only 12 had pain according to nurses’ reports. Nurses reported an increase in pain in the post-implementation phase. Of the 80 patients charts checked, nurses reported 47 (59%) patients were in pain, and 33 (41%) were not. These results show that nurses started to report more pain than before embarking upon the study (see figure 10.2).

**Figure 10.2 Nurses' pain reporting before and after the intervention**

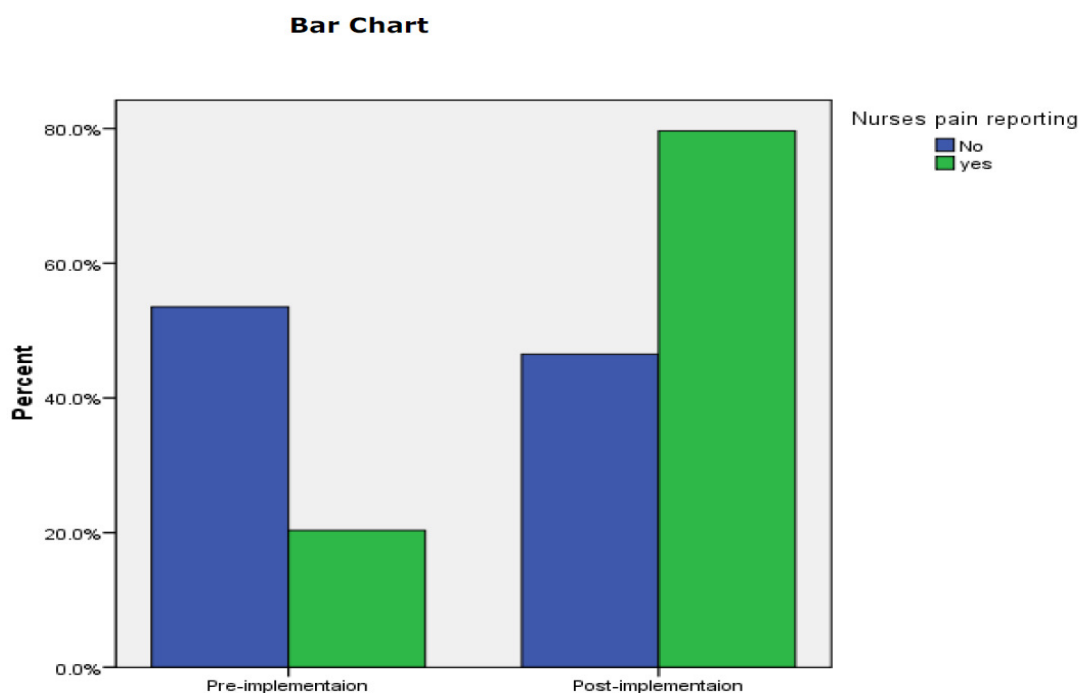


Figure 10.2 shows the considerable increase in patients reported with pain, which is most likely due to the education and use of pain assessment tool BPI. To examine whether the difference was significant or not, the Chi-square Test was conducted, finding a significant difference between pain reporting before and after the intervention ( $X^2=14.99$ ,  $df=1$ ,  $p < 0.001$ ). It can be concluded that the intervention was significantly associated with increased pain reporting.

It was observed that nurses initiated pain reporting, and the pain was assessed and documented. In addition, the content of nurses' pain reports to physicians was also improved. They provided longer and richer descriptions than before, including pain severity score, location, onset and some hints about how the pain interfered with patients' daily lives. Although this change may be small, it shows that slow and steady efforts when given time can improve the quality of the care given to patients.

*N12 reported to the nurse in charge that he assessed Mrs H's pain and found that she was experiencing pain with a score of eight out of ten and was not able to go the bathroom, her pain had started an hour before and in her upper body. Field note*

*N10 called the doctor to inform that Mr M.O is complaining of pain (3 out of 10) near the central line insertion port. He said the patient's pain was steady and increased when he moved his shoulder. Field Note*

## 10.5 Tool adoption and sustainability

The percentage of tool adoption was determined through a chart audit. It was found that from the 50 charts checked in the pre-implementation phase, the old pain assessment tool was used in 16 medical charts. However, after implementation and in the first follow-up, the BPI was found to be completed in 31 charts out of a total of 40 charts checked. In the second follow-up, the BPI was found to be completed in 32 of the charts checked (n= 40). Thus, after three months of implementation, the tool was found to be in use in about 79% of medical charts. This was a very good sustainability; unfortunately, because of the study time limit, the researcher was not able to evaluate tool sustainability for a longer time period (see figure 10.3).

**Figure 10.3 The use of pain assessment tool in daily practice**

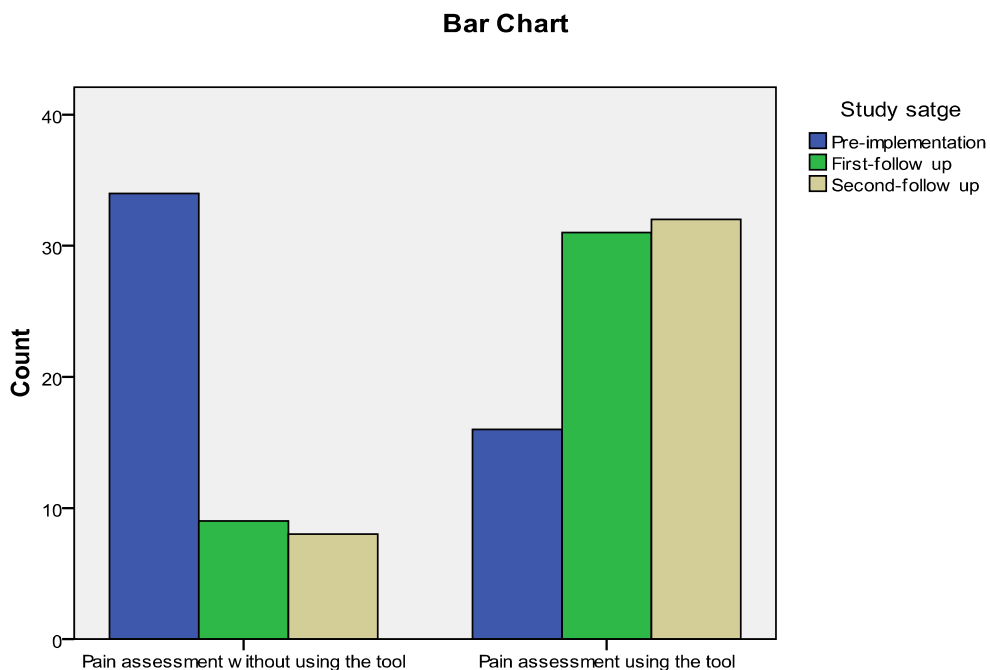


Figure 10.3 shows that the tool use increased markedly in the first follow-up following its introduction into practice, and the highest percentage of tool use was seen after 14 weeks (second follow-up). The Chi-square Test for trend was conducted, and it was found that there was a significant linear association between tool use and study stages ( $X^2 = 28.3$ ,  $df=2$ ,  $p < 0.001$ ). In other words, the improvement in tool use was associated with implementation of the PMP.

## 10.6 Adequacy of pain management

One of the main outcomes of interest for the PMP is the adequacy of cancer pain management. From observing the practice in the unit, it was found that the pain management improved slowly and in small amounts, but this may still be of clinical significance. The important change observed was that nurses started thinking positively about cancer patients and their need for pain relief. As shown in the following two examples:

**Situation 1:** *The doctor returned to station and said: 'I think he is seeking attention and missing his wife as well, anyway, please do ECG, Cardiac enzyme test and give him 50 mg Tramal I.V, and will see what tests will tell us.'* The patient was given the Tramal dose and no re-assessment was done. Field note

**Situation 2:** *The doctor's opinion was to advise the patient to stabilize the shoulder; there was no need for medication. N10 insisted that the patient deserved medication. The clinical pharmacist came and she supported the nurse's opinion and recommend Ibuprofen 400 x 3. Finally, this medication was prescribed and given. Field note*

This could be explained by the growth of nurses' knowledge and confidence regarding cancer pain management. Also, pain re-assessment and documentation seem to be improved. In both cases patients received pain medications for their complaints, although, still inadequately in one of the two cases.

### **Pain Management Index (PMI)**

The PMI was used as an indicator of adequacy of pain management in the oncology unit. The mean score of PMI was  $-0.69$  (SD 0.99) before embarking on the study. This figure was increased to  $0.00$  (SD 0.76) in the first follow-up, and then to  $0.04$  (SD 0.75) in the second (see figure 10.4). This means that pain treatment had improved since the implementation of the PMP. There was a significant difference in the mean PMI scores between the pre- and post-implementation patients groups ( $U=522.2$ ,  $P=0.001$ ). The distribution of PMI score among the three study stages was then compared using the Kurskal-Wallis test. The use of ANOVA was not possible because of violation of the normal distribution assumption, and the unequal sample size in the three groups which may result in a less robust test and invalid interpretations (Field, 2009). However, significant differences in mean PMI score were found between the three stages (Kurskal-Wallis  $T= 10.42$ ,  $df=2$ ,  $p=0.005$ ). To determine where the difference lay, the researcher conducted three



Mann-Whitney Tests post hoc. To avoid inflating the type one error, the Bonferroni correction was used, so all effects were reported at a 0.0167 level of significance. There were significant differences between the mean PMI scores in **pre-implementation** and **first follow-up** ( $U=272.5$ ,  $P=0.009$ ) and the **second follow-up** ( $U= 250.0$ ,  $P=0.006$ ). In both cases the PMI score was higher in the follow-up group, which meant that PMI was better in the follow-ups. There was no significant difference in mean PMI score between the first and second follow-ups ( $U=291.0$ ,  $P=0.847$ ). Overall, the results indicated the positive effect of using PMP on the nurses' daily practices.

**Figure 10.4 PMI scores by study stage**

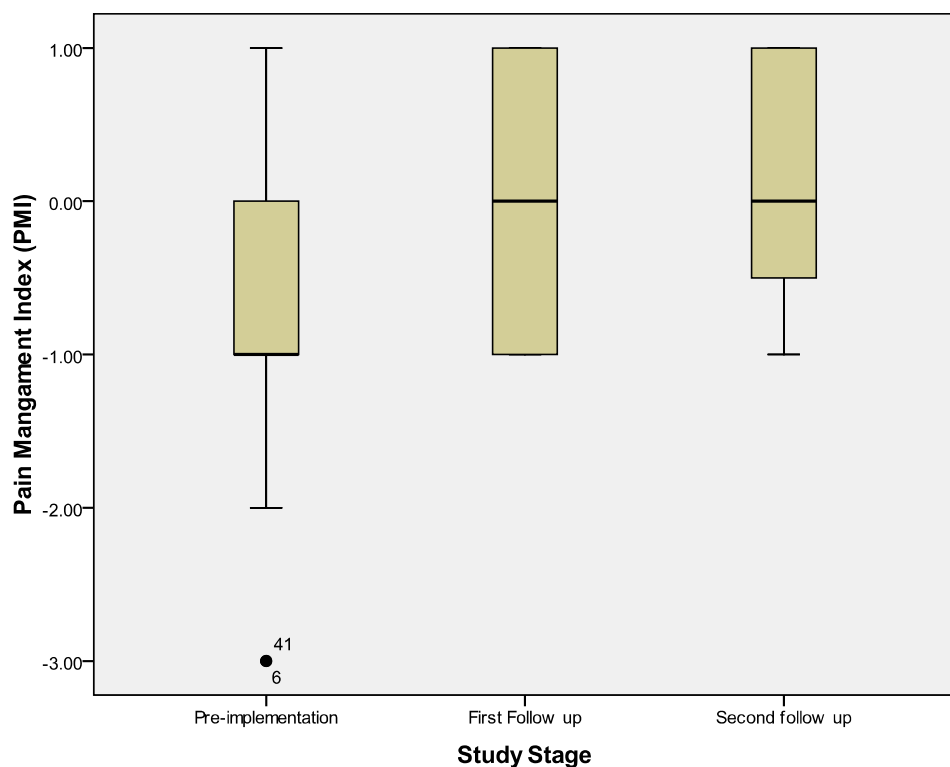


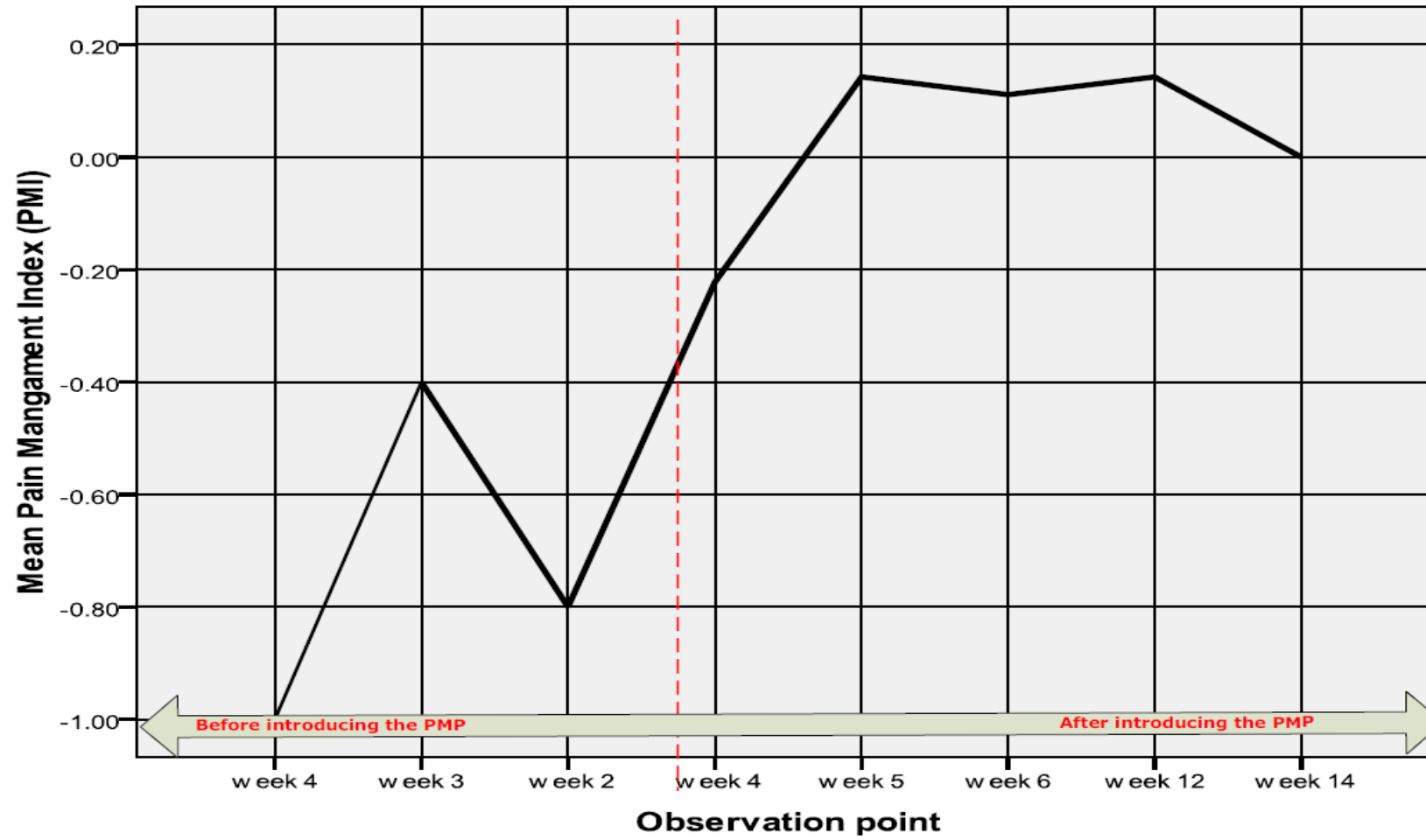
Figure 10.4 shows a boxplot for the PMI and study stage. Boxplots are a graphic demonstration that visualizes the differences between the three study groups in respect to their PMI score. The box in the middle represents the interquartile range (where half of the data lies). The vertical line across the box represents the median.

Since data was collected over eight different time points, the mean PMI scores during the course of the study were drawn (see figure 10.5). The figure suggests an immediate effect on PMI that can be seen after four weeks. The red dotted line represents the introduction of the PMP. The PMI was considerably increased after teaching and using the tool. Before using the tool, the PMI mean scores were negative. Then, after using the tool (red dotted line represents the date of the

introduction of PMP), the PMI started to increase, reaching its maximum after five weeks, and remaining above zero level (adequate pain treatment) for the rest of the period. Although the mean PMI scores fluctuated, an adequate status of pain management was indicated each time. This improvement in cancer pain treatment in the Oncology Unit can be associated with the implementation of PMP (BPI and education). This confirmed the positive impact of using the pain assessment tool in daily practice.

The presence of the researcher in the unit helped to rule out any co-factor that may have contributed to false positive results (positive effect on PMI). No education was given to physicians during that period. In addition, no changes (Apart from preparation for JCI inspection) took place in the unit concurrently with the study. For example, the documentation and file-keeping process continued as before. Furthermore, the immediate improvement in PMI after implementation suggested the positive change in PMI was most likely related to the use of intervention. Although the change was small, it provides evidence of improvement in pain management when pain assessment tool combined with education is employed. This has great clinical importance, since it indicates improvement in a highly complicated process which is essential to the care of cancer patients.

Figure 10.5 The impact of using tool on PMI



## 10.7 Nurses' experience of the BPI

One of the aims of PMP evaluation was to explore nurses' experience of using BPI. This was conducted in the first follow-up. Most of the interviewed nurses summarized their experience into three main themes:

- Immediate tool advantages
- Tool attributes
- Simplicity

### Immediate tool advantages

Nurses appreciated the BPI listing quick completion and ease of use as its virtues. They found the tool helpful in detecting pain among cancer patients. Most of them were surprised by how many patients had pain without complaining of pain. For example, first charge nurse said:

*We used to wait for the patient to call us for help, but the surprising thing is that many more patients were in pain than I ever expected. N01 Charge Nurse*

Other nurses were also surprised by the large number of patients that were not complaining of pain:

*I've notice an increase in pain reporting, and many patients reported mild to moderate pain. N10 Registered Nurse*

*I have seen that many of patients are found to be in pain after using the tool. N02 Charge Nurse*

*Using it regularly was a new practice for us and results show many patients to be in pain. N11 Registered Nurse*

For some nurses, BPI was a means to induce physicians to treat patients' pain, which was the optimal goal. They believed that the tool provided documented proof of patients' pain, and since it was written in the medical chart, physicians could not ignore it, as stated by N10.

*We enjoyed using the tool; we assess patient's pain and then just document it and inform the physician. And then they hurry to write medication, since they cannot ignore documented evidence. N10 Registered Nurse*

*I did not know that a considerable number of patients were in pain until I used the tool. The interesting thing is that physicians responded and started treating this pain; we can say most of pain above score of four has received some kind of pharmacological treatment N07 Registered Nurse.*

These two advantages may encourage nurses to use the tool, and thus improve the adoption rate.

### **Tool attributes**

Nurses were asked to list the best and bad things about using the BPI. Nurses' answers can be classified into positive and negative categories.

#### *Positively perceived features*

Most of the nurses found that BPI was easy to use and comprehend, for both nurses and patients. This led to an increased confidence in using the tool, and facilitated its dissemination amongst nurses and patients. Many nurses, when asked about the best thing about the tool, always began with its ease of use:

*BPI was easy to understand and use compared to our old tool, I think it is comprehensive and covers many aspects we used to ignore. N01 Charge Nurse*

*I used your tool many times and each time I use it, I love it. It is really easy and simple. N07 Registered Nurse*

*The tool was easy not that complex and needs a few minutes ...  
N07 Registered Nurse.*

In addition, unit nurses valued the multidimensionality of BPI, since they were used to employing a unidimensional tool that only asked about pain severity. One nurse learned that having the same pain score does not necessary mean the same experience:

*Good to use for pain screening and it evaluates not only the severity but also the interference which is very important, for example a score of four may limit the patient's ability to walk while another patient may walk and even have no limitation with a score as high as eight. N07 Registered Nurse*

Other nurse confirmed the importance of assessing two dimensions of pain rather one:

*BPI evaluates two dimensions of pain which is better than evaluating only one; we always evaluate the severity and ignore all other aspects N10 Registered Nurse*

Furthermore, almost all nurses in the unit appreciated the Body Map in the tool. They deemed the body map a convenient device for the location and description of a patient's pain. This improved communication between nurses and patients, and was indicated clearly in nurses' suggestions to improve the tool use as follows:

*The body map was very good and helpful; it required the patient only to spot the pain without the need to speak for a long time describing the location. N10 Registered Nurse*

*I too loved the body map that helps determine the exact pain location without the need for detailed description. N02 Charge Nurse*

*The body drawing is great aid for patient and nurses to exactly locate the pain site. N09 Registered Nurse*

Finally, patients were able to participate in their care by completing the tool, and this was appreciated by nurses. Nurses considered this an aid to reducing their workload. In addition, theoretically, it enabled patients to report their pain, and gave them a voice.

*In addition, it was good idea to involve patient in their care. Many patients were active and liked to complete it. N01 Charge Nurse*

*The idea of using such tool was good and involved patients in their care. N10 Registered Nurse*

*Many patients completed it and by doing so they took a part of our lovely job. N07 Registered Nurse*

*Also, I can give it to the patient, and many patients were able to complete the tool without difficulties and I believe this was good for nurses. It reduces our paper work and patients may like to assess their pain rather being assessed by another person. N12 Registered Nurse*

These above quotations indicated a change in nurses' perception of patients' pain reporting when compared to the pre-implementation phase.

### *Negatively perceived features*

Nurses also identified aspects of the tool that were unhelpful, and may impact negatively on their decision to use the tool. These aspects included the following:

First, many nurses commented on the similarity between the questions in the BPI. They argued that this confused patients, and it took them time to explain it. They suggested replacing the questions with one or two clearly stated questions:

*Some patients found it difficult to answer the very similar questions. N01 Charge Nurse*

*It is to some extent long and asking many similar questions which sometimes confused patients. N06 Registered Nurse*

*Patient gets confused by similar questions. Not all patients can complete it; it is not suitable for all patients, such as elderly and tired patients. N08 Registered Nurse*

Secondly, nurses reported that the BPI was a single use tool that could not be used multiple times, thus many copies of BPI accumulated in the medical charts. This made following patients' pain scores difficult, and sometimes a considerable number of BPI copies were lost. In addition, nurses complained that BPI did not contain a part dealing with pain re-assessment after medication administration. They suggested that the tool should be able to accommodate the re-assessment part, and it should be reasonable and logical. Many nurses complained about this issue as follows:

*Oh, the worst thing is that many papers accumulated in the medical record, and you know how the situation here is, many people use the medical record, many papers were lost and it is difficult to follow-up pain assessment scores. N01 Charge Nurse*

*Your tool was quite long and asks some questions that cannot logically be asked more than once a day. For example, asking about sleeping or interference in relationships. In addition, asking about the worst, average, and lowest pain in the last 24 hours is not practical because we use the tool two times a day and there is no 24 hour interval. N02 Charge Nurses*

*Its single use results in many papers; any proposed tool should be suitable to our work environment which is complex and busy. N06 Registered Nurses*

*The re-assessment was not possible using the same long questions, we need to ask about how the medication works and how much it relieved the pain. I found it funny and clumsy to ask about how the pain affected sleep or relations with others every half hour or even twice daily. N06 Registered Nurses*

*Then in the night shift the other nurse will ask about life enjoyment again; all cancer patients are depressed, how can they enjoy life? Some patient was laughing at me because of this question. N05 Registered Nurses*

Thirdly, nurses believed that the BPI might not be suitable for weak, tired and severely ill patients:

*Also it is quite long; although many patients can tolerate this number of questions, but in the same time weak, elderly, and terminally ill patients are burdened by this hassle. N09 Registered Nurse*

*And illiterate and elderly people can face problems in filling the tool .N011 Registered Nurse*

*So, elderly, tired and less educated patients will find it easier to answer two questions rather than more than ten. N10 Registered Nurse*

### **Simplicity**

The nurses urged the need for a simple tool to be implemented in daily practice. They wanted a tool suitable for the busy work environment, which would add no paper work, and would be able to give details about patients' pain. The BPI was able to meet some of nurses' criteria, but not all. They suggested that simplicity in pain assessment could be achieved by using lesser, shorter and more direct questions, using a paperless tool (for example a pocket card), and recording pain scores and full assessment on a pain flow sheet. Simplicity was the most interesting attribute mentioned, and an important predictor for tool uptake in the daily practice for nurses; they indicated the need for simplicity in many quotes:

*the first thing is to make it shorter, for example, we need to ask about the worst pain score now, how much the pain interferes with daily live activities, and keep a body map. N10 Registered Nurse*

*It would be a brilliant tool if you just include four questions that are, asking about pain severity, interference with general life*



*activity and sleeping, and do not forget the body map, the tool works better with it. N07 Registered Nurse*

*I do suggest you to think in a way that makes less use of many papers and to make re-assessment feasible and sensible; all nurses hate paper work, so your tool might end up on the shelf if you do not make it easier. N06 Registered Nurse*

*You have to cut it down and introduce it in card form and not as paper work; you need to assess pain severity, sleep disturbance and pain location so keep that map. N08 Registered Nurse*

## **10.8 Summary**

Evaluation phase results showed that patient's pain was more likely to be acknowledged in the follow-up period. A clinically significant increment in the PMI mean scores after the implementation of BPI was noticed. Two of the three pain management indicators used, including the percentage of the tool use and adequacy of pain treatment, seem to be suitable for evaluating the effects of the PMP on the quantity and quality of cancer pain management. Although the BPI was easy to use and provided good information about pain, a number of changes were required to make it a clinically useful tool. The results of the entire study are discussed in the next chapter.

## **11. Chapter Eleven: Discussion, Conclusions and Recommendations**

## 11.1 Introduction

This study was intended to implement a change, namely a Pain Monitoring Programme (PMP) into the daily practice of Jordanian nurses in one oncology unit. In addition, cancer pain management was explored in terms of barriers to optimal pain management, and outcomes of introducing a PMP on the total pain management in the unit. A single-embedded case study design was used.

This chapter discusses the main findings of the case study. It begins by discussing the PARIHS model's advantages and disadvantages with regard to its use in Arabic-Islamic culture. Furthermore, it provides an account of the lessons learned from the implementation process and the factors leading to the inadequacy of pain management in the unit. In addition, it discusses the main PMP outcomes in terms of the feasibility of using the Brief Pain Inventory (BPI) to assess pain in daily practice, pain prevalence, and measurement of PMP outcomes. Moreover, the study limitations and strengths are explained. Finally, conclusions, and recommendations for policy makers, clinicians, and researchers are presented.

Three theoretical propositions were written prior embarking the main study which included the following:

- The use of the PARIHS model and change theory was expected to guide the implementation process and the interpretation of results.
- An implementation process that closes the gap between managers and clinical staff would have a better chance of success in terms of adoption of the pain assessment tool.
- The use of a PMP in daily nursing practice would have a positive impact on the pain management process.

These propositions were revisited and discussed within this chapter. The first one was discussed by examining the transcultural use of the PARIHS model and its utility for this study. Then the second proposition informed the discussion of the lessons learnt from this implementation process in the Arabic Islamic-culture. Thus, it provides an overview of the possible determinants of successful research utilization in this new culture that little is known about. Finally the last one was discussed in terms of the possible impacts of the PMP on pain reporting, tool use and adequacy of pain management which may give hints about the nature of the effects that would be caused by the PMP implementation.

## **11.2 Transcultural use of PARIHS model**

This section discusses the aspects of the use of a theoretical framework in the implementation process, which was conducted within the context of Arabic-Islamic culture. Two models were used in this study: the PARIHS model (Kitson et al., 1998) and change theory (Rocchiccioli and Tilbury, 1998). The PARIHS model was nested within change theory as the wider framework. This formed a comprehensive implementation model, which was incorporated into the implementation process. In the context of this study, the implementation model (PARIHS and change theory) was used in:

- 1- Constructing the study stages and events within each stage
- 2- Assessing the readiness of the context for change
- 3- Identifying the facilitators and barriers in the context in regard to the proposed study (analysis of driven vs. restraining forces)
- 4- Maintaining the researcher's focus on the aims of the case study while conducting the field work.

The PARIHS model was used to guide this prospective implementation study. However, it is acknowledged that previously the PARIHS model has not been used in this way in implementation study (Helfrich et al., 2010). The PARIHS model has been used as a framework in reviewing literature in order to determine how a postoperative pain management protocol can be developed and used in practice (Brown and McCormack, 2005). In addition, another use was to construct a tool to assess the readiness of the organization for change (based on the PARIHS sub-domains) (Helfrich et al., 2009). This study was similar to a validation study which tested the PARIHS model components numerically for the first time (Helfrich et al., 2009), and confirmed its content validity although this was not the main aim if the study reported here. However, in the context of PMP implementation studies, the use of a theoretical framework was not common. For example, amongst the eight studies that implemented a PMP (related to cancer pain), only two studies used a theoretical framework, and this use was limited to explaining some of the findings and reflecting retrospectively on the studies' methods (Bourbonnais et al., 2004; Finley et al., 2008).

The PARIHS model was useful in gathering baseline information that informed the planning of the implementation process. In addition it assisted in assessing the willingness and readiness of the organization (hospital) for change. This was

accomplished through the application of the PARIHS elements (evidence, context and facilitation) on the change setting. This enables a judgement to be made as to whether the setting is ready and welcoming to the change. This assessment would help identifying possible champions who would facilitate and promote the change.

Although the champions' role was valuable for this study, the PARIHS model did not acknowledge such a role. The PARIHS talked about facilitators who may be external (i.e. the researcher in this study) or internal, and mentioned their role as being different from the champions' role, but omitted to provide any clear-cut differences (Rycroft-Malone et al., 2002), which may result in confusion with these concepts. However, defining the facilitation and determining its role within the PARIHS model is needed. The champion role did not seem to fit within the current PARIHS structure, as confirmed by the factor analysis by Helfrich et al. (2009). In the case of this study, it is possible to say that champions are part of the context and could also be described as internal facilitators, who were senior members of staff, and who bought into and helped secure the changes. This is consistent with what has been described in previous work about facilitation in research utilization field (Harvey et al., 2002). A champion with power may be considered as an 'opinion leader' rather than a champion (such as the CNO in this study). On the other hand, external individuals cannot become champions. They may increase the resistance as they are perceived as intruders by the change adopters. Champions are regular employees who are motivated for change, and voluntarily participate in bringing about the change. This description may help in defining the champion role that was not included in the PARIHS model.

Two PMP implementation studies that used champions reported similar characteristics, and facilitators were not mentioned (Bourbonnais et al., 2004; Finley et al., 2008). In the PARIHS model the facilitation is mentioned as a role but it did not explain how facilitators can mediate the implementation process (Helfrich et al., 2010). Therefore, one improvement that can be added to PARIHS is to determine what methods would be used to embed evidence into practice, not only assessing the context readiness for change and assisting in the planning of the implementation process.

In the context of the case study, it was also found that having a feedback strategy to evaluate the outcomes of change in the oncology unit was essential to determine the success of the adoption. Since the hospital lacked such a system, the PARIHS model prompted the researcher to construct a feedback strategy that was suitable for the context. This was used to evaluate how the PMP affected practice in the unit and determine the factors that may improve or hinder its integration within the

unit's routine. This was considered to be one of the model's strengths, and a determinant of the implementation's success (Greenhalgh et al., 2004).

According to the PARIHS model, an institution that utilises an autocratic administration style is less receptive to change (Kitson et al., 1998; Kitson et al., 2008). However, although the hospital (study context) adopted the autocratic administration style, this did not prevent the unit from receiving and implementing the proposed change. This might be the result of a difference in culture. Kitson et al. (1998) conducted her work within a Western cultural environment, along with another study conducted in UK, reported that the top-down administration style adopted in the National Health Service (NHS) is thought to be a barrier to research uptake in practice (Pearcey and Draper, 1996). This study was conducted within the Arab culture, wherein the support of higher level administration may mean that people in the lower levels should obey without objection. Within this culture it is integrated within the norms that the orders of the higher level should be implemented. In other words, culture could be an important factor in any implementation process. Kitson et al. (1998) uses culture in terms of the locality for the implementation rather than broader societal culture, and the latter has to be taken into account when taking models out of context. An alternative and equally plausible explanation was that the hospital may have been in need of the proposed PMP, since they were preparing for JCI accreditation that required the hospital to have a pain assessment tool in place, and the researcher's efforts could have been perceived as free expertise to achieve the institutional goal. In addition, nursing administration may have thought that this work would help the hospital in improving patients' care. It is not unusual for researchers' and hospitals' goals to coincide, Pronovost et al. (2006) implemented an intervention to reduce infection rates in the ICUs (USA), and they reported that hospital administration wanted the intervention to be implemented. This is because they intended to improve patients' care, and the researcher's work was consistent with the hospital's goals, hence promoting evidence adoption. Therefore, this suggests that the organization's need for the change is one of the determinants of taking or refusing the evidence. This may highlight that bringing change into practice may be difficult if the nursing administration is convinced otherwise. This may especially take on extra importance within the Arab culture, where new change may be perceived as criticism (with the implication that the administration is not doing its job as it should). Thus, denying the need for change may be used as protective mechanism against change. However, this study did not investigate this issue and this would be an interesting topic for further research.

Despite the benefits of PARIHS, it only describes a one-off measurement. This may result in limiting the use of the PARIHS model to that of a tool to assess context

readiness for change and therefore, compromising its benefits in guiding the implementation process. This result was in agreement with the findings of Helfrich (2010; 2009). The discontinuity of the PARIHS model did not fit with the continuous nature of the implementation, which has been described as being a process rather than a single event (Rogers, 2003). Finally, this study has demonstrated that it is possible to use the PARIHS model in the Arabic-Islamic culture, without major obstacles. This may be due to the Westernization of Jordan's healthcare system in most of aspects.

### **11.3 Implementing the evidence: lessons learnt**

The main elements of the implementation process were the following: access to the setting, assessing the organization's readiness for change, gathering the baseline information about the oncology unit, educating and training nurses as means of change, and finally, evaluating the impacts of the PMP and estimating its outcomes. This study did not investigate individuals' research utilization determinants, though it reported lessons learnt from conducting implementation study within Arab-Islamic culture. These lessons were mainly related to evidence and organization determinants. This study presents the results of the earlier efforts of bringing evidence into practice in Jordan; only one previous study had documented such a process in the country. This may raise issues that need further discussion, for instance, whether the process was successful or not in embedding the use of BPI into the daily practice of nurses in the oncology unit.

#### **Success or failure**

It can be difficult to determine in implementation work when a success can be claimed. This study showed that the tool was adopted (the BPI was used in 79% of the time). Helfrich et al. (2010) set a criterion comprising three conditions to decide whether the change was successful or not. Firstly, the researcher should design a plan of implementation, which should be followed and applied throughout the study. In this study there was a plan for the entire study (the research proposal), and pilot work was conducted to assure the feasibility of the study plan. Although in the main study there were times when some modifications had to be made, the essence of the plan remained constant. Secondly, it is advocated that new (implemented) practice should be evidence-based and its use should be continuous; good evidence exists on cancer pain management as outlined in chapter two and in this study, the continued use of pain assessment tool was found in the nurses' practice in the

follow-up period (3 months). Thirdly, the outcomes of the new change should be maintained. In this case study, improvement in the adequacy of cancer pain management was continuous during the follow-up period as well. It is regrettable that follow-up could not continue as planned (see page 186).

Despite the usefulness of the above-mentioned criteria, it is still not easy to evaluate the outcomes of the implementation process, and distil the decision to a simple 'yes' or 'no' answer. Different methods have been used to evaluate the success or failure of research utilization studies. This may take the form of a self-report questionnaire, interview, audit and observations. The use of self-report methods may inflate the effect size or even devalue the importance of the change that was made in the study (Stacey et al., 2006). This may suggest the use of more than one method, for example, in this study the researcher used interviews, chart audit, and observation. This enabled constant evaluation and revision of the evidence in order to fit the hospital's needs (context) and nurses' preference, as recommended by the research utilization literature (Estabrooks et al., 2006; Greenhalgh et al., 2004; Kitson et al., 2008; Pentland et al., 2011; Rogers, 2003). On the other hand, it can be argued that the longer the tool is used, the greater the success. Unfortunately, this assumption was not tested in this study, since the follow-up period was only three months.

To follow-up on the BPI use (and because of the researcher's own curiosity), one of the champions was contacted upon the completion of the first thesis draft and the champion informed the researcher that:

- The BPI was used until December 2010 (started March), and then nursing administration asked nurses to use the previous tool with the same protocol proposed by the researcher for the BPI. That is once a day (with 10 am vital signs round), reassessing patients with pain (each hour and a half after intervention), and pain scores are recorded on the pain flow sheet that was recommended by the researcher.
- The pain policy has been activated and implemented.
- The education course has been repeated twice.
- Regular morphine is now a mandatory prescription to any patients with severe pain.

Although the use of the BPI was stopped, the researcher's work has acted as a catalyst for the improvement in cancer pain management within the unit. Cancer pain management is now on the agenda of the nursing administration and this may



indicate the potential for further improvement that with no doubt had been embarked by this research project.

### **Nursing administration support**

It was found that gatekeepers' support, as suggested by the PARIHS model, was essential for the occurrence of change (i.e. access to the setting). It determined the acceptance of the study in the hospital or not. Also the gatekeepers' continuous support kept the implementation process alive, in a culture with top-down approach (Arab-Islamic culture), without which the study would not have flourished. Within this approach the decision for adoption is taken and disseminated from the top of the hierarchy (nursing administration) to the bottom (nurses in the unit). This was also reported by Finley et al. (2008), who conducted an implementation study in Jordan as well. In other cultures, administrator support is also deemed to be a determinant of 'successful implementation', for example Zhang et al. (2008), in China, created a support team which comprised of the deputy nursing directors, two consultants, and three head nurses. The results indicated that about 67% of nurses used the pain assessment tool and most of the nurses attended the six-hour pain education program. In another study in the UK, the authors were not able to get the administration to support the study (Simons and MacDonald, 2006). They reported that tool usage percentage was 40%, and only three nurses attended the two-hour pain education session. In addition, a recent overview concluded that administrative support fosters bringing about the change and is necessary to better integrate research findings into practice (Pentland et al., 2011). If this support is lost during the course of the implementation process, it may result in discontinuation of the process or putting the study on hold. Nursing administration support was mandatory to the success of the implementation in this study, while in Western culture (where individual choice is respected) administration support may be perceived as a facilitator.

In the researcher's opinion, this study mixed both Western and top-down styles. The administrative support was useful in getting the study underway and supported by the unit staff. In contrast to the top-down style, participants were given choices in some aspects of the study, such as choosing the champions and times at which they wanted to attend the education sessions suggesting the content of the course, and modifications to the BPI and pain assessment protocol.

It is noteworthy that prior to the three-month follow-up session, the researcher lost the support of the nursing administration (CNO), and access for the study was withheld. Later, after some re-negotiation, the researcher was allowed to continue his work. At this point, the researcher found (see page186) that work conducted in

the unit for six months was introduced as an autonomous effort by the hospital in its efforts to improve the quality of healthcare in the unit to attain JCI accreditation. This can be explained by the fact that the hospital administration seeks a prestigious and top position among Jordanian hospitals, which can be achieved by adopting research-based evidence (e.g. use of pain assessment tool). They additionally want to hold the 'pride of ownership' by being the initiator and developer of the PMP implementation process (Rogers, 2003).

In Western literature, an external change agent is considered as one of the positive determinants of successful implementation (Greenhalgh et al., 2004), which was not the case in this study. In another study conducted in Jordan by a Canadian team (Finley et al., 2008), the external change team was reported to be linked with successful implementation. However, since the researcher had worked in the hospital for three years, he may not be considered a total outsider. This situation brought the researcher's attention to an idea mentioned by Rogers (2003), which is about giving the adopters the chance to modify the evidence (with keeping its main features) in order to fit their preference, the context norms, culture, and routine. This may provide a possible way to avoid such a situation (losing support) in future work. According to Rogers (2003), this process is called 'reinvention' and is deemed to improve the adoption rate. It is argued that re-invention occurred here as evidenced the changes made to the pain assessment tool.

### **The need for change**

The early pilot (feasibility) work showed that the hospital was ready to implement a PMP that comprised pain assessment tool and education session. Nursing administration had previously tried to put a pain assessment tool into practice, but the implementation process was unsuccessful and the tool was not embedded into everyday practice (This may indicate the passive resistance from nurses to top down command and obey approach). There was a need for PMP due to the overall quality enhancement strategy applied in the hospital to receive the JCI accreditation. Added to that, the researcher's efforts were considered as a free service to the hospital. Therefore, the implementation of PMP was in accordance with the agenda of the nursing administration in the hospital. It was believed that this convergence between the interests of the researcher and the hospital were essential to the success of this study. A considerable amount of previous work in the implementation field acknowledged that the organization's need for change is one of the determinants of successful implementation (Greenhalgh et al., 2004; Rogers, 2003). This need can also be at the individual level, for example, in the UK, two studies that explored the midwives and oncology nurses opinions on research utilization, participants reported that the significance of research findings to clinical

practice affect the decision for adoption (Luker et al., 1996; Luker et al., 2004). In the context of this study, nurses expressed their need for training on how to assess and manage cancer pain. Thus, the PMP was timely and consistent with the unit's needs at both the administrative and individual levels. However, the need for change and its relevance to practice may go under the innovation features, which govern innovation adoption, as described by Rogers (2003). These features included the "relative advantage of innovation, compatibility, complexity, trialability and observability" (Rogers, 2003 p. 223). Alternatively, they may also go under the evidence (should meet adopter's preference and clinical needs) umbrella as an element of the PARIHS model (Kitson et al., 1998).

### **Complex rather than single intervention**

This study introduced a combined intervention that comprised a pain assessment tool (BPI) and educational sessions (together called the PMP). The pilot work showed that a pain assessment tool was recently introduced by the hospital without the appropriate education or even instructions for nurses on how to use it, which led to only a few nurses adopting the tool. However, this combination made use of the tool easier, as the nurses were provided with proper instructions, and further educated about cancer pain management. Therefore, this improved the nurses' willingness to adopt the BPI. In the broader field of implementation, a study was conducted to implement an electronic card (which included information about patients) into daily medical team practice for a year. The results showed that educating the adopters on how to use the card was appreciated and positively related to successful implementation (Aubert and Hamel, 2001). However, in the context of PMP implementation studies, most of the studies reported using both interventions (education and pain assessment tool)(Bouvette et al., 2002; de Rond et al., 2001; Finley et al., 2008; Zhang et al., 2008). This confirmed the suggestion that a multifaceted intervention is to be considered a mandatory component of the implementation process (Grol and Grimshaw, 2003). An overview of systematic reviews showed that there were four means used to enhance the translation of research findings into practice. These included audit (feedback), computerised decision making support, opinion leaders, and multifaceted interventions. This review reported that the multifaceted intervention was the most commonly used (nine reviews out of 13). The results indicated that this strategy was linked with more research being integrated successfully within clinical practice (Boaz et al., 2011). In this study three methods were used to change practice; education, champions, and audit and feedback. This was found to enhance the research uptake into nurses' practice, consistent with previous studies and reviews (Boaz et al., 2011; Dijkstra et al., 2006; Pentland et al., 2011).

## **Champions' role**

In this study, champions acted as role models for other nurses in the unit; they adopted and used the pain assessment tool first. This encouraged other nurses to follow the champions' steps, as one of the champions was the most senior nurse in the unit and had the respect of the junior nurses. In addition, the second champion was socially well-connected in the unit and the hospital, which helped to increase the acceptance of change amongst the nurses in the unit. This leads to the conclusion that champions with long clinical experience and good social connections are an essential determinant of successful implementation.

Role modelling and networking are like advertisements; they encourage people to adopt research evidence, and thus are important roles for a champion. These roles fall in the communication element of the innovation diffusion, as described by Rogers (2003). The previous work in this area was consistent with the results seen in this study and reported that a champion in an implementation study can enhance the uptake of PMP into practice (Bourbonnais et al., 2004; Finley et al., 2008; Greenhalgh et al., 2004). However, clearer and detailed description of the champions' role is needed. This lack of complete description may be as result of word limits applied to journal articles.

## **11.4 Barriers to cancer pain: a multi-factorial problem**

This study shows that a high percentage of cancer pain was untreated (the mean of Pain management index (PMI) was  $-0.69$ ) in the oncology unit, a phenomenon not exclusive to Jordan (Deandrea et al., 2008; Naveh et al., 2011; Okuyama et al., 2004). However, this study enabled the researcher to highlight the multi-dimensional factors that were found to contribute to the inadequate pain management in the unit. The obstacles to cancer pain management in the unit were clustered into three main categories: barriers related to healthcare providers, to patients, and to the healthcare setting. In addition, belief in God's Will was another major barrier. These factors (barriers) were similar to those found in previous studies (Beck, 2000; David et al., 2003; Jacobsen et al., 2009; Oldenmenger et al., 2009).

There was a high level of barriers among healthcare providers, patients and their primary family caregiver (mean of the total Barriers Questionnaire (BQ) score was 2.0, 2.58, 2.62 respectively) in the oncology unit. In comparison to previous studies, the mean of total BQ for patients were similar to findings in Taiwan, China, Turkey, Australia, USA, and Puerto Rico (Bagçivan et al., 2009; Chung et al., 1999; Edrington et al., 2009; Lin and Ward, 1995; Ward et al., 1993; Ward and Hernandez, 1994). The mean total BQ score ranged from 1.65 (USA) (Ward et al.,

1993) to 2.99 (Ward and Hernandez, 1994) in Puerto Rico. It seems the barriers level may vary depend on the institution. For example, in the USA, one study found that the mean for BQ was 1.65 (Ward et al., 1993), while another study (Ward et al., 1996) reported a higher concerns level (mean = 1.94). The latter study (Ward et al., 1996) was conducted in hospice setting where pain was expected to be higher, but the 1993 study was conducted in outpatient oncology clinics. Therefore, cancer patients generally may have high level of concerns regarding their pain treatment. This study was conducted in an inpatients oncology care unit and it included patients who were newly diagnosed (high stress), or on active chemotherapy treatment (high fatigue). Therefore patients were undergoing a unique and difficult experience which may explain the higher level of barriers. Also the results were consistent with the findings of previous research (Aranda et al., 2004; Lin, 2000; Vallerand et al., 2007; Ward et al., 1993) with regard to reporting high concern levels among family caregivers. However, family caregivers in this study reported the greatest mean of total BQ score (even higher than patients), which contradicts what was reported by previous studies (Lin, 2000; Ward et al., 1993)(family caregivers mean score of BQ was less than patients score). One explanation for this may be that because most family caregivers were first-degree relatives of the patient, working and living in the same house, they may feel overwhelmed and emotionally exhausted. In addition, according to the Arabic culture, it is a must for first-degree relatives to care for relatives, and they should not complain about this and are expected to maintain the care until the death of the patient or the cure. Finally, it was found that fear of drug addiction is a mutual barrier between nurses, patients and their family caregivers and this was consistent with results reported in previous studies (Beck, 2000; David et al., 2003; Edrington et al., 2009; Finley et al., 2008).

### **Healthcare providers' characteristics**

The results indicated that healthcare providers in the unit held a negative attitude towards cancer pain. Nurses lacked adequate knowledge to enable them to manage cancer pain adequately, which tended to devalue the patients' pain reports. These results were not specific to Jordanian healthcare workers (Beck, 2000; David et al., 2003; Elliott et al., 1995; Finley et al., 2008; Furstenberg et al., 1998; Ger et al., 2000; Johnson et al., 2005; McCaffery and Ferrell, 1995; Morley-Forster et al., 2003; Sapir et al., 1999). The lack of knowledge about cancer pain management among nurses may lead to little information being given to the patients and their families. One explanation for the lack of knowledge may be the lack of cancer pain management education in nursing schools. On the other hand, the negative attitude towards cancer pain management may have originated from the fact that cancer is a progressive disease that leads to death. Moreover, nurses in the interviews

tended to devalue patients' pain report, which is consistent with what was previously reported (Beck, 2000; David et al., 2003; Finley et al., 2008). This may be because nurses believe that patients tend to exaggerate their feelings of pain. In addition, nurses may have thought that any patient who reported too much pain and asked for medication was an addict. Overall, this is believed to negatively impact the total pain management process.

### **Spiritual versus physiological pain**

Belief in the God's Will is common in many religions, particularly the Abrahamic traditions (Judaism, Christianity and Islam)(Forgeron et al., 2006). It was found that this belief tended to prevent patients from taking narcotics to treat their pain. Many nurses and patients reported refusal of narcotics, preferring to wait for God's reward, as they feared committing a sin (by taking narcotics) in treating their pain. This may shift the issue of untreated pain from being a problem of not using the available medications to a religious and spiritual context, which may have extra importance in the religious communities, such as Jordan. For example, in South Africa, Beck (2000) found that Africans refused to receive cancer treatment because they believed that cancer needed no treatment, but rather a witch doctor to remove the bad spirit from the body. This was consistent with the findings of Koffman et al. (2008), who found that Black Caribbean patients in the UK perceived pain as God's punishment for their misconduct (committing sins), or a test of their faith, compared to white British patients who did not express such perceptions. This can be mapped to the fact that cancer pain is a culturally sensitive phenomenon (Al-Atiyyat and Mohammed, 2009; Chen and Tang, 2011) rather than being treated purely as a physiological disease symptom. In another example from Asia, it was clearly indicated in a recent meta-analysis that Asian patients perceive barriers to cancer pain management differently when compared to patients in Western countries, as they had higher concern levels (Chen and Tang, 2011).

Some patients in this study perceived taking narcotics as being against Islamic instructions. They deemed that Islam requires them to tolerate pain and abstain from the use of narcotics. Contrary to this popular belief, Muslims are doctrinally required to seek pain treatment (Abushaikha, 2007). This seems to be a very common belief amongst Jordanians, as they do not distinguish between the medical and non-medical uses of narcotics; Islam only prohibits the use of narcotics (under the umbrella of intoxicants) for recreational purposes (non-medical use)(Abushaikha, 2007). Therefore, lay people may need religious clarification and education on this issue, which can be achieved through leaflets and education sessions that target students and other people in the community.

In this study, patients are believed to have experienced various barriers to accessing and accepting pain medication, especially the use of narcotics, including fear of addiction, the interference of family members, and fear of pain medication side-effects. Many systematic and traditional reviews were in accord with the barriers that were discovered in this regard (Glajchen, 2001; Jacobsen et al., 2009; Oldenmenger et al., 2009).

### **11.5 Pain monitoring programme outcomes**

Cancer pain management is considered to be a multi-dimensional process that needs a collaborative approach. It was proposed that introducing a pain assessment tool (BPI), in combination with pain education, would optimally improve cancer pain management. The pain assessment tool that was used in the study is the BPI. It was developed to measure cancer pain, but the legitimate question is whether or not the use of BPI is feasible in clinical practice.

#### **Was the use of BPI feasible in clinical practice?**

Most nurses found that the BPI was easy to use and detected pain. These two features were perceived as the relative advantages of using the tool and can improve nurses' willingness to adopt the BPI (Rogers, 2003). However, on the other hand, nurses complained that the use of the numerous similar questions in the BPI was time consuming and confusing. In addition, many nurses found the single use of the BPI to be problematic and a burden for old and ill patients. Therefore, it can be said that the BPI is a research tool rather than a tool for daily use in clinical practice.

The BPI has been extensively translated and validated into different languages and cultures (Cleeland, 2009). However, when it comes to implementation, nurses prefer to use tools that usually suit their setting regardless of the popularity of BPI. For example, many PMP implementation studies used a non-validated tool, such as the study that used a tool that has been developed by the research team of (Bourbonnais et al., 2004), while in another study authors simply used a numerical rating scale (de Rond et al., 2000a). This suggests that although the BPI remains a valid tool, it is not necessarily feasible in daily use.

In the context of this study, nurses suggested that the ideal pain assessment tool should be simple. Regarding BPI (the tool used in this study), nurses suggested that simplicity can be accomplished by asking two questions in the form of a numerical rating scale (to rate pain severity now, and the interference of pain with daily living activity in general). In addition, a body map to locate pain should be included. Finally, this tool should be used in the form of a pocket card to allow

multiple uses. This makes the tool simple and multi-dimensional at the same time (this may be an area the worth further work). Therefore, the main modification suggested was replacing a few questions in the BPI with one question about the worst pain score. This seemed to be consistent with the fact that the worst pain score alone can provide information about a patient's pain. In a study conducted to determine the types of pain correlated with various interferences within daily living elements in the BPI, it was found that worst pain score was highly correlated with all interference elements (Harris et al., 2007). Overall, pain assessment tools that are brief, in card form, and multi-dimensional, seem to be suitable for use in clinical practice; BPI is not yet compatible with such criteria. Therefore, pain assessment tools developed for research purposes, such as BPI, may not be usable in daily practice. This is due to the fact that each setting has its cultures and needs that determine the suitable tool for use within its premises, which explains the existence of a large number of available pain assessment tools and the lack of a universally adopted one. However, nurses' need of simple easy tool confirmed the fact that simple and easy to use evidence (BPI) is more likely to be adopted.

### **Cancer pain prevalence and intensity**

It was found that 84 (65%) of the 130 patients had some pain at the time of the survey, and the patients' pain was high (mean of worst pain score was 5.9 out of 10). No significant change to pain prevalence has been seen after the implementation of PMP, as each stage recruited a different set of patients and the pain data was collected at a single point.

Cancer pain was prevalent in the unit, in accord with previous studies (Breivik et al., 2009; Forgeron et al., 2006; Ger et al., 1998; Larue et al., 1995; Wang, 2008; Yun et al., 2003). In these studies, comparable pain prevalence was reported, ranging from 57% to 70%. On the other hand, some previous studies reported a lesser prevalence (Beck and Falkson, 2001; Menzies et al., 2000; Starr et al., 2010) (28% to 35.7%). This may be due to one of the studies (Beck and Falkson, 2001) being conducted with African people, who tend to report less pain than other ethnic groups (Beck, 2000). In addition, the author of the study acknowledged that it only represented people who have had access to medical care, while there were many cancer patients who were not able to attend hospitals or any other medical setting (Beck and Falkson, 2001). However, the other two studies (García de Paredes et al., 2010; Menzies et al., 2000) represent well-developed countries (the UK and Spain), which usually have better pain management services than developing countries with limited resources, which produced reports of lesser pain (Finley et al., 2008; McCaffery and Ferrell, 1995). It can also be explained by the



fact that Menzies et al. (2008) conducted their study as a one day chart audit in a cancer care specialized centre (pain oriented), where pain treatment is a priority.

Patients reported higher worst pain mean score in this study, compared with the four studies that used the BPI to assess pain (Ger et al., 1998; Yun et al., 2003; Beck and Falkson, 2001; Larue et al., 1995). It could be argued that patients' anxiety during the initial treatment increase their feelings of pain, causing them to report higher pain scores. In addition, cultural differences may also have caused a severe pain perception. Patients may also be admitted for pain treatment since that unit is the only place where cancer and its consequences are treated.

### **Measures to use in evaluating the PMP outcomes**

In this study, to evaluate the effects of the PMP on cancer pain management in the unit, two outcomes were selected based on the literature: the percentage of tool usage and the percentage of pain reported by nurses in particular (since pain can also be reported by patients, physicians or family caregivers) and the PMI. It was found that PMI was significantly improved (the mean score of PMI was  $-0.69$  before embarking on the study, and it increased to  $0.04$  after three months of implementation of the PMP), along with tool usage percentage (from 32% to 80%). Although the PMI was developed to evaluate the adequacy of pain management, it was not used in any of the previous implementation studies. This outcome indicates the change in pain treatment, and could be one of the best measures, despite being criticised for not reflecting the dynamic (changing) aspect of the pain management process (Russell et al., 2006). In addition, the PMI was sensitive to the change in cancer pain management. Based on this study it is recommended to calculate the PMI for each dose to ensure that patients would receive adequate pain management and repeat it with a consequent dose, as there is no universal method available to measure the adequacy of pain management (de Wit et al., 1999; de Wit et al., 2001; Passik et al., 2004; Russell et al., 2006). Based on the researcher's experience of using the PMI, it can be said that PMI has the potential to be a reliable evaluation tool.

Measuring the percentage of tool usage may reflect the change in the nurses' attitude towards use of the pain assessment tool; this was the most commonly used measurement in PMP implementation studies (de Rond et al., 1999; de Rond, 2000a; Finley et al., 2008; Martoni et al., 2007; Rhodes et al., 2001). It is information that is easy to extract from the charts and provides a proxy for the integration of the tool into practice. Previous PMP implementation studies agreed with this study on the fact that PMP would lead to increasing the nurses' use of the pain assessment tool (de Rond et al., 1999; Finley et al., 2008; Martoni et al.,

2007; Rhodes et al., 2001). Interestingly, it was noticed that tool use would be better if the tool was used once a day (as in this study)(de Rond et al., 1999; Rhodes et al., 2001). This may be because nurses needed the tool use frequency to be feasible within their busy work environment.

Finally, determining the percentage of pain reported by nurses seems to be a confirmatory measure, but in this study it did not add any new information and caused confusion with percentage of tool usage. When the researcher checked the medical charts, it was difficult to extract the identity of the pain reporter (patient or nurse). This reduces the potential for interpretations sought from this information. Thus, the researcher does not recommend its usage.

In previous implementation studies, different measures were used to evaluate the impacts of PMP on the pain management. They included communication and pain documentation (de Rond, 2000a), pain severity and pain reporting (Choi et al., 2006; Devi and Tang, 2008), and pain medication prescriptions (de Rond et al., 2000b; Forgeron et al., 2006). In addition, no study used the PMI as outcome of the PMP and therefore this limited comparison between this and previous studies. Considering this, two domains may reflect the outcomes of PMP, which are attitudes and behaviours, and adequacy of pain management. The attitude may be measured using the percentage of tool usage, knowledge, and attitude survey or BQ, while the adequacy of pain management can be assessed using the PMI or time to reach free pain (calculating number of days a patient express no pain). Therefore, it is recommended that using two domains will provide a clearer picture about cancer pain management.

## **11.6 Strengths and limitations of the study**

### **11.6.1 Study limitations**

This study used a single-embedded case study design that was conducted in a single healthcare setting (a hospital). Therefore, the findings of this study may only be applicable to this hospital or other similar healthcare settings in Jordan. Furthermore, as this study was restricted to a single oncology unit, small participant numbers from different groups were used. In addition, convenience sampling approach was utilized. Thus, convenience sampling and a small sample size may severely compromise the findings' external validity and their representation for larger populations. However, case study design does not seek statistical generalization; its intention is to generalize to theoretical propositions. Another threat to external validity was the use of Arabic non-validated questionnaires, such as BPI and BQ, which were not previously used in the Arab

world. The use of subjective data sources such as: interview and observation would threaten the internal validity of the case study. In particular, short duration of observation is one limitation that results in few situations (total 10 in the whole study) observed where cancer pain is being managed and thus this may threaten the internal validity of the study. In addition, one of the limitations was the language, most of the interviews' text were in Arabic which needed to be translated to English in order to be analysed and readable for the supervisors (since they did not understand Arabic). Although the researcher was keen to correctly translate the text to English, reflecting the exact meaning was still not guaranteed, which may have threatened the internal validity of the study.

Another limitation was the difficulties faced when conducting in-depth interviews with nurses and audio-recording was not possible (as explained in chapter six), hence the general quality of the interviews was reduced. This was mainly due to the nurses being unwilling to speak in detail and requesting the researcher to ask very specific rather than general questions. Additionally, the researcher was not successful in recruiting physicians who are the most important participants in the process of cancer pain management. Although they were invited three times and telephoned consistently, they did not participate in the study; the efforts to recruit a physician champion also failed. Had they agreed to participate, doctors would have enhanced the integration of the BPI in daily use and the adequacy of pain treatment would have been improved because they are responsible for the prescription of pain medications.

This case study was part of a three-year PhD programme. The researcher was funded by an academic institution and the scholarship was restricted to a period of three years. Therefore, this compelled the follow-up duration to be shorter than would have been preferred. Added to that, the loss of the nursing administration's support further limited the follow-up duration.

For the purposes of rigour, it is advised that the case study report be read by the participants, if possible, in order to include their inputs and suggestions (Creswell, 2008). This was not possible because of the complex nature of the report (PhD thesis), the large number of participants, and the lengthy distance between researcher (in the UK) and the participants (in Jordan) during the writing phase.

An education programme of a very short duration (only one day and repeated three times) was provided to the nurses. It may be argued that a longer education programme may be more complementary to tool usage, and improve the nurses' knowledge and attitudes towards cancer pain. However, because of the limited time and resources available to the researcher, a longer course was not possible.

The presence of a researcher in the unit may induce the nurses to work harder, leading to false-positive results. The double-blind approach was not possible, therefore the researcher tried to encourage the nurses to perceive his presence as part of the unit by spending long lengths of time in the field and assuring the nurses that he was present for research purposes only, with no intention to criticize.

Finally, the researcher was motivated to conduct this work based on his personal experience of working in the hospital for three years. Hence, personal bias may have affected the study findings by being the facilitator in this implementation study. This may imply the tendency to push toward preferable outcome. In addition, being the facilitator and the evaluator may lead to bias in reporting of the results. This was minimized as far as possible through the use of a detailed description of the study process, using a robust method, using objective outcome measures and the presence of the supervisory team.

### **11.6.2 Study strengths and contributions to knowledge**

The use of a single-case study design provided a thorough description of the implementation process, and described how the use of a pain assessment tool has an impact upon the pain management process aspects in the unit. The flexibility of such a design allowed the researcher to use different data collection methods and sources. This contributes to building a broader understanding of the case being studied. This was found essential for a successful implementation study and was not used in any of the previous studies. This study used the case study design to implement and evaluate the intervention effects; at the same time, it is believed that case study is one of the designs that fit implementation science (Rogers, 2003; Stacey et al., 2006; Yin, 2009).

In addition, this study used both quantitative and qualitative data sources, collection methods and analyses, which result in a more comprehensive understanding of the process of translating knowledge into practice and cancer pain management process in a new culture and geographical area. In addition, both approaches were complementary to each other. For example, the BQ was used to collect quantitative data about barriers to cancer pain management, and the interviews with nurses confirmed the quantitative data and added information not covered by the BQ. This led to an expansion of knowledge of barriers and revealed some new data (e.g. belief in God's Will) that could not be discovered using the survey (BQ) alone.

Previous studies urged the need for the use of a theoretical framework to facilitate the translation of knowledge into practice. Therefore, theoretical frameworks

(PARIHS and change theory) were used to guide the provision of this study and enhance the integration of the change (PMP) into the nurses' practice. This study has for the first time used the PAHRIS model in a prospective way in Arabic culture.

It is believed that this case study provides preliminary information about cancer pain and its treatment in Jordan. This information comes from a culture (Arabic-Islamic), where little is known about cancer pain management and its boundaries. In addition, this study extensively describes a process of translation of knowledge into practice within the culture. Thus, it lends itself to comparison with studies from other cultures, especially Western ones.

As a case study, one of its main strengths is the thorough description of both the process of implementing knowledge into practice and cancer pain management. This helps in its comparison with other studies and gives a chance for study replication in other settings in Jordan.

This study represents the early efforts to shed light on and improve cancer pain management in Jordan. In terms of contribution to current knowledge, this study adds that:

- 1- Cancer pain is prevalent among Jordanian cancer patients, and is frequently undertreated.
- 2- Barriers to cancer pain management were abundant and consistent with reports from previous studies. However, the results revealed that culture-related barriers were present, such as belief in God's Will, which contributed to inadequate management of cancer pain.
- 3- The use of a theoretical framework is important to successful translation of knowledge into practice, and the PARIHS model has utility in Arab culture.
- 4- Case study design is one of the promising research designs to be used in the field of translating knowledge into practice (implementation studies). It is a flexible design that can be used effectively in Arab culture.
- 5- The context of the implementation study and its culture are important determinants in the implementation process. Thus, both should be assessed prior to embarking on any change and the process should be designed in a way that does not contradict context norms, ritual and culture. In addition, it should meet the contextual needs and serve its ultimate goals.

6- The outcomes of pain assessment tool usage in practice can be evaluated using the following reliable indicators: percentage of tool usage, and calculating the pain management index (PMI) scores.

7- It is possible to bring about a change in practice using the case study approach; however, its duration is unknown.

## **11.7 Conclusions**

Taking into consideration the previously listed limitations, this study has achieved its aims in answering the questions posed. However, there is no doubt that there are things that the researcher (with hindsight) might have done differently, for example, more effort could have been expended in motivating and recruiting physicians and involving them more actively in the study. In addition, the research would have been strengthened by extending the follow-up to at least one year, in order to enable the appropriate assessment of the embedding of the BPI tool in practice, and conducting more open and in-depth interviews with nurses and other healthcare team members, such as social workers and pharmacists.

This research demonstrates that knowledge translation theories shaped the study as a three-stage changing process. These stages included the preparation, changing, and evaluation phases. The implementation process of the PMP was a challenging process within the Arab-Islamic culture. Implementation science is newly introduced to this culture; hence, its movement towards evidence-based practice appears to be quite distant at the moment. However, each implementation process might vary in its ingredients and procedures, according to its context. In addition, this study illustrated that the PARIHS model can foster the translation of evidence into practice in Jordan and the Arab-Islamic culture in general, without major obstacles. The case study methodology was found to have fit the complexity and multi-faceted features of the implementation process.

In regard to the cancer pain management process, this study highlights the high prevalence of pain among cancer patients, which was consistent with the previous reports from other parts of the world. It was found that cancer patients were experiencing high levels of pain, which was undertreated. This study also showed that barriers to cancer pain management, and misconceptions were high and abundant among patients, family caregivers, and healthcare providers. These barriers, in general, were similar to barriers within the other cultures. However, a PMP that combines education sessions on pain management and a pain assessment tool may represent an opportunity to overcome the obstacles to optimal cancer pain management, and may eventually improve the adequacy of cancer pain

management. Overall, this study confirmed that pain assessment and the use of a pain assessment tool are important to improve cancer pain management.

## **11.8 Recommendations**

### **Recommendations for practice and policy**

This study aimed to implement a PMP into the nurses' daily practice using knowledge translation theories. It highlighted how pain assessment tool usage could improve the cancer pain management process, in general, and the adequacy of treatment in particular. Based on the findings, the following are recommended:

- 1- Pain assessment is the first step to better pain management; thus, pain assessment should be applied in all oncology units as the fifth vital sign.
- 2- A pain assessment tool should be used at least once a day. Patients in pain should be reassessed repeatedly until the pain is optimally relieved.
- 3- Each unit should adopt a specific pain assessment tool that meets the needs of the healthcare providers and patients. According to our findings, tools that ask few questions (e.g. one about pain intensity and the other about pain interference with daily living activity), contain a body map, and are manufactured as a pocket card, are more likely to be used by nurses. The information gathered by this tool should be recorded on a pain flow sheet designed for this purpose, and kept in the patients' medical charts.
- 4- Pain management policy should clarify the roles of doctors and nurses, and determine the responsibilities and accountability for each role. The ultimate goal of the policy is to provide an efficient pain management to cancer patients, and minimize professions interfering with the adequacy of treatment, as much as possible.
- 5- Pain policy should contain guidelines for pain assessment, documentation, and management. These guidelines should detail the steps of assessment and documentation, and determine the responsible professionals for these steps. In addition, they should recommend the type of pain medications, dosage, and frequency, according to the pain intensity score. This should maintain a systematic cancer pain management, independent of a person's beliefs and attitudes.
- 6- Hospital administration should be required to include the pain monitoring programme into the general hospital orientation programme, which is usually provided for the newly employed nurses and doctors.

- 7- Pain education should be conducted by the Continuous Medical Education Department on a regular basis.
- 8- Leaflets about cancer pain causes, assessment, management, and barriers to management, should be developed and written in a language readable to a layman. These leaflets should also be provided to cancer patients and their caregivers on admission to oncology units.
- 9- Healthcare providers should be given access to the latest updates and research related to pain. In addition, dissemination of such knowledge, through journal club meetings, should be encouraged. This may also create a culture that appreciates research and evidence-based practice.

### **Areas for further research**

This study was a single-case study conducted in a single setting. It is recommended to replicate this case in multi-centres to enable cross-comparisons, which would increase the findings' credentials' and external validity (Yin, 2009).

As this study explored cancer pain management at a single hospital, it is deemed that a study at the national level is required to estimate cancer pain prevalence, intensity, and adequacy of treatment among adult cancer patients. In addition, identification of the barriers to cancer pain management would be helpful. Literature-related cancer pain in Jordan is not available, and such study would help close this gap of knowledge.

Most of the previous studies that implemented PMP lacked the use of knowledge translation theories, which were responsible for positive impacts on the implementation process. It is recommended for prospective researchers to use at least one of the available knowledge translation models. Being of special importance for studies which will be conducted within the Arab-Islamic culture, it will enable the comparison with the Western culture where most of the knowledge translation work has occurred.

The PARIHS and change theory combination shows positive indications of the ability to enhance research uptake into practice. Further work using these together is needed and recommended. In addition, factors that comprise the PARIHS need to be numerically tested, for example, using logistic regression to determine the factors that may predict the best integration research into practice. Moreover, definition of the facilitation element of PARIHS is needed since it is not yet well-identified.



No physicians actively participated in this study, although they are believed to be key players in cancer pain management. Therefore, it is recommended that future PMP implementation studies include physicians, and investigate the impact of their participation on the study progress and outcomes.

Finally, this study suffered from the short follow-up period, and the researcher was not able to evaluate the long-term tool usage sustainability and patterns. Therefore, a longer follow-up period is recommended for the future PMP implementation studies.

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## Appendices

### Appendix 1: Hawker's assessment tool

Author and title:					
Date:					
	Good	Fair	Poor	Very poor	Comment
1. Abstract and title					
2. Introduction and aims					
3. Method and data					
4. Sampling					
5. Data analysis					
6. Ethics and bias					
7. Findings/results					
8. Transferability/generalizability					
9. Implications and usefulness					
Total					

**1. Abstract and title:** Did they provide a clear description of the study?

Good            Structured abstract with full information and clear title.

Fair             Abstract with most of the information.

Poor             Inadequate abstract

Very Poor      No abstract

**2. Introduction and aims:** Was there a good background and clear statement of the aims of the research?

Good            Full but concise background to discussion/study containing up-to date literature review and highlighting gaps in knowledge.

Clear statement of aim AND objectives including research questions

Fair             Some background and literature review.

Research questions outlined.

Poor             Some background but no aim/objectives/questions, OR

Aims/objectives but inadequate background

Very Poor      No mention of aims/objectives

No background or literature review.

**3. Method and data:** Is the method appropriate and clearly explained?

Good	Method is appropriate and described clearly. Clear details of the data collection and recording
Fair	Method appropriate, description could be better. Data described.
Poor	Questionable whether method is appropriate Method described inadequately. Little description of data
Very Poor	No mention of method, AND/OR Method inappropriate, AND/OR No details of data.

**4. Sampling:** Was the sampling strategy appropriate to address the aims?

Good	Details (age/gender/race/context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates shown and explained
Fair	Sample size justified. Most information given, but some missing
Poor	Sampling mentioned but few descriptive details.
Very Poor	No details of sample

**5. Data analysis:** Was the description of the data analysis sufficiently rigorous?

Good	Clear description of how analysis was done. Qualitative studies: Description of how themes derived/respondent validation or triangulation. Quantitative studies: Reasons for tests selected hypothesis driven/ numbers add up/statistical significance discussed.
Fair	Qualitative: Descriptive discussion of analysis. Quantitative
Poor	Minimal details about analysis
Very Poor	No discussion of analysis

**6. Ethics and bias:** Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?

Good	Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed. Bias: Researcher was reflexive and/or aware of own bias.
Fair	Lip service was paid to above

Poor	Brief mention of issues
Very Poor	No mention of issues

**7. Results:** Is there a clear statement of the findings?

Good	Findings explicit, easy to understand, and in logical progression. Tables, if present, are explained in text. Results relate directly to aims. Sufficient data are presented to support findings.
Fair	Findings mentioned but more explanation could be given. Data presented relate directly to results.
Poor	Findings presented haphazardly, not explained, and do not progress logically from results.
Very Poor	Findings not mentioned or do not relate to aims.

**8. Transferability or generalizability:** Are the findings of this study transferable to a wider population?

Good	Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).
Fair	Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.
Poor	Minimal description of context/setting
Very Poor	No description of context/setting

**9. Implications and usefulness:** How important are these findings to policy and practice?

Good	Contributes something new and/or different in terms of understanding/insight or perspective. Suggests ideas for further research Suggests implications for policy and/or practice
Fair	Two of the above (state what is missing in comments).
Poor	Only one of the above
Very Poor	None of the above

## Appendix 2: Brief pain inventory (long form)

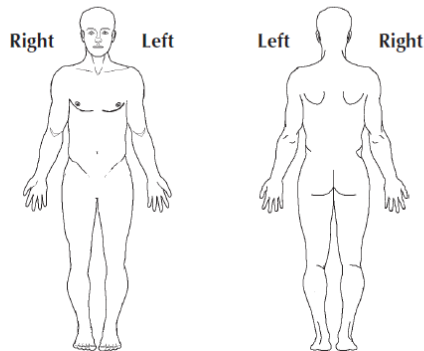
### BRIEF PAIN INVENTORY

Date \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ Time: \_\_\_\_\_

Name: \_\_\_\_\_  
Last First Middle Initial

1) Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?  
 1. Yes      2. No

2) On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.



3) Please rate your pain by circling the one number that best describes your pain at its **WORST** in the last 24 hours.

**0 1 2 3 4 5 6 7 8 9 10**  
 No Pain      Pain as bad as you can imagine

4) Please rate your pain by circling the one number that best describes your pain at its **LEAST** in the last 24 hours.

**0 1 2 3 4 5 6 7 8 9 10**  
 No Pain      Pain as bad as you can imagine

5) Please rate your pain by circling the one number that best describes your pain on the **AVERAGE**.

**0 1 2 3 4 5 6 7 8 9 10**  
 No Pain      Pain as bad as you can imagine

6) Please rate your pain by circling the one number that tells how much pain you have **RIGHT NOW**.

**0 1 2 3 4 5 6 7 8 9 10**  
 No Pain      Pain as bad as you can imagine

7) What treatments or medications are you receiving for your pain?  
 \_\_\_\_\_  
 \_\_\_\_\_

8) In the last 24 hours, how much relief have pain treatments or medications provided? Please circle the one percentage that shows how much **RELIEF** you have received.

**0% 10 20 30 40 50 60 70 80 90 100%**  
 No relief      Complete relief

9) Circle the one number that describes how, during the past 24 hours, pain has interfered with your:

#### A. General activity

**0 1 2 3 4 5 6 7 8 9 10**  
 Does not interfere      Completely interferes

#### B. Mood

**0 1 2 3 4 5 6 7 8 9 10**  
 Does not interfere      Completely interferes

#### C. Walking ability

**0 1 2 3 4 5 6 7 8 9 10**  
 Does not interfere      Completely interferes

#### D. Normal work (includes both work outside the home and housework)

**0 1 2 3 4 5 6 7 8 9 10**  
 Does not interfere      Completely interferes

#### E. Relations with other people

**0 1 2 3 4 5 6 7 8 9 10**  
 Does not interfere      Completely interferes

#### F. Sleep

**0 1 2 3 4 5 6 7 8 9 10**  
 Does not interfere      Completely interferes

#### G. Enjoyment of life

**0 1 2 3 4 5 6 7 8 9 10**  
 Does not interfere      Completely interferes

Brief Pain Inventory (Short Form). Source: Pain Research Group, Department of Neuro-Oncology, The University of Texas MD Anderson Cancer Center. Used with permission. Adapted to single page format.

Provided as an educational service by ENDO PHARMACEUTICALS

In addition to completing the Brief Pain Inventory, to help your doctor better manage your pain, please tell us:

**What does the pain feel like? Circle those words that describe your pain.**

- |            |           |             |
|------------|-----------|-------------|
| aching     | throbbing | shooting    |
| stabbing   | gnawing   | pricking    |
| sharp      | tender    | burning     |
| exhausting | tiring    | penetrating |
| nagging    | numb      | miserable   |
| unbearable | dull      | radiating   |
| squeezing  | cramping  | deep        |

**How long have you had this pain? (Circle one)**

- |                  |                   |
|------------------|-------------------|
| less than a week | 1 to 2 weeks      |
| 2 to 4 weeks     | more than a month |

**What kinds of things make your pain feel better (for example, heat, medicine, rest)?**

.....  
.....

**What kinds of things make your pain worse (for example, walking, standing, lifting)?**

.....  
.....

**Do you have any other symptoms? Circle any that apply:**

- |                     |                |
|---------------------|----------------|
| nausea              | vomiting       |
| constipation        | diarrhea       |
| lack of appetite    | indigestion    |
| difficulty sleeping | feeling drowsy |
| nightmares          | dizziness      |
| tiredness           | itching        |
| urinary problems    | sweating       |
| weakness            | headaches      |

**Talking About Your Pain**

It's important to remember that each person's pain is different. The pain that you experience can't be compared to another person's pain. ONLY YOU know how and when you hurt, and how the pain affects your life.

It is important to describe what you are feeling to those who are trained to help you. Don't be embarrassed to talk to your doctor, nurse, or pharmacist. They need to know as much as possible about your pain in order to develop the best plan to control it. The questions on this form can help you describe your pain.

**Why Is Pain Relief So Important?**

Proper treatment for pain is not only a matter of comfort. Unrelieved pain can lead to nausea, loss of sleep, depression, loss of appetite, weakness, and other problems. Pain can also affect your life at home and at work. Relieving your pain means that you can continue to do the day-to-day things that are important to you.

**Most Pain Can Be Controlled**

It is important to know that most pain CAN be relieved. Your doctor will work with you to find the treatment that may be best for your pain.

The key to effective pain control is to take the RIGHT AMOUNT, of the RIGHT MEDICINE, at the RIGHT TIME. You should take your pain medicine on a regular schedule, as your doctor, nurse, or pharmacist tells you. Don't wait until the pain becomes severe. Pain is easier to control when it is mild than when it has reached full force.

If your pain medicine wears off too soon, is not relieving the pain, or causes problems with side effects, you should call your doctor because you may need to have your treatment plan changed.

**Comments: Write down any questions or information you need to share with your doctor, nurse, or pharmacist about your pain.**

.....  
.....  
.....  
.....  
.....

**Appendix 3: Brief pain inventory (short form)**

STUDY ID# \_\_\_\_\_ HOSPITAL # \_\_\_\_\_

DO NOT WRITE ABOVE THIS LINE

---

**Brief Pain Inventory (Short Form)**

**Date:** \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ **Time:** \_\_\_\_\_

**Name:** \_\_\_\_\_

Last First Middle Initial

**1.** Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?

1. Yes 2. No

**2.** On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.

**3.** Please rate your pain by circling the one number that best describes your pain at its **worst** in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10

No Pain Pain as bad as you can imagine

**4.** Please rate your pain by circling the one number that best describes your pain at its **least** in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10

No Pain Pain as bad as you can imagine

**5.** Please rate your pain by circling the one number that best describes your pain on the **average**.

0 1 2 3 4 5 6 7 8 9 10

No Pain Pain as bad as you can imagine

**6.** Please rate your pain by circling the one number that tells how much pain you have **right now**.

0 1 2 3 4 5 6 7 8 9 10

No Pain Pain as bad as you can imagine



7. What treatments or medications are you receiving for your pain?

8. In the last 24 hours, how much relief have pain treatments or medications provided? Please circle the one percentage that most shows how much relief you have received.

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%  
No Complete  
Relief Relief

9. Circle the one number that describes how, during the past 24 hours, pain has interfered with your:

**A. General Activity**

0 1 2 3 4 5 6 7 8 9 10  
Does not Completely  
Interfere Interferes

**B. Mood**

0 1 2 3 4 5 6 7 8 9 10  
Does not Completely  
Interfere Interferes

**C. Walking Ability**

0 1 2 3 4 5 6 7 8 9 10  
Does not Completely  
Interfere Interferes

**D. Normal Work (includes both work outside the home and housework)**

0 1 2 3 4 5 6 7 8 9 10  
Does not Completely  
Interfere Interferes

**E. Relations with other people**

0 1 2 3 4 5 6 7 8 9 10  
Does not Completely  
Interfere Interferes

**F. Sleep**

0 1 2 3 4 5 6 7 8 9 10  
Does not Completely  
Interfere Interferes

**G. Enjoyment of life**

0 1 2 3 4 5 6 7 8 9 10  
Does not Completely  
Interfere Interferes

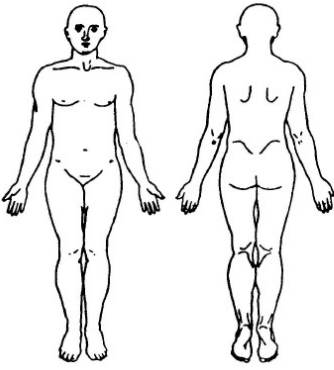
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Pain Research Group  
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**Appendix 4: McGill pain questionnaire (long form)**

**McGill Pain Questionnaire**

Patient's Name \_\_\_\_\_ Date \_\_\_\_\_ Time \_\_\_\_\_ am/pm

PRI: S \_\_\_\_\_ A \_\_\_\_\_ E \_\_\_\_\_ M \_\_\_\_\_ PRI(T) \_\_\_\_\_ PPI \_\_\_\_\_  
 (1-10) (11-15) (16) (17-20) (1-20)

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**FIG. 2.** McGill Pain Questionnaire. The descriptors fall into four major groups: sensory, 1 to 10; affective, 11 to 15; evaluative, 16; and miscellaneous, 17 to 20. The rank value for each descriptor is based on its position in the word set. The sum of the rank values is the pain rating index (PRI). The present pain intensity (PPI) is based on a scale of 0 to 5. Copyright 1970 Ronald Melzack.

## Appendix 5: McGill pain questionnaire (short form)

### SHORT-FORM MCGILL PAIN QUESTIONNAIRE RONALD MELZACK

PATIENT'S NAME: \_\_\_\_\_ DATE: \_\_\_\_\_

	<u>NONE</u>	<u>MILD</u>	<u>MODERATE</u>	<u>SEVERE</u>
THROBBING	0) _____	1) _____	2) _____	3) _____
SHOOTING	0) _____	1) _____	2) _____	3) _____
STABBING	0) _____	1) _____	2) _____	3) _____
SHARP	0) _____	1) _____	2) _____	3) _____
CRAMPING	0) _____	1) _____	2) _____	3) _____
GNAWING	0) _____	1) _____	2) _____	3) _____
HOT-BURNING	0) _____	1) _____	2) _____	3) _____
ACHING	0) _____	1) _____	2) _____	3) _____
HEAVY	0) _____	1) _____	2) _____	3) _____
TENDER	0) _____	1) _____	2) _____	3) _____
SPLITTING	0) _____	1) _____	2) _____	3) _____
TIRING-EXHAUSTING	0) _____	1) _____	2) _____	3) _____
SICKENING	0) _____	1) _____	2) _____	3) _____
FEARFUL	0) _____	1) _____	2) _____	3) _____
PUNISHING-CRUEL	0) _____	1) _____	2) _____	3) _____

NO PAIN |-----| WORST POSSIBLE PAIN

P P I

0 NO PAIN \_\_\_\_\_

1 MILD \_\_\_\_\_

2 DISCOMFORTING \_\_\_\_\_

3 DISTRESSING \_\_\_\_\_

4 HORRIBLE \_\_\_\_\_

5 EXCRUCIATING \_\_\_\_\_

© R. Melzack, 1984

Fig. 1. The short-form McGill Pain Questionnaire (SF-MPQ). Descriptors 1–11 represent the sensory dimension of pain experience and 12–15 represent the affective dimension. Each descriptor is ranked on an intensity scale of 0 = none, 1 = mild, 2 = moderate, 3 = severe. The Present Pain Intensity (PPI) of the standard long-form McGill Pain Questionnaire (LF-MPQ) and the visual analogue (VAS) are also included to provide overall intensity scores.

## Appendix 6: Hospital approval<sup>2</sup>

[On Hospital letterhead]

Date <u>31-8-2009</u>	التاريخ: _____
	الموافق: _____

**Professor K. Luker**  
**Dr. C. Richardson**  
**School of nursing midwifery and social work**  
**The University of Manchester**  
**Jean McFarlane building**  
**Manchester M13 9PL**

**Dear Mr's**

Referring to your letter, in which you confirm that Mr. Mohammad Ibrahim Qadire joined the University of Manchester to undertake a PhD, research project entitled " **The Use of a Pain Assessment Tool in the Daily Practice of Jordanian Oncology Nurses: A Case Study**".

We would like to inform you that we accept Mr. Mohammad to conduct his proposal here in our hospital for the purpose mentioned above, under the following conditions:

1. Confidentiality is required while collecting data.
2. Informed consent is required to be kept in the medical record.
3. Provide us with the names of patients (project sample) and the final results of the research.

Sincerely,,,

<sup>2</sup> The name of the hospital, logo, and director name were removed for anonymity reason.

## Appendix 7: Consent form

### [English and Arabic versions]

Dear participant

You are invited to participate in a research study entitled "**The Use of a Pain Assessment Tool in the Daily Work of Jordanian Oncology Nurses.**" This study aims to explore how cancer pain is assessed and managed in Jordan and to implement pain assessment tool into nursing work. In addition, we intend to know the barriers to optimal cancer pain management in Jordan. Moreover, nurses' knowledge and attitudes about pain management will be evaluated. The results of this study are expected to provide baseline information about nurses' practice in pain management and barriers to effective pain management.

The participation in this study is **voluntary** and you have the right to **refuse** to participate or **withdraw** at any time without affecting your medical care. Your identity and records as a participant in this study will remain confidential with respect to any publications/reporting of the results of this study. Your records in connection with this study will be kept confidential to the extent permitted by the law.

### **I confirm that, I am informed the following information (a copy of consent will be kept in your medical file):**

- I acknowledge that I have read, or it had been explained to me in a language that I understand, the attached Research Participant Information Sheet.**
- I understand that this study is not intended to be of any direct therapeutic or financial benefits to me.**
- I understand that I am free to withdraw this authorization and to discontinue participation in this study at any time.**
- I understand that such withdrawal will not affect my medical care (for patients only).**
- I confirm that I have read, or had read to me, the foregoing authorization.**

### **Participant:**

Name: \_\_\_\_\_ Date: \_\_\_\_\_ Signature: \_\_\_\_\_

### **Researcher or his representative:**

Name: \_\_\_\_\_ Date: \_\_\_\_\_ Signature: \_\_\_\_\_

## الموافقة الخطية المتنوره

### عزيزي المشارك \ المشارك

أنت مدعو للمشاركة في دراسة بحثية بعنوان "إستخدام مقياس الألم في الممارسه اليوميه للمرضي الأورام في الأردن". وتهدف هذه الدارسه إلى وضع مقياس الألم في الإستخدام اليومي وجعلها ممارسه يومية يقوم فيها مرضين الأورام في الاردن وذلك للنهوض بمستوى الرعاية المقدمه للمرضى و المساهمه في تخفيف الألم الذي يعانون منه. بالإضافة الى التعرف على كيفية قياس الألم وتوثيقه حالياً. في هذه الدارسه سيتم أخذ رأيك ( ممرض ، مريض، طبيب، مرافق) في ماهية الحواجز التي تمنع المرضى من إستقبال علاج كامل وكافي للألم بالإضافة الي بعض المعلومات الشخصية. وايضاً سيتم تقييم مستوى معرفتك (ممرضين) بالمبادئ الأساسية لعلاج الألم و رأيك بمقياس الألم الذي وضع قيد التنفيذ.

المشاركة في هذه الدراسة طوعه وإذا قررت عدم المشاركة أو الانسحاب من الدراسة، فانك لن تتعرض لأي مضايقات أو لفقدان أي من حقوقك المشروعة . ستكون هويتك كمشارك في هذه الدراسة سرية فيما يتعلق بجميع المنشورات والتقارير ذات الصلة بنتائج الدراسة. كما سيبقي سجلك سرياً في الحدود التي يسمح بها القانون. كما وانك تستطيع الاستفسار بشكل تفصيلي عن الدارسه من الباحث مباشره او بالاتصال على تلفون رقم **0776852572** وفي أي وقت، وكما أنه ليس هناك اي عائد مادي لك نتيجة مشاركتك في الدارسه.

اقر بأنى تم إبلاغى بالمعلومات التالية ( سيتم وضع نسخة من هذا الاقرار فى ملف المريض الطبى ):

- تم تقديم معلومات كافيه عن الدراسة وأنا على دراية تامة بدوري في هذه الدراسة.
- أعرف أن هذه الدراسة ليست لها أي فائدة علاجية أو ماليه مباشرة لي ، وأنى أتطوع بالمشاركة فيها.
- أدرك أن لي مطلق الحرية بسحب هذه الموافقة الخطية وإنهاء مشاركتي في هذه الدراسة في أي وقت أشاء.
- أفهم أن انسحابي من هذه الدراسة لن يؤثر على حقي في تلقي العناية الطبية اللازمة (للمرضى فقط).
- لقد قرأت - أو قترأت لي - هذه الموافقة الخطية قبل توقيعى عليها .

### المشارك :

الاسم : \_\_\_\_\_ التاريخ : \_\_\_\_\_ التوقيع: \_\_\_\_\_

### الباحث او ممثله :

الاسم : \_\_\_\_\_ التاريخ : \_\_\_\_\_ التوقيع: \_\_\_\_\_

## **Appendix 8: Information sheet**

**[English and Arabic versions]**

### **Improving cancer pain management in Jordan: A case study University of Manchester, School of Nursing, Midwifery and Social work**

Dear participant:

You have been invited to take part in a research study. Before you decide whether to participate or not, you need to comprehend why the study is being conducted and what is your role in the study. However, we will give you enough time you to decide to participate or not, please feel free to talk with others about the study if you like. There are three people from the University of Manchester involved in this study; Professor Karen Luker, Dr Cliff Richardson, and Mohammad Al Qadire. We will provide you with all information needed about the study. However, if you need further information, discuss some issue related to the project, or need an explanation, please feel free to contact the Mohammad Al Qadire either by phone on the number 026353953 or by email at [Mohammad.Qadire@postgrad.manch.ac.uk](mailto:Mohammad.Qadire@postgrad.manch.ac.uk).

## **What is the purpose of this study?**

This study aims to explore how cancer pain is assessed and managed in Jordan and to implement pain assessment tool into nursing practice. In addition, we intend to know the barriers to optimal cancer pain management in Jordan. Moreover, nurses' knowledge and attitudes about pain management will be evaluated. The results of this study are expected to provide baseline information about nurses' practice in pain management and barriers to effective pain management. In addition, the result may provide a model for changing practice that may be used by clinicians and policy makers to improve pain assessment and management.

## **Why have I been chosen?**

You have been chosen because the study involved cancer patients, nurses, physicians, and family caregivers, in this Hospital and you are one of those of our interest.

## **Do I have to participate?**

The participation in this study is entirely voluntary and you have the right to withdraw at any time you want.

## **What will happen if I agreed to participate?**

This depend on who are you; if you are

**Cancer patients:** you will be given some questionnaires (barrier questionnaire) to be filled in an interview; your pain will be assessed once before the implementation and three times after the implementation of new pain assessment tool.

**Nurses:** in the pre-implementation stage, you will be required to complete two questionnaires: a) the barrier questionnaire, b) knowledge and attitudes survey regarding pain management. In addition, you will be interviewed and asked some questions relating to your pain assessment and management practice. Following the interview you will be offered a pain assessment and management education course and thereafter you will be asked to use the new pain assessment tool. Finally, we need you to share us your experience of using the tool and give us your evaluation and feedback.

**Physicians and family caregivers:** both of you will only required to complete the barriers questionnaire.

## **What I have to do if I want to participate?**

Notify the researcher who will be available on the oncology unit (where is the study being conducted). Albeit you will be asked to sign a consent form, you still free to



withdraw at any time without any have given justification. Also your medical care will not be affected by your refusal to participate or withdrawal.

### **Who is funding and organising the research?**

This research is being funded by Al Al-Bayiet University in Jordan. The school of Nursing, Midwifery and Social Work is the organising body of the study. Professor Karen Luker, and Dr Cliff Richardson are leading the research project and Mohammad Al Qadire is the principal investigator.

### **Will this study be confidential?**

Identities of participants will be not revealed, and only aggregate data will be reported. All responses will be anonymous and remain confidential and also will be used for the purpose of this study. The data from this study will be kept and processed using computer in accordance with the University of Manchester registration under the data protection Act 1998.

### **Who has approved this study?**

This study has been approved by the Hospital and the University of Manchester, School of Nursing, Midwifery and Social work research ethics committees.

### **What will happen with the results of the study?**

It is anticipated that the study results will provide baseline information about Jordanian nurses' knowledge, attitudes regarding pain management and barriers to optimal cancer pain management. On the local level, the results of this study will be presented in the research setting using the intra-network, posters and presentations. In addition, it may be integrated in the hospital policy and may be used to implement other tools in different hospital departments. In regard to the national and international levels, the researcher will present the results in related conference and it will be published in a medical or academic journal.

### **Are there any risks if I participated?**

There is no known physical or psychological harm expected as result of taking part in this study.

### **What are the benefits I should receive as result of my participation?**

No direct benefits for you are expected. But the results of this study may help to improve cancer pain assessment and management for those patients. In addition, a baseline information about Jordanian nurses' knowledge, attitudes regarding pain

management and barriers to optimal cancer pain management will be provided which could be utilised in future research.

**In case I have complaints or concerns about the study, what I shall do?**

If you have any complaint, first you can contact Mohammad Al Qadire, if you still not satisfied with this, contact Professor Karen Luker in University of Manchester, School of Nursing, Midwifery and Social Work. She is reachable on phone number + 44 161 306 7639 or at [Karen.luker@manchester.ac.uk](mailto:Karen.luker@manchester.ac.uk) .

"إستخدام مقياس الألم في الممارسه اليوميه للمرضي الأورام في الأردن"

## معلومات المشارك

### عزيزي المشارك \ المشاركة

أنت مدعو للمشاركة في دراسة بحثية بعنوان "إستخدام مقياس الألم في الممارسه اليوميه للمرضي الأورام في الأردن". قبل ان تتخذ قرارك بالمشاركة أو عدمها ، من المهم أن تعرف ماهية هذه الدراسه وما الهدف منها وما هو دورك كمشارك فيها. سنعطيك الوقت الكافي لاتخاذ هذا القرار. فلا تتردد في الحديث او السؤال عن الدراسة إذا كنت ترغب في ذلك. هناك ثلاثة اشخاص من جامعة مانشستر في المملكة المتحدة يشاركون في هذه الدراسة هم البروفسور كارين لوكر والدكتور كليف ريتشاردسون ، ومحمد القادري اذا كنت بحاجة الى مزيد من المعلومات ، ومناقشة بعض القضايا ذات الصلة بالدراسة ، أو بحاجة إلى التوضيح ، فلا تتردد في الاتصال بالباحث محمدالقادري إما عن طريق الهاتف على الرقم 026353953 أو على البريد الالكتروني:

Mohammad.Qadire@postgrad.manchester.ac.uk

### **ما هو الغرض من هذه الدراسة؟**

تأتي هذه الدراسة لمعرفة الكيفية التي يتم فيها تقييم الألم وعلاجه في الأردن و أيضاً لوضع مقياس للألم قيد الممارسه اليومية للمرضي الارورام في الأردن. بالاضافه الى ان هذه الدراسة تهدف الى الحواجز التي تمنع علاج الألم بشكل فعال وايضا سنقيم معلومات المرضى ومقهم من علاج الألم في مرضى السرطان. يتوقع أن توفر نتائج الدراسه معلومات اساسيه عن ممارسات الممرض لمعالجة الألم ومعرفة المعوقات للوصول لعلاج الألم بشكل فعال. كما ان النتائج يمكن ان تشكل نموذج يمكن اتباعه من قبل صانعي القرار والكادر الطبي لتحسين تقييم وعلاج الألم.

### **لماذا تم إختياري للمشاركة في هذه الدراسة؟**

لقد تم اختيارك لان الدراسة تضم الاطباء والممرضين والمرضى ومرافقيهم في قسم الارورام في هذه المستشفى وانت من ضمن هذه الفئات.

### **هل يجب أن أشارك؟**

المشاركة في هذه الدراسة هي مشاركة طوعية تماما ، ولك الحق في أن ترفض المشاركة او الانسحاب من الدراسة في أي وقت تريده.

### **ما هو المطلوب مني إذا قررت المشاركة؟**

المطلوب يعتمد علو من هو انت، فإذا كنت:

**مريض:** سوف يطلب من ملئ استبيان "معوقات علاج الألم" بالاضافه الي انه سيتم تقييم المك قبل وبعد عملية وضع مقياس الالم حيز التنفيذ.

**ممرض:** قبل عملية وضع مقياس الالم حيز التنفيذ سيطلب منك ملئ الاستبانات التاليه: "معوقات علاج الألم" "المعرفه والمواقف تجاه علاج الالم". وسيكون هناك مقابله معك يتم فيها طرح اسئلة متعلقه بكيفية تقييمك وعلاجك للالم في ممارستك اليوميه. وبعد ذلك سوف يطلب منك استخدام أداة تقييم جديدة للألم. وأخيرا نريد منك اخبارنا بتجربتك اثناء استخدام هذا المقياس وتقييمه.

**طبيب أو مرافق:** سوف يطلب من ملئ استبيان "معوقات علاج الألم" فقط.

### ماذا يجب على أن أفعل إذا اردت المشاركة؟

عليك أن تبلغ الباحث الذي سوف يكون متواجد في القسم الذي يجرى فيه البحث برغبة في المشاركة. وبعدها سوف يطلب منك أن توقع نموذج الموافقه الخطيه المتنوره، مع العلم انه يحق لك الانسحاب من الدراسة في اي وقت دون أن يؤثر ذلك على الرعاية الصحية المقدمة لك.

### من يمول وينظم هذا البحث؟

هذا البحث يمول من قبل جامعة ال البيت في الأردن وينظم هذه الدراسة كلية التمريض في جامعة مانشستر في المملكة المتحدة. البروفسور كارين لوكر والدكتور كليف ريتشاردسون يقودون هذا البحث ومحمد القادري هو الباحث الرئيسي.

### ماذا عن سرية المشاركة في هذا البحث؟

لن يتم كشف هويات المشاركين في البحث باي شكل من الاشكال. وجيع المعلومات الشخصيه والاجابات ستبقى سرية وسوف تستخدم فقط لاغراض هذه الدراسة فقط. البيانات سوف يتم معالجتها في الكمبيوتر وفقا لقانون حماية المعلومات في جامعة مانشستر الصادر سنة 1998 م.

### من أجاز إجراء هذه البحث؟

لقد تمت الموافقه على إجراء هذا البحث من قبل لجنتي أخلاقيات البحث العلمي في المستشفى في الأردن وفي جامعة مانشستر في المملكة المتحدة.

### ماذا سيحدث بنتائج هذا البحث؟

يتوقع أن توفر نتائج الدراسه معلومات اساسيه عن ممارسات الممرضين لمعالجة الالم ومعرفة المعوقات الوصول لعلاج الالم بشكل فعال. كما ان النتائج يمكن ان تشكل نموذج يمكن اتباعه من قبل صانعي القرار والكادر الطبي لتحسين تقييم وعلاج الالم. على الصعيد المحلي سيتم عرض نتائج هذه الدراسه في المستشفى عن طريق

المحاضرات والملصقات. و أيضاً سيتم عرض نتائج دراسته في المؤتمرات العلمية ذات الصلة في الأردن والدول الأخرى إن أمكن. و سيتم نشرها في المجلات العلمية والاكاديمية.

### **هل هناك اي مخاطر تنتج عن المشاركة في البحث؟**

ليس هناك ضرر جسمي او نفسي متوقع نتيجة المشاركة في هذا البحث.

### **هل هناك اي فوائد تنتج عن مشاركتي في البحث؟**

ليس هناك فائده مباشره لك كمشارك ولكن يتوقع أن توفر نتائج دراسته معلومات اساسيه عن ممارسات الممرضين لمعالجة الالم ومعرفة المعوقات للوصول لعلاج الالم بشكل فعّال. كما ان النتائج يمكن ان تشكل نموذج يمكن اتباعه من قبل صانعي القرار والكادر الطبي لتحسين تقييم وعلاج الالم وبالتالي تحسين نوعية الرعاية المقدمة للمرضى في الأردن.

### **ماذا افعل في حال وجود شكوى أو استفسار عن الدراسة؟**

إذا كان لديك أي شكوى فيمكنك أولاً الاتصال بالباحث محمد القادري لكن أن لم تكن الاجابه مرضية فيمكنك الاتصال بالبروفيسور كارين لوكر في كلية التمريض في جامعة مانشستر على

هاتف رقم: 00 44 161 306 7639

أو على البريد الإلكتروني : [Karen.luker@manchester.ac.uk](mailto:Karen.luker@manchester.ac.uk)

## Appendix 9: University of Manchester ethics committee approval

[On university letterhead]

Our Ref: HS/MH/10/1035/NMSW

Mr M Al Qadire  
PhD Student  
School of Nursing, Midwifery & Social Work  
Jean McFarlane Building  
University of Manchester  
Oxford Road  
Manchester  
M13 9PL

11 February 2010

By email and internal post

Re: The Use of a Pain Assessment Tool in the Daily Work of Jordanian Oncology Nurses: A Case Study.

Proposal Number: 10/1035/NMSW

Dear Mr Al Qadire,

Thank you for the clarifications and amendments to the above study as requested by the Research Ethics Committee

I am of the opinion that no major concerns or objections are evident of an ethical nature. Therefore on behalf of the Committee and taking Chair's Action, I am happy to grant full ethical approval.

During the progress of the study please inform the Committee of any changes or amendments that may be necessary.

On completion of the study would you please provide the Committee with a "Completion of Study Report".

In order to arrange University Insurance Cover please forward the completed Insurance Form (enclosed) along with your Research Proposal and a copy of this letter to the Purchasing Office at the address printed on the form.

Best wishes for your study. Yours

sincerely



Howard Shilton  
Chair: School Research Ethics Committee

## Appendix 10: Demographic data sheet

### **Part A: General Information**

Serial Number: \_ \_ \_ \_ \_

Date: \_ \_ / \_ \_ / \_ \_

--

1-The participant is a:

- Nurse       Physician       Patient       Family caregiver
- 

2- Age in years: [      ]

---

3- Gender:

- Male       Female
- 

4- Highest Education Level:

- Illiterate       Primary school       Secondary school       Diploma
- Bachelor Degree       Masters       PhD
- 

5-Marital Status:

- Married       Single       Divorced       Widowed       Engaged

6- Where do you live?

- City       Village       Camp
- 

7- Religion:

- Muslim       Christian
- 

### **Part B: health care provider related Information**

8- How many years have you been qualified? \_\_\_\_\_

9- Have you attend any pain related education at King Abdullah University Hospital?

- Yes                       No

**Part C: Patient related Information**

10- Profession: \_\_\_\_\_

11- Diagnosis: \_\_\_\_\_

12- Cancer Stage: \_\_\_\_\_

13- Date diagnosed?    -----/-----/ -----

14- What type of treatment have you received?

- Chemotherapy     Surgery     Radiotherapy     Biotherapy     Hormonal
- Combination

15- Do you have other chronic disease?

- Yes, (state) \_\_\_\_\_                                       No

16- Who is your primary family caregiver? \_\_\_\_\_

**Part D: Caregiver related Information**

17- Profession: \_\_\_\_\_

18- Do you live with the patient in the same house?

- Yes                       No

19- Is this the first time you care for person with cancer?

- Yes                       No





- at all much
- 8) Pain medicine can effectively control cancer pain.
- 0      1              2              3              4              5
- Do not agree Agree very  
at all much
- 9) Many people with cancer get addicted to pain medicine.
- 0      1              2              3              4              5
- Do not agree Agree very  
at all much
- 10) Nausea from pain medicine cannot be relieved.
- 0      1              2              3              4              5
- Do not agree Agree very  
at all much
- 11) It is important to be strong by not talking about pain.
- 0      1              2              3              4              5
- Do not agree Agree very  
at all much
- 12) It is important for the doctor to focus on curing illness, and not waste time controlling pain.
- 0      1              2              3              4              5
- Do not agree Agree very  
at all much
- 13) Using pain medicine can harm your immune system.
- 0      1              2              3              4              5
- Do not agree Agree very  
at all much
- 14) Pain medicine makes you say or do embarrassing things.
- 0      1              2              3              4              5
- Do not agree Agree very  
at all much
- 15) If you take pain medicine when you have some pain, then it might not work as well if the pain becomes worse.
- 0      1              2              3              4              5
- Do not agree Agree very  
at all much
- 16) Pain medicine can keep you from knowing what's going on in your body.
- 0      1              2              3              4              5
- Do not agree Agree very

at all  
much

17) Constipation from pain medicine cannot be relieved.

0 1 2 3 4 5

Do not agree

Agree very

at all

much

18) If doctors have to deal with pain they won't concentrate on curing the disease.

0 1 2 3 4 5

Do not agree

Agree very

at all

much

19) Pain medicine can hurt your immune system.

0 1 2 3 4 5

Do not agree

Agree very

at all

much

20) It is easier to put up with pain than with the side effects that come from pain medicine.

0 1 2 3 4 5

Do not agree

Agree very

at all

much

21) If you use pain medicine now, it won't work as well if you need it later.

0 1 2 3 4 5

Do not agree

Agree very

at all

much

22) Pain medicine can mask changes in your health.

0 1 2 3 4 5

Do not agree

Agree very

at all

much

23) Pain medicine is very addictive.

0 1 2 3 4 5

Do not agree

Agree very

at all

much

24) Medicine can relieve cancer pain.

0 1 2 3 4 5

Do not agree

Agree very

at all

much

25) Doctors might find it annoying to be told about pain.

0 1 2 3 4 5

Do not agree

Agree very

at all

much

26) Reports of pain could distract a doctor from curing the cancer.

0	1	2	3	4	5
Do not agree					Agree very
at all					much

27) If I talk about pain, people will think I'm a complainer.

0	1	2	3	4	5
Do not agree					Agree very
at all					much

## **Appendix 12: Permission to use the BQ**

Mr. Qadire,

Attached you will find the BQ-II, and you have permission to use it, and several articles that will soon be appearing in print.

Best wishes in your work,

Sandy

At 07:50 AM 6/1/2009, you wrote:

Dear Dr,

I am Mohammad Qadire, a PhD student at Nursing school in University of Manchester. I am intending to do my research in the area of pain management of cancer patients. However, I would like to ask you to send me a copy of barriers questionnaire if it is possible? or helping me in getting a copy. I did a litterateur review and I found that you are one of leading person who research barriers to pain management. I am originally from Jordan and I found that no such research was conducted in my country. Although my research will be more complex but exploring the barriers will be an important element of my research.

Thank you in advance

## Appendix 13: Arabic barriers questionnaire

Serial Number: \_\_\_\_\_

عزيزي المشارك \ المشاركة:

نحن مهتمين بمعرفة وجهة نظرك ورأيك تجاه بعض الامور المتعلقة بعلاج الالم ( الحواجز والمعوقات). ستلاحظ وجود اسئلة متشابهه نرجوا منك الاجابه عن جميع الاسئلة. نرجوا منك اختيار رقم من ( ٥ - ٠ ) والتي تتناسب مع مدى موافقتك على صحة كل جزء لكل من الاسئلة التاليه.

**(1)** من الممكن علاج الالم الناتج عن مرض السرطان

5	4	3	2	1	0
أوافق بشده					لا أوافق أبداً

**(2)** هناك خطر للإدمان على الأدوية المسكنه للالم

5	4	3	2	1	0
أوافق بشده					لا أوافق أبداً

**(3)** يصعب السيطرة على الخمول الناتج عن أخذ الأدوية المسكنه للالم

5	4	3	2	1	0
أوافق بشده					لا أوافق أبداً

**(4)** تضعف الأدوية المسكنه للالم جهاز المناعة

5	4	3	2	1	0
أوافق بشده					لا أوافق أبداً

**(5)** يصعب السيطرة على حالة التشويش التي تنتج عن الأدوية المسكنه للالم

5	4	3	2	1	0
أوافق بشده					لا أوافق أبداً

**(6)** عندما تستخدم الادوية المسكنه للالم فإن الجسم يتعود عليها وتصبح غير فعاله بسرعة

5	4	3	2	1	0
أوافق بشده					لا أوافق أبداً

**(7)** يمنع استخدام الأدوية المسكنه للالم قدرتك على معرفة إذا ما كان لديك ألم جديد ام لا

5	4	3	2	1	0
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لا أوافق أبداً

أوافق بشده

**(8)** تستطيع الأدوية المسكنة للألم علاج الألم الناتج عن مرض السرطان

0 1 2 3 4 5  
لا أوافق أبداً أوافق بشده

**(9)** يتعرض العديد من مرضى السرطان للامان على الأدوية المسكنه للألم

0 1 2 3 4 5  
لا أوافق أبداً أوافق بشده

**(10)** لا يمكن علاج الغثيان الذي تسببه الأدوية المسكنه للألم

0 1 2 3 4 5  
لا أوافق أبداً أوافق بشده

**(11)** من المهم أن تكون قويا وذلك بعدم التحدث عن أمك

0 1 2 3 4 5  
لا أوافق أبداً أوافق بشده

**(12)** يجب على الأطباء التركيز على شفاء المرض نفسه وعدم اضاءة الوقت بعلاج الالم

0 1 2 3 4 5  
لا أوافق أبداً أوافق بشده

**(13)** ان استخدام الادوية المسكنه للألم يضر جهازك المناعي

0 1 2 3 4 5  
لا أوافق أبداً أوافق بشده

**(14)** ان الادوية المسكنه للألم تجعلك تقول وتفعل أشياء محرجه

0 1 2 3 4 5  
لا أوافق أبداً أوافق بشده

**(15)** إذا تناولت الأدوية المسكنه للألم لعلاج الم خفيف فان فاعليتها تقل في حال الالم الشديد

0 1 2 3 4 5  
لا أوافق أبداً أوافق بشده

**16) الأدوية المسكنه للألم تجعلك لا تعرف ما يجري داخل جسمك**

0 لا أوافق أبداً  
1  
2  
3  
4  
5 أوافق بشده

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**17) الإمساك الذي تسببه الادويه المسكنه للألم لا يمكن تخفيفه**

0 لا أوافق أبداً  
1  
2  
3  
4  
5 أوافق بشده

---

**18) إذا كان على الاطباء التعامل مع الالم فإنهم لن يركزوا على شفاء المرض نفسه**

0 لا أوافق أبداً  
1  
2  
3  
4  
5 أوافق بشده

---

**19) ان الادويه المسكنه يمكن أن تضر جهازك المناعي**

0 لا أوافق أبداً  
1  
2  
3  
4  
5 أوافق بشده

---

**20) إنه من الأسهل التعامل مع الالم بدل من التعامل مع الاعراض الجانبية للادويه المسكنه للألم**

0 لا أوافق أبداً  
1  
2  
3  
4  
5 أوافق بشده

---

**21) إذا تناولت الادويه المسكنه للألم الان، فإنها لن تعمل بنفس الفاعليه فيما بعد**

0 لا أوافق أبداً  
1  
2  
3  
4  
5 أوافق بشده

---

**22) يمكن للأدويه المسكنه للالم ان تخفي التغيرات في صحتك**

0 لا أوافق أبداً  
1  
2  
3  
4  
5 أوافق بشده

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**23) الأدوية المسكنه للالم إدمانيه**

0 لا أوافق أبداً  
1  
2  
3  
4  
5 أوافق بشده

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**(24) يمكن أن تخفف الأدوية الممرض السرطان**

0 لا أوافق أبداً  
1  
2  
3  
4  
5 أوافق بشده

---

**(25) قد يجد الاطباء انه من المزعج أن تخبرهم عن ألمك**

0 لا أوافق أبداً  
1  
2  
3  
4  
5 أوافق بشده

---

**(26) إخبار الأطباء عن الألم قد يشتتهم عن علاج المرض نفسه**

0 لا أوافق أبداً  
1  
2  
3  
4  
5 أوافق بشده

**(27) إذا تكلمت عن الألم، فإن الناس سيعتقدون اني كثير الشكوى**

0 لا أوافق أبداً  
1  
2  
3  
4  
5 أوافق بشده

---

**عزيزي المشارك \ المشاركة:**

قد يكون هناك حواجز واسباب اخرى تؤودي الى عدم كفاية علاج الألم المقدم لمرضى السرطان و لم تُذكر في الجمل السابقه. الرجاء منك ذكر هذه الاسباب في الفراغ المخصص للاجاباه:

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"شكرًا لمشاركتك"

## Appendix 14: Permission to use the BPI



Charles S. Cleeland, PhD  
Professor and Chair  
McCullough Professor of Cancer Research

Department of Symptom Research - Box 1450  
Tel: 713-745-3470  
Fax: 713-745-3475  
E-mail: [ccleeland@mdanderson.org](mailto:ccleeland@mdanderson.org)

April 20, 2009

Mr. Mohammad Qadire  
University of Manchester, Nursing School  
Groove House - Acomb 7.51  
Manchester, United Kingdom M13 9WJ

Re: Authorization to use the Brief Pain Inventory

Dear Mr. Qadire:

I am pleased that you have considered using the Brief Pain Inventory® (BPI) in your upcoming study. The study description you provided seems to be congruent with the intended use of the BPI. You are hereby granted permission to use it in your study. Please note that:

- Your use of the BPI is limited only to the study specified above; to use the BPI in additional studies, you must reapply online at [www.mdanderson.org/departments/prg](http://www.mdanderson.org/departments/prg) > Symptom Assessment Tools > The Brief Pain Inventory (BPI).
- You are permitted to reproduce the copy of the BPI that is included with this Letter of Authorization; however, you must not remove the copyright notice.
- The BPI may not be modified or translated into another language without the express written consent of the copyright holder, Charles S. Cleeland, PhD. Failure to comply may result in legal action. Permission to alter or translate the instrument may be obtained by contacting me at [symptomresearch@mdanderson.org](mailto:symptomresearch@mdanderson.org) or by mail.

We would greatly appreciate your sending us a summary of your study results after the completion of your project, so that we can continue to evaluate the performance of our instrument.

Sincerely,

A handwritten signature in black ink, appearing to read "Charles S. Cleeland".

Charles S. Cleeland, PhD  
McCullough Professor of Cancer Research and Chair  
Department of Symptom Research

CARING • INTEGRITY • DISCOVERY  
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*A Comprehensive Cancer Center designated by the National Cancer Institute located in the Texas Medical Center*

## Appendix 15: Arabic BPI

Study ID # \_\_\_\_\_ Hospital # \_\_\_\_\_

DO NOT WRITE ABOVE THIS LINE

### Brief Pain Inventory (Short Form)

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_ Time: \_\_\_\_

Name: \_\_\_\_\_

Last First Middle Initial

(١) خلال حياتنا، يعاني معظمنا من بعض الآلام بين حين وآخر (كالصداع البسيط أو التواء عضلة أو ألم الأسنان). هل عانيت خلال الأسبوع الماضي من ألم يختلف عن هذه الأنواع من الآلام العادية؟

(١) نعم (٢) لا

(٢) في المخطّط التالي، ظلّل مواضع الألم الذي تشعر به. ضع علامة X في الموضع الأشدّ ألماً.

(٣) من فضلك، ضع دائرة حول الرقم الذي يصفُ ألمك في أسوأ حالاته خلال الأربع والعشرين ساعة الماضية.

. ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠

لا يوجد ألم أسوأ ما يمكن تصوره من الألم

(٤) من فضلك، ضع دائرة حول الرقم الذي يصفُ ألمك في أضعف حالاته خلال الأربع والعشرين ساعة الماضية.

. ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠

لا يوجد ألم أسوأ ما يمكن تصوره من الألم

(٥) من فضلك، ضع دائرة حول الرقم الذي يصفُ ألمك في مُعظم الأوقات في الأربع والعشرين ساعة الماضية.

. ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠

لا يوجد ألم أسوأ ما يمكن تصوره من الألم

(٦) من فضلك، حدّد درجة ألمك بوضع دائرة حول الرقم الذي يصفُ مستوى ألمك الآن.

. ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠

لا يوجد ألم أسوأ ما يمكن تصوره من الألم

BPI-SF Arabic 2006

٧) ما هي أنواع العلاج أو الأدوية التي تتلقاها عن الألم؟

٨) خلال الأربع والعشرين ساعة الماضية، ما مدى الارتياح الذي استفدته من العلاج أو الأدوية التي أعطيت لك؟ من فضلك ضع دائرة حول النسبة المئوية التي توضح مدى الارتياح الذي استفدته.

٠٪ ١٠٪ ٢٠٪ ٣٠٪ ٤٠٪ ٥٠٪ ٦٠٪ ٧٠٪ ٨٠٪ ٩٠٪ ١٠٠٪  
لم يحصل أي ارتياح ارتياح كامل

٩) ضع دائرة حول الرقم الذي يصف مدى الإعاقة أو العرقلة التي سببها لك الألم خلال الأربع والعشرين ساعة الماضية في النواحي التالية:

أ) النشاطات العامّة

٠ ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠  
لا إعاقة إعاقة كاملة

ب) الزواج

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لا إعاقة إعاقة كاملة

ج) القدرة على المشي

٠ ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠  
لا إعاقة إعاقة كاملة

د) العمل العادي (يشمل ذلك العمل خارج المنزل والعمل المنزلي)

٠ ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠  
لا إعاقة إعاقة كاملة

هـ) العلاقات مع الناس الآخرين

٠ ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠  
لا إعاقة إعاقة كاملة

و) النوم

٠ ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠  
لا إعاقة إعاقة كاملة

ز) الاستمتاع بالحياة

٠ ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠  
لا إعاقة إعاقة كاملة

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Pain Research Group  
1515 Holcombe, Box 221  
Houston, Texas 77030  
All rights reserved

## Appendix 16: Example of observation notes

Day: Sunday

Date: 7/03/2010 Day shift

Today I (Researcher) asked RN10 to allow me to shadow him during the shift for two or three hours. He welcomed the idea and called me the assistant. I followed him in his work and helped him in carrying trolleys, medications handling, and responding to patient's bells. I mimic unit nurses for three hours.

While we were in the unit, patient in room (1091) ring the bell and we went to his room for help. Then the following dialog happened between the nurse and the patient.

**RN10** knocked the door, and said Assalam Alukom (equivalent to hi in English) Hajji (word used to call old men and it show respect), what's up

**Patient:** I feel sick and nauseated

**RN10:** since when?

**Patient:** early morning but thought it will go away. It is killing me.

**RN10:** ok I will call your doctor and see what he can do.

**Patient:** please hurry and don't forget me for the God sake.

**RN10:** no worries hajji.

We (Researcher and RN10) return back to station and RN10 called the physician and doctor came after 10 minutes to examine the patient. After two hours another patient (room 1089) ring the bell and RN10 asked me to go and see what he wants. I knocked the door and I said: Assalam Alukom, I am working with RN10 today and would like to hear you need.

**Patient:** oh really, I am not good, feel dizzy and feel my shoulders crashing. It is painful and cant lying down. Please I want my nurses.

**Me:** ok as you wish, I will bring him.

I told RN10 about patient complain. N10 said no need to go there; I will call the doctor and see what he will do. After 10 minutes the doctor called RN10 and told him to give the patient 50 mg diclogesic P.O. We went to patient room and RN10 brought the tablet and gave it to the patient.

**Patient:** oh this tablet again, what is it for?

**RN10:** I told your doctor and he ordered this tablet.

**Patient:** yesterday he gave me the same one and it doesn't work and still have this nagging pain and dizziness.

**RN10:** I can't do anything more, you just take it and if it doesn't work, we can call him again.

**Patient:** OK, Give me it. I thanked N10 and I was lucky enough to catch this event after 15 days work in the field. I returned to my work collecting survey data.

**Appendix 17: Data extraction sheet**

Serial Number:.....

Diagnosis:.....

Treatment:.....Chronic disease: .....Age:.....

**A) Prescribed Pain Medication**

Drug name	Drug classification (Potency)	Date prescribed	Route	Average total dose		Frequency
				Prescribed	Given	

**B) Pain Management Index score**

Patient worst pain score (in the last 24hrs )	Potent pain medication score (in the last 24hrs )	PMI score

**C) Pain assessment and documentation was included in:**

- Pain assessment tool
- Nursing note
- Only pain medications were given and signed
- Nothing found about pain

## Appendix 18 Pain indicators comparisons between two group

**Mann-Whitney U test results analysing the difference in worst pain score between two groups**

<b>Variable</b>	<b>N</b>	<b>Mann-Whitney U</b>	<b>p</b>
<b>Gender</b> Male Female	15 20	139.5	0.723
<b>Education</b> Low education Highly educated	21 14	104.5	0.146
<b>Type of cancer</b> Leukaemias and lymphomas Solid tumour	13 22	106	0.202
<b>Type of cancer treatment</b> Chemotherapy only Combination therapy	24 11	129.5	0.928
<b>Stage of cancer</b> Early stages Advance stages	10 15	54.5	0.252
<b>Have had chronic disease</b> Yes No	04 31	34	0.142

**Mann-Whitney U test results analysing the difference in lowest\_pain score between two groups**

<b>Variable</b>	<b>N</b>	<b>Mann-Whitney U</b>	<b>p</b>
<b>Gender</b> Male Female	20 15	114	0.219
<b>Education</b> Low education Highly educated	21 14	105	1.000
<b>Type of cancer</b> Leukaemias and lymphomas Solid tumour	13 22	102	0.137
<b>Type of cancer treatment</b> Chemotherapy only Combination therapy	24 11	106	0.342
<b>Stage of cancer</b> Early stages Advance stages	10 15	48	0.130
<b>Have had chronic disease</b> Yes No	4 31	56	0.753

**Mann-Whitney U test results analysing the difference in average pain score between two groups**

<b>Variable</b>	<b>n</b>	<b>Mann-Whitney U</b>	<b>p</b>
<b>Gender</b> Male Female	20 15	138	0.687
<b>Education</b> Low education Highly educated	21 14	139	0.786
<b>Type of cancer</b> Leukaemias and lymphomas Solid tumour	13 22	132	0.705
<b>Type of cancer treatment</b> Chemotherapy only Combination therapy	24 11	118	0.616
<b>Stage of cancer</b> Early stages Advance stages	10 15	60	0.403
<b>Have had chronic disease</b> Yes No	4 31	28	0.071

**Mann-Whitney U test results analysing the difference in pain now score between two groups**

<b>Variable</b>	<b>n</b>	<b>Mann-Whitney U</b>	<b>p</b>
<b>Gender</b> Male Female	20 15	146	0.893
<b>Education</b> Low education Highly educated	21 14	120	0.360
<b>Type of cancer</b> Leukaemias and lymphomas Solid tumour	13 22	139	0.891
<b>Type of cancer treatment</b> Chemotherapy only Combination therapy	24 11	102	0.275
<b>Stage of cancer</b> Early stages Advance stages	10 15	62	0.468
<b>Have had chronic disease</b> Yes No	4 31	48	0.465



**Appendix 19: The mean score for patients resapons on BQ**

<b>Subscale</b>	<b>Items</b>	<b>Mean (SD)</b>
Physiological Effects	Drowsiness from pain medicine is difficult to control.	2.5 (1.5)
	Confusion from pain medicine cannot be controlled.	2.3 (1.6)
	When you use pain medicine your body becomes used to its effects and pretty soon it won't work any more	2.9 (1.7)
	Using pain medicine blocks your ability to know if you have any new pain.	3.4 (1.4)
	Nausea from pain medicine cannot be relieved	2.0 (1.6)
	Pain medicine makes you say or do embarrassing things	1.7 (1.5)
	If you take pain medicine when you have some pain, then it might not work as well if the pain becomes worse	2.9 (1.7)
	Pain medicine can keep you from knowing what's going on in your body	3.2 (1.6)
	Constipation from pain medicine cannot be relieved.	2.3 (1.7)
	It is easier to put up with pain than with the side effects that come from pain medicine	2.7 (1.5)
	If you use pain medicine now, it won't work as well if you need it later	3.2 (1.5)
	Pain medicine can mask changes in your health	3.1 (1.7)
Fatalism	Cancer pain can be relieved.	1.3 (1.4)
	Pain medicine can effectively control cancer pain	2.3 (1.5)
	Medicine can relieve cancer pain	1.6 (1.5)
Communication	It is important to be strong by not talking about pain	3.1 (1.7)
	It is important for the doctor to focus on curing illness, and not waste time controlling pain.	3.2 (1.7)
	If doctors have to deal with pain they won't concentrate on curing the disease	2.2 (2.8)
	Doctors might find it annoying to be told about pain	2.2 (1.8)
	Reports of pain could distract a doctor from curing the cancer.	1.8 (1.7)
	If I talk about pain, people will think I'm a complainer.	2.5 (1.8)
Harmful Effects	There is a danger of becoming addicted to pain medicine	3.0 (1.8)
	Pain medicine weakens the immune system	2.6 (1.6)
	Many people with cancer get addicted to pain medicine	2.6 (1.6)
	Using pain medicine can harm your immune system	2.7 (1.7)
	Pain medicine can hurt your immune system	2.3 (1.6)
	Pain medicine is very addictive	3.2 (1.7)

## Appendix 20: The mean score for family caregivers' response on BQ

Subscale	Items	Mean (SD)
Physiological Effects	Drowsiness from pain medicine is difficult to control.	2.7 (1.4)
	Confusion from pain medicine cannot be controlled.	2.5 (1.4)
	When you use pain medicine your body becomes used to its effects and pretty soon it won't work any more	3.1 (1.7)
	Using pain medicine blocks your ability to know if you have any new pain.	2.9 (1.4)
	Nausea from pain medicine cannot be relieved	2.2 (1.5)
	Pain medicine makes you say or do embarrassing things	2.1 (1.6)
	If you take pain medicine when you have some pain, then it might not work as well if the pain becomes worse	3.1 (1.7)
	Pain medicine can keep you from knowing what's going on in your body	3.2 (1.6)
	Constipation from pain medicine cannot be relieved.	2.2 (1.7)
	It is easier to put up with pain than with the side effects that come from pain medicine	2.5 (1.5)
	If you use pain medicine now, it won't work as well if you need it later	3.2 (1.6)
	Pain medicine can mask changes in your health	3.3 (1.4)
	Fatalism	Cancer pain can be relieved.
Pain medicine can effectively control cancer pain		2.3 (1.5)
Medicine can relieve cancer pain		1.8 (1.4)
Communication	It is important to be strong by not talking about pain	2.9 (1.7)
	It is important for the doctor to focus on curing illness, and not waste time controlling pain.	2.9 (1.7)
	If doctors have to deal with pain they won't concentrate on curing the disease	2.0 (1.8)
	Doctors might find it annoying to be told about pain	1.9 (1.8)
	Reports of pain could distract a doctor from curing the cancer.	2.1 (1.7)
	If I talk about pain, people will think I'm a complainer.	2.7 (1.8)
Harmful Effects	There is a danger of becoming addicted to pain medicine	3.3 (1.2)
	Pain medicine weakens the immune system	3.0 (1.4)
	Many people with cancer get addicted to pain medicine	3.0 (1.5)
	Using pain medicine can harm your immune system	2.5 (1.6)
	Pain medicine can hurt your immune system	2.6 (1.6)
	Pain medicine is very addictive	3.2 (1.7)

**Appendix 21: The mean score for healthcare providers' response on BQ**

<b>Subscale</b>	<b>Items</b>	<b>Mean (SD)</b>
Physiological Effects	Drowsiness from pain medicine is difficult to control.	2.7 (1.4)
	Confusion from pain medicine cannot be controlled.	2.5 (1.4)
	When you use pain medicine your body becomes used to its effects and pretty soon it won't work any more	3.1 (1.7)
	Using pain medicine blocks your ability to know if you have any new pain.	2.9 (1.4)
	Nausea from pain medicine cannot be relieved	2.2 (1.5)
	Pain medicine makes you say or do embarrassing things	2.1 (1.6)
	If you take pain medicine when you have some pain, then it might not work as well if the pain becomes worse	3.1 (1.7)
	Pain medicine can keep you from knowing what's going on in your body	3.2 (1.6)
	Constipation from pain medicine cannot be relieved.	2.2 (1.7)
	It is easier to put up with pain than with the side effects that come from pain medicine	2.5 (1.5)
	If you use pain medicine now, it won't work as well if you need it later	3.2 (1.6)
	Pain medicine can mask changes in your health	3.3 (1.4)
Fatalism	Cancer pain can be relieved.	1.8 (1.6)
	Pain medicine can effectively control cancer pain	2.3 (1.5)
	Medicine can relieve cancer pain	1.8 (1.4)
Communication	It is important to be strong by not talking about pain	2.9 (1.7)
	It is important for the doctor to focus on curing illness, and not waste time controlling pain.	2.9 (1.7)
	If doctors have to deal with pain they won't concentrate on curing the disease	2.0 (1.8)
	Doctors might find it annoying to be told about pain	1.9 (1.8)
	Reports of pain could distract a doctor from curing the cancer.	2.1 (1.7)
Harmful Effects	If I talk about pain, people will think I'm a complainer.	2.7 (1.8)
	There is a danger of becoming addicted to pain medicine	3.3 (1.2)
	Pain medicine weakens the immune system	3.0 (1.4)
	Many people with cancer get addicted to pain medicine	3.0 (1.5)
	Using pain medicine can harm your immune system	2.5 (1.6)
	Pain medicine can hurt your immune system	2.6 (1.6)
Pain medicine is very addictive	3.2 (1.7)	

## Appendix 22: Education course lectures handout.

MANCHESTER

# Cancer pain management

Mohammad Al Qadire  
University of Manchester  
School of Nursing, Midwifery and  
social work

## Course objective

- By the end of this course, you are expected to:
  - Correctly demonstrate an understanding of pain as a multi-dimensional experience.
  - Identify causative factors for cancer pain.
  - Recognise the importance of pain assessment and management.

## Course objective

- Be informed about the barriers to optimal cancer pain management.
- Demonstrate competence in assessing cancer pain.
- Demonstrate competence in using the brief pain inventory.
- Comprehend the available pharmacological and non-pharmacological interventions to treat pain.
- Understand the nursing role in cancer pain management

## Course structure

- *Part one (2hours)*
  - defining pain
  - aetiology of pain in cancer
  - prevalence of cancer pain
  - importance of pain assessment
- *Session two (2 hours)*
  - myths and misconceptions about pain
  - pain assessment
  - how to use the brief pain inventory
- *Session three( 2hours)*
  - overview of pain management intervention
  - nursing role in pain management
  - barriers to cancer pain management

## Defining pain

- What is pain?
- "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage"

(International Association for the Study of Cancer Classification of Chronic Pain, 1987, 1994)

## Pain definition

- We could define pain simply as:
- Whatever the person says it is, existing whenever the person says it does (MacCaffery and Pasero, 1999).
-

## Cause of cancer pain

- Cancer pain is a result of tumor invading pain sensitive structures such as bone, soft tissue, nerves, viscera, blood vessels and from cancer treatment.
- Patient may have more than causative factor at the same time.
- Stress accompanying cancer diagnosis and treatment can cause pain.

## Types of pain

Pain Type	Example	Characteristics / Description
<b>Noiceptive</b>		
Visceral	Liver capsule Pain	Sharp / stabbing / ache
Somatic	Bone pain	Deep aching / like toothache / "gnawing" cramp, spasm, achey, intermittent
<b>Neuropathic</b>		
Nerve Injury		
◀ Peripheral	neuroma, brachial plexus infiltration	burning / stabbing / "pins and needles"
◀ Central	Spinal cord compression	numbness / weakness / tight chest pain / cutting / stabbing / shooting / burning
◀ mixed	post herpetic neuralgia	
Sympathetically maintained	chronic post surgical pain	burning (superficial), arterial distribution

Source: <http://www.cancerpain.org.uk/module1d.htm>

## Why pain assessment?



## Research Evidence

Author	Design	Group of patient	of Framework or theory	Main results
(Carr et al, 1997)	Not determined	Elderly patients	NA	Using a pain assessment tool can improve the communication between patients and professionals and among professional themselves. In addition, teaching healthcare professional about pain assessment and management strategies may improve the likelihood of integrating such tool into practice.
(Rhodes et al, 2001)	Pre and post intervention (chart review)	Oncology outpatients	NA	The use of Visual Analogue Scale (VAS) was feasible and leads to identify many patients with pain. However, the overall pain documentation has been increased from 1% to 73% after the use of pain assessment tool.

## Research Evidence

Author	Design	Group of patient	Use frequency	Main results
(de Rond et al, 1999)	Quasi-experimental	Oncology (50%) and non oncology patients	Two times a day (at morning and evening)	It was found that the use of pain assessment tool in daily practice is feasible and valued by nurse and patients. In addition, the compliance rate is 73.9% among nurses. However, the implementation process needs to be tailored according to the needs and culture of setting.
(Bourbonnais and Bourvett, 2004)	Multi-central study	Palliative care patients	Not indicated	The use of a pain assessment tool can significantly improve the total pain management. However, using change model, in addition, to education are essential to sustain the long term use of such tool.

## Research Evidence

Author	Design	Group of patient	Use frequency	Main results
(Martoni et al, 2007)	Chart auditing	Medical oncology	Twice a day	The use of pain assessment tool (VAS) was feasible and patient complies with the use of such tool. However, the role of pain assessment tool in guiding analgesic treatment is not well established.

## Prevalence of cancer pain

- Unfortunately pain is highly prevalent among cancer patient.
- According Everdingen et al (2007),
- 64 % of cancer patients experience pain in advanced stages.
- 54 % during the treatment period (chemotherapy, radiotherapy and others),
- 33 % after completion of the treatment regimen,
- and the prevalence in all types (pooled prevalence) was > 50 %

## Prevalence of cancer pain

- One third of cancer patients described their pain as moderate to severe.
- Unidentified and untreated pain can:
  - Negatively impacts patient quality of life.
  - Cause patients to lose hope.
  - Impede their response to treatment

Cancer pain prevalence

Author, year	Country	Sample	Pain prevalence	Quality score
(Forgeron et al., 2006)	Jordan	35	57%	23
(Wang, 2008)	China	923	68%	15
(Bruster et al., 1994)	UK	5150	61%	30
(Menzies et al., 2000)	UK	186	28%	20
(Yun et al., 2003)	Korea	655	70%	21
(Brelvik et al., 2009a)	Czech Republic	5084	70%	25
	Denmark			
	Finland			
	France			
	Ireland			
	Israel			
	Italy			
	Norway			
	Romania			
	Sweden			
	Switzerland			
	UK			
(Larue et al., 1995)	France	601	57%	23
(Beck andFalkson, 2001)	South Africa	263	35.7%	22
(Holtan et al., 2007)	Norway	1337	52%	25
(Okuyama et al., 2004)	Japan	282	60%	22

Thanks

MANCHESTER

# Cancer Pain Assessment

Mohammad Al-Qadire

- ## Introduction
- Pain is a multidimensional and subjective phenomenon.
  - to achieve effective pain management, comprehensive pain assessment is required.
  - completely valid and reliable pain assessment tool are not yet available.

- Pain screening should be integrated into nursing practice.
- Pain assessment can help in identifying ongoing or new pain.
- Patient should be assessed daily for pain.

- ## 1- History
- Medical history include asking about:
    - Cancer stage
    - Previous cancer treatment
    - Cancer pain syndromes.
    - Other physical symptoms.
    - History of alcoholism

- ## 2- Physical examination
- Cancer patients should undergo a complete and comprehensive physical examination on admission.
  - This include examining all the possible causes of pain.
  - This will add more information to completely understand patient pain.

- ## 3- Investigations
- Include :
    - laboratory work
    - CT scan
    - MRI
    - X-RAY
    - bone scan, etc
  - They help in clarifying and understanding of pain causes.
  - Aid in choosing the appropriate pain treatment.



#### 4- Initial Pain assessment

- It is the first assessment that patient received when visit healthcare setting.
- This assessment asking about having pain or not?
- If yes more detailed assessment should be conducted.
- Initial assessment guides clinicians in diagnosing and treating cancer pain.

- Initial Pain assessment includes asking about:
  - Intensity: current, worst and average pain
  - Location: origin of pain
  - Onset
  - Duration
  - Intensifier
  - Nullifiers
  - Radiation

- Everyday, an assessment should be made of the patient's pain and any side effects of current treatment.
- Frequency with which pain should be assess varied according to the patient situation.
- For example in uncontrolled pain( 10 out of 10 point score scale) where rapidly acting medication in use, pain assessment should be done every 15 minutes until the pain become controlled.

- In well controlled pain once each 8 to 12 hrs is considered to be enough.
- After initial pain assessment patient should be assessed for pain intensity and its interference with daily living activity at least
- The nurse should learn to ask patient about pain since patients are reluctance to report pain unless they asked.

- Pain related information should be communicated and passed between nurse across shifts rotation and with other professionals.

#### Pain assessment tools

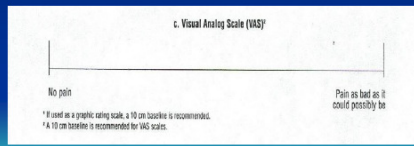
- A plethora of pain measurement tools are available, but no are universally tool as yet.
- About 91 pain assessment tool are currently available.
- Measurement tools were divided into two broad categories one-dimensional and multidimensional.



## Uni-dimensional

- The three most widely used scales are:

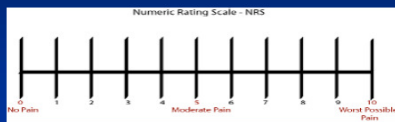
### 1- Visual Analog Scale (VAS)



### 2- Verbal Rating Scale (VRS)

Pain Score	Description
0	No pain or discomfort at all.
1	Sensation of mild discomfort only.
2	Sensation of moderately severe pain.
3	Sensation of severe pain and/or grating or withdrawal of limb.

### 3- Numerical Rating Scale (NRS).



- In general, they are valid, reliable and feasible, but they only measure one domain and that is pain intensity.

- According to the European Association of Palliative Care (EAPC) all three scales are considered as having equal recommendation for use in practice.

## Multidimensional Tools

- Most of these tools are disease specific, partially validated and were developed without using systematic methods.

Of these tools only the :

- The Brief Pain Inventory.
- McGill Pain Questionnaire.

Were systematically developed and validated in different languages and cultural backgrounds.

## The Brief Pain Inventory (BPI)

- The BPI is constructed of 23 self-report items
- It covers two main domains:
  - Pain intensity

Patients rate their pain on a (1-10) points numerical scale for the current, worst, lowest and average pain in last 24 hours.  
the higher the score in this subscale the more severe the pain.

- Pain interference
- Pain interference ask patients to rate how much pain impacts on their activity and mood on a (1 to 10) numerical scale.
- Interference scales start with words "no interference" and end with "interferes completely".
- Body map also available to allow patient locate pain location.

- Patients have the chance to express how they perceived the cause of pain.
- The completion of the BPI should not take more than 10 minutes but a short form is also available and need maximum 5 minutes to be completed.
- we will use the short form.
- See the following slides

### Comparison between BPI and MPQ

	MPQ	BPI
Author	Melanick and Ferguson 1971	Cleveland 1989
Population	Non- cancer patients but it used in cancer pain.	Cancer patients but it used in non-cancer pain.
Short-form	Yes	Yes
Pain descriptors	Yes	No
Domains	Sensory, affective, evaluative	Sensory and pain interference
Formulation	Yes, Arabic not inclusive	Yes, inclusive Arabic
Validity	Yes, but not in Arabic culture	Yes, but not in Arabic culture
Sensitivity	Yes	Yes
Discriminative capacity	Yes	No
Easy to use	Yes	Yes

### Why BPI?

- It is already translated into the Arabic language and is currently under validation.
- It was originally developed for use with cancer patients.
- it is extensively validated in different languages and cultural backgrounds which provide material for comparison.

- BPI user guide booklet has become available, which indicated that the BPI was validated in 72 studies.
- The short form of the BPI contains simple adjectives and translation can give the exact meaning of the original English version into Arabic.
- It is a valid tool that balances between the need for detailed data about pain and the shortage of staff time.

### How to use it?

- It can be given to the patient and ask him to complete it.
- Or you can simply ask the patients the questions and write down their answers.
- our plan is to use it twice a day, once per shift.
- It should be filled with the vital signs round at 10 am and 10 pm to make it more convenient.

- Patients with pain should be re-assessed after the medication dose (every 15 minutes) and until they report 0 pain level.
- Re-assessment is important and should not be ignored.
- The most important idea to take home that pain is the fifth vital signs.

- I will be available in the unit for any help.
- Our change champions (Mariam and Mohammad) can help.
- For the time being I will distribute the tool and you can have the chance to use it with you colleagues.

- Imagine that you colleague is the patient.
- Assess his/her pain
- See how the tool work
- What possible problem with the BPI
- Or any other related question
- Lets start guys

- Discussion after the trial

The end

- Thanks

# Cancer pain management

Mohammad Al-Qadire

- Patients presenting with pain should be assessed and then placed on suitable treatment.
- Pharmacological treatment is the most commonly used in cancer pain treatment, but non-pharmacological interventions are also available.

## WHO ladder

- The World Health Organization (WHO) approach to pain management has been shown to be effective in relieving pain in 90% of patients with cancer and 75% of terminally ill cancer patients.
- The WHO recognized the negative impacts of cancer pain on patient life quality and the importance of alleviating patient suffering

## Principles of pain management

- Drug therapy should be administered:
- **By the mouth:** Oral administration is convenient, non invasive, cost effective and well tolerated in most patients.
- **By the Clock:** Regular analgesia (4-6 hourly) with breakthrough doses when needed provide a more constant level of drug in the body and reduce pain recurrence.

- **By the ladder:** Patients should move up the ladder as necessary, but may also move down the ladder if pain decreases.
- **For the individual:** Patients presenting with moderate to severe pain can be started on a higher step in the ladder. Some patients will not be able to tolerate oral medication and may need other preparations. Patients may need non drug therapies. There is no standard dose of opioid - morphine requirements can vary from 5mg to 1000mg every four hours.

- **With attention to detail:** Total analgesia usage should be monitored every 24 hours, and the maintenance dose adjusted accordingly.
- Breakthrough doses should be adjusted in line with changes to regular medication.
- New pain should be assessed promptly to ascertain the cause and to allow treatment.
- Patients should be informed of possible adverse drug effects.

## The Pain Ladder: Overview



- This diagram represents the different steps of the pain ladder.
- Patients can be started on any stage of the ladder and moved up until they are free from pain.
- If pain decreases or becomes steady, drug dosages may be reduced and patients may be moved down a step.
- We will look at each step in depth later on

## Drug Classes

- There are three main classes of drugs used in the pain ladder:
- non opioids
- opioids
- and adjuvant.

- **Non opioids**
- These include simple analgesics such as **Paracetamol** and **Aspirin**, as well as Non-Steroidal Anti Inflammatory Drugs (NSAIDs) such as **Ibuprofen**, **Ketoprofen** and **Diclofenac**.
- **Opioids:** The opioids are a large group of drugs that include **codeine**, **tramadol**, **morphine** and **methadone**. They play an important role in the management of pain in a large proportion of cancer patients.

- **Adjuvant**
- These include analgesics for specific types of pain, drugs that enhance the effect of other analgesics, and drugs that help treat concurrent symptoms that exacerbate pain.
- They include **Gabapentin** (neuropathic pain), **Midazolam** (agitation, anxiety), **Baclofen** (muscle spasm), **Zoledronic Acid** (bone pain), and **Dexamethasone** (nerve root compression).
- Adjuvants can be added in at any step of the ladder as the need arises.
- Often more than one adjuvant may be needed

STEP 1 non opioid +/- adjuvant 1

- A useful first line of treatment is often the use of simple analgesics and NSAIDs.
- When prescribing NSAIDs:
  - check for any history of Asthma.
  - previous hypersensitivity reaction.
  - active bleeding / ulceration. In all cases when NSAIDs will be used for a prolonged period, a gastroprotective drug should be prescribed e.g.. **Lansoprazole 15mg od**.

The table below shows a list of typical dosages.

Drug	Dosage	Frequency	Route
Paracetamol	500mg - 1g	6 hourly	PO, PR
Ibuprofen	400mg - 800mg	6 hourly	PO
Diclofenac	50mg	6 hourly	PO
Diclofenac	100mg	18 hourly	PR
Ketoprofen	50mg	8 hourly	PO

PO = oral, PR = rectal

opioid for mild to moderate pain  
+/- non opioid  
+/- adjuvant

- If pain persists or increases, patients move up from step 1 to step 2.
- They will typically continue on any NSAID / adjuvants already prescribed, but should also be commenced on a weak opioid, such as Codeine, Dihydrocodeine or Tramadol.
- If they were also on Paracetamol, a combined preparation can be prescribed, being careful not to exceed the maximum recommended dose of Paracetamol of 4g in 24 hours.

The table below shows typical dosages of some commonly used drugs.

Drug	Dosage	Frequency	Route
Codeine phosphate	30mg - 60mg	6 hourly	PO
Dihydrocodeine	30mg - 60mg	6 hourly	PO
Cocodamol (30/500)	1-2 tabs	6 hourly	PO
Codydramol	1-2 tabs	6 hourly	PO

opioid for moderate to severe pain  
+/- non opioid  
+/- adjuvant

- If pain persists or increases, patients move up from step 2 to step 3.
- The opioid drugs used in this stage will be more potent drugs such as morphine, fentanyl and methadone. Morphine is the most commonly used first line in this step, and the only one we will consider here.

- To calculate a suitable starting dose, patients should have an oral morphine preparation prescribed as needed, usually oral morphine.
- The total opiate used in 24 hours will give an indication of the best starting dose.
- So if a patient uses a total of 60mg of morphine, they can be started on either 10mg every four hours, or preferably, 30mg twice daily of a modified release preparation.

- The PRN (as needed) dose of oral morphine should be increased such that the PRN dose is 50% to 100% of the calculated regular four hourly dose.
- Examples are given in the table in the next slide.



Drug	Dosage	Frequency	Total in 24h	PRN dose (4 hourly)
Morphine sulphate	20mg	4 hourly	120 mg	10-20mg
Morphine Sulphate	40 mg	4 hourly	240mg	20-40mg
Morphine sulphate MR (eg Zomorph)	60mg	12 hourly	120mg	10-20mg
Morphine sulphate Sustained Release (eg MXL)	200mg	24 hourly	200mg	15-30mg

- So a patient on Step 3 may be on a drug regime like this:
- Morphine sulphate modified release 30mg twice a day
- Diclofenac 50mg three times a day
- Lansoprazole 15mg once a day
- + / - any adjuvants as needed.

## Morphine

- Morphine is the most widely used strong opioid used in cancer pain management and usually the drug of choice.
- Wherever possible, the preferred route is oral, and it is available as a liquid, tablets or as capsules.
- There are both normal release (4 hourly) and slow release preparations (12 hourly or 24 hourly).
- Morphine is metabolised in the liver, but liver disease does not contraindicate its use.

- Morphine 6 Glucuronide (M6G), an active metabolite of morphine is excreted by the kidney, so renal dysfunction can increase accumulation of M6G.
- This can lead to central depression (sedation / respiratory depression) and may require the use of lower doses or changing to another opioid in some cases.

- Morphine can also be administered subcutaneously, intramuscularly or intravenously.

## Side effects of opioids

- **Constipation** - this is the most common side effect. To reduce this, all patients started on opioids should be started on a laxative.
- **Nausea and vomiting** - this occurs in up to 50% of patients on opioids for moderate to severe pain.
- **Drowsiness and confusion** - this is particularly common in elderly patients. All patients should be warned about initial drowsiness (which often improves after 3-5 days on the drug).



- **Respiratory depression** - this is a less common side effect in cancer patients with pain as the pain acts as a physiological respiratory stimulant, balancing the depressive effect of the opioids. However, it can still occur (especially in heavily sedated patients), and can be counteracted by administering naloxone at a dose of 0.2 - 0.4 mg. This may not be appropriate in all patients.

- **Rare side effects** - these include opioid induced psychosis, or symptoms related to histamine release (pruritis, bronchospasm).
- These patients may need to be changed to another strong opioid.

## Changing opioids

- Reasons for switching between strong opioids:
  - if patients have poor renal function
  - experience heavy sedation or develop some of the less common side effects.
  - if patients are unable to comply with the medication - because they are too frail, confused or if they are unable to swallow.

- Whatever the route or opioid used, it is important to consider the correct conversion to ensure adequate pain relief continues.

Table 1 lists common opioids (and routes) used as alternatives to oral morphine, with the equivalent dose compared to oral morphine.

Drug	Dose	Route
Morphine	10mg	oral
Diamorphine	3mg	subcutaneous / intramuscular
Hydromorphone hydrochloride	1.3mg	oral
oxycodone	5mg	oral

Transdermal fentanyl preparations are sometimes used for patients having problems taking oral morphine. The patches come in fixed sizes, and the equivalent oral morphine doses are shown below.

24 hour oral morphine	Equivalent Fentanyl dose (every 72 hours)
90mg	25 micrograms/hour (Fentanyl 25 patch)
180mg	50 micrograms/hour (Fentanyl 50 patch)
270mg	75 micrograms/hour (Fentanyl 75 patch)
360mg	100 micrograms/hour (Fentanyl 100 patch)

## Adjuvant medications

- Adjuvant medications may be used for several reasons. These include:
- to treat the adverse effects of opioid analgesics (eg antiemetics, laxatives)
- to enhance pain relief (eg corticosteroids in nerve compression pain)
- to treat psychological disturbances such as depression, insomnia or anxiety (eg antidepressants, night sedation, anxiolytics)

Drug	Uses	Dose (example)
Corticosteroids	Analgesia (nerve compression), improves appetite, antiemetic	Dexamethasone 2mg - 16mg daily (higher end for nerve compression)
Diazepam	Analgesia (muscle spasm), anxiolytic	2-5mg up to TDS
Halopendol	Anxiolytic, antiemetic	0.5-3mg up to TDS
Prochlorperazine	anxiolytic, antiemetic	5mg TDS
Amitriptyline	analgesia (neuropathic pain), antidepressant, anxiolytic	25-75mg od
Zoledronic acid	Bone pain (prophylaxis with metastases)	4mg infusion IV, every four weeks

## Non-pharmacology approaches

- Non-pharmacologic intervention can be used as adjuvant therapy
- It is believed that these interventions are capable of drug sparing and enhance patient comfort.

- These interventions can be divided into two main categories;
- 1- Physical interventions include heat or cold, massage, exercise and splinting.
- 2- Behavioural approaches include relaxation, guided imagery and hypnosis.

## *Nursing Role in cancer pain management*

- The effective pain management required multidisciplinary collaboration.
- Nurses in particular have a unique role in managing cancer pain.
- Nurses spend the longest time with patient among the healthcare providers.

- Nursing roles in pain management include the following:
- 1) Overcoming Barriers to cancer pain management.
  - The barriers to optimal cancer pain management are related to patients, healthcare providers and healthcare system.
  - Through open communication and teaching, nurses can reduce barriers

## 2) Pain assessment.

The second role is conducting complete pain assessment since that it is the responsibility of nurse to assess patients' pain. Thus, it is crucial for nurses to be trained in pain assessment as the fifth vital signs.

## 3) Administering pharmacological treatment.

- Although most nurses do not prescribe medication, their engagement in pain management is significant.

- The revolution in pain medications, route of administration and high technological equipments required complex treatment regimens for patients.

- This complexity needs knowledgeable and skilled nurses to deal with this advancement and to monitor side effects.
- Finally, patient education about pain, medication, side effects and non-pharmacological techniques is another nursing role.

## Barriers to Cancer Pain Management.

Mohammad Al-Qadire

## Introduction

- Pain continues to be a problem for most cancer patients.
- It has been proposed that many barriers hinder patients from receiving the optimal pain management including patients and provider related factors.

- Recently, one study found barriers to cancer pain management are prevalent in the general population before a cancer diagnosis.
- Barriers to effective cancer pain management have been identified within healthcare provider, patient and family caregivers.

### *Healthcare provider – related barriers*

- Healthcare providers related barriers include:
- lack information regarding pain assessment, management and the consequences of unrelieved pain.
- They may have negative perceptions of cancer pain, cancer patients and negative attitudes toward cancer itself (Kearney et al., 2003, Ger et al., 2000).

- poor communication between nurses, physicians and patients is well documented (David et al., 2003).
- In a study that have been carried out in Sweden to assess healthcare providers' (n = 456) knowledge regarding cancer pain management (Rawal et al., 1993),

- It was found that 50% of healthcare provider's lacked sufficient knowledge of pain assessment and pain management including the effects and side effects of medication.
- For example, few physicians prescribed laxatives concurrently with pain medication (Breivik et al., 2009, Rawal et al., 1993).

- Fife et al (1993) compared physicians and nurses attitudes towards cancer pain management in Indiana, US. A questionnaire was sent to randomly selected physicians and nurses. The sample represents different geographical and speciality areas. 500 physicians and 471 nurses completed the modified questionnaire.

- It was found that 84 % of nurses recognised pain as an obvious problem in cancer patients compared to 73 % of physicians, also nurses emphasised the fact that cancer patients suffered from pain. In contrast, physician indicated that cancer pain might be treated.
- Physicians and nurses (76 %, 67 % respectively) believed cancer pain to be under treated, but they urged the need to restrict the use of pain medication in advanced cancer

### *Patient - related barriers to cancer pain management*

- Cancer pain management is not only hampered by healthcare providers' barriers, but the patients themselves may also block the potential for optimal pain relief.
- The most commonly reported barriers are the following:
- patients lack the knowledge about pain assessment and management.
- Patients concerned about addiction.

- Denial of pain as may mean disease progression.
- Poor communication between healthcare providers and patients.
- it is common that patients poorly complied with pain treatment regimens.
- fear of pain medication side effects.
- fear of tolerance.

- In Australia a study was conducted to explore patient barriers to effective cancer pain management (Potter et al., 2003).
- Ninety three patients were recruited.
- Most patients reported at least one barrier.

- The highest rated concerns (barriers) were:
- Fear of being dependent on pain medication.
- Matched increase pain intensity with disease progression,
- and bad effects of pain medications (76%, 71 %, and 67% respectively).

### Barriers caused by family members or significant others

- Family caregivers are also contributors to the inadequacy of cancer pain management.
- Especially once patients are being cared for at home.
- The main family caregiver concerns are:
  - Addiction.

- Reserve strong medication to worst pain.
- Side effects of pain medication such as constipation (Lin, 2000).
- Family caregivers hesitated to administer medication

• The end

# Misconception about Pain

Mohammad Al-Qadire

- Pain subjectivity believed to be the main cause behind its misunderstanding and perception.
- There are many misconception and myths about pain among clinicians especially nurses.
- Knowing and understanding of these misconception may help in overcoming the barriers to optimal pain management.

1- Patients self report of pain intensity is not correct and should not be the base for treatment.

- Clinicians and family caregiver are most likely do not trust patients pain self reporting and they frequently deemed to be able to estimate patient's pain correctly more than the patient himself.
- In reality, patient is the most reliable indicator of pain existence and intensity (Acute pain management guideline Panel, 1992).

- According to the American Pain Association, healthcare workers should accept patient's report of pain.
- Jacox (1994) emphasis on the fact that patient is the foundation of pain assessment.
- Non of the health workers and family caregivers have the right to divest the patient from receiving adequate pain management simply because they believe the patient is lying.

2- Comparable pain stimuli produce a comparable pain sensation among different persons.

- This is completely wrong since that the same pain stimulus can result in different pain experience among different patients.
- Pain stimulus can also produce diverse pain sensation within the same person.
- Pain is a totally personal, subjective and unpredictable experience.

3- The repetitive and prolong experience with pain make patient to feel less pain.

- In fact the vice is correct, this can exaggerate patient response to pain due to the bad previous experience and put patient under high stressful situation.
- Prolong exposure to pain can result in:
  - increasing pain feeling
  - low endorphin level in the blood.

Patient with pain should have physiological or behavioural manifestations.

- Physiological manifestations: increased blood pressure and heart rate.
- Behavioural manifestations: grimacing, rigid body posture, frowning, and crying.

- These symptoms seem to combine severe and acute pain briefly.
- The absence of them does not necessarily mean the absence of pain.
- Most of patients make efforts to stop the behavioural symptoms.

- Human body always seeks the homeostasis which may hide the physiological symptom.
- Some patients may have medical conditions (low blood pressure, pacemaker) that mask the physiological symptoms that usually linked with other diseases.

4- Patient can easily become addicted to Opioids/ Narcotics

- Nurse frequently become confused to differentiate between the following concepts:
- A) **Tolerance**: The process by which the body requires a progressively greater amount of a drug, over time, to achieve the same results.

**B) Physical dependence:**

A physical response of the body to a substance characterized by signs of withdrawal if the substance is stopped without tapering, markedly reduced after prolonged use, or if an antagonist is administered"

**C) Addiction:**

A neurobehavioral disorder characterized by compulsive seeking of mood-altering substances and continued use despite harm"



- One of these can occur alone
- occur in combination or all of them in the same patients
- Physical dependence and tolerance are a result of repeated use of opioids (APS,1992).

- Addiction is rare, it could occur in only 1% of patient receiving opioids for pain relief.
- Results of literature review of studies on patient receiving opioids treatment for pain indicated that only 7 out of 24,000 patient become addict on opioids (Friedman, 1990).

- Heroin was used as pain killer in the UK in 1970.
- Two studies were conducted on 500 patients taking heroin for pain treatment.
- The results showed that no patient has become addict on Heroin (Twycross,1974; Twycross, Wald, 1976)

5- Positive placebo response indicate the absence of pain.

- Patient with physical pain stimulus frequently respond to Placebo.
- In a study on post operative pain, the effects of placebo was examined.
- The results show that 36% of patient positively respond to placebo and have their pain relieved.

- The placebo mechanism is still not known.
- The positive placebo response doesn't mean the absence of pain.
- Placebo doesn't work all the time.
- It is unethical to give patients placebo while he expect you to treat his/her pain with real drug.

• Thanks

## Case Studies

Mohammad Al-Qadire

## Case 1

- Patient A: Andrew is 25 years old and this is his first day following abdominal surgery. As you enter his room, he smiles at you and continues talking and joking with his visitor.
- Your assessment reveals the following information: BP = 120/80; HR = 80; R = 18; on a scale of 0 to 10 (0 = no pain/discomfort, 10 = worst pain/discomfort) he rates his pain as 8.

## Questions

On the patient's record you must rank his pain on the scale below. Circle the number that represents your assessment of Andrew's pain.

0 1 2 3 4 5 6 7 8 9 10  
-----  
No pain/discomfort Worst  
Pain/discomfort

- B. Your assessment, above, is made two hours after he received morphine 2 mg IV. Half hourly pain ratings following the injection ranged from 6 to 8 and he had no clinically significant respiratory depression, sedation, or other untoward side effects. He has identified 2/10 as an acceptable level of pain relief. His physician's order for analgesia is "morphine IV 1-3 mg q1h PRN pain relief."
- Check the action you will take at this time.

1. Administer no morphine at this time.
2. Administer morphine 1 mg IV now.
3. Administer morphine 2 mg IV now.
4. Administer morphine 3 mg IV now.

## Case 2

- Patient B: Robert is 25 years old and this is his first day following abdominal surgery. As you enter his room, he is lying quietly in bed and grimaces as he turns in bed. Your assessment reveals the following information: BP = 120/80; HR = 80; R = 18; on a scale of 0 to 10 (0 = no pain/discomfort, 10 = worst pain/discomfort) he rates his pain as 8.

A. On the patient's record you must rank his pain on the scale below. Circle the number that represents your assessment of Robert's pain:

0 1 2 3 4 5 6 7 8 9 10  
-----  
pain/discomfort Worst No  
Pain/discomfort

- B. Your assessment, above, is made two hours after he received morphine 2 mg IV. Half hourly pain ratings following the injection ranged from 6 to 8 and he had no clinically significant respiratory depression, sedation, or other untoward side effects. He has identified 2/10 as an acceptable level of pain relief. His physician's order for analgesia is "morphine IV 1-3 mg q 1h PRN pain relief."
- Check the action you will take at this time:
  - \_\_\_ 1. Administer no morphine at this time.
  - \_\_\_ 2. Administer morphine 1 mg IV now.
  - \_\_\_ 3. Administer morphine 2 mg IV now.
  - \_\_\_ 4. Administer morphine 3 mg IV now.

## Discussion

- Thanks