# A qualitative study of Spanishspeaking patients' experiences of pain after surgery

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#### <u>Abstract</u>

The aim of this study was to acquire knowledge of the way Spanish-speaking patients experience pain and pain management after surgery and to analyse how their experiences, lack of knowledge of the English language and their cultural beliefs may influence their experiences. The study outcomes will assist health professionals to provide a culturally appropriate pain management plan when not able to speak English and to care appropriately for Spanish-speaking patients and for other Culturally and Linguistically Diverse (CALD) patients.

An interpretive phenomenological approach informed by Gadamer's (1979) theory was used to explore seven participants' in-depth stories. The study sought to answer the following research question: What are Spanish-speaking patients' experiences of postoperative pain and pain management in an acute setting?

The findings that emerged from the data analysis were grouped within eight main "having your pain assessed", "having your pain relieved", "not understanding the medication"," trying to communicate but not being understood", "having no voice", "not understanding what they are saying", "wanting and needing an interpreter", and "having an accredited interpreter".

Throughout the data analysis, it emerged that while pain and its management were a significant part of the participants' postoperative experiences, their pain experiences were often overshadowed by problems with language and communication. Overall, the findings showed that communication (and its lack) and staff attitude and knowledge were the most significant issues when managing the participants' postoperative pain.

The major practice and education implications from the study findings include the need for staff education on the need for holistic pain assessments, use of interpreters and

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associated policies and guidelines as well as staff cultural awareness and sensitivity when caring for CALD patients and their families.

This is to certify that

- i. the thesis comprises only my original work,
- ii. due acknowledgement has been made in the text to all other material used,
- iii. the thesis is less than 60,000 words in length, exclusive of tables, bibliographies and appendices

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Nelly Beatriz Bruinsma Date: 9 June 2011

# **Dedication**

I wish to dedicate this thesis to my beloved parents – Max Alberto Laredo (now deceased) and Irma Laredo (nee Rodriguez), to my husband Jan, to my beautiful daughter Saskia Eva and to the rest of my family and friends for their continued support, encouragement and unconditional love.

Also I would like to dedicate this thesis to my research supervisors, work colleagues and managers for their patience and support throughout my years of study.

# <u>A qualitative study of Spanish-speaking patients'</u> <u>experiences of pain after surgery in an acute setting</u>

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"The migrant's sense of being rootless, of living between worlds, between a lost past and a non-integrated present...."

lain Chambers (1994)

# **CHAPTER ONE**

## **INTRODUCTION**

This thesis is a qualitative study that explored stories obtained from Spanish-speaking patients of their past experiences and perceptions of pain and their care after surgery in an acute care setting. This thesis aims to ascertain the experiences of postoperative pain and pain management by Spanish-speaking patients in an acute care setting. By doing this, it is hoped that health professionals will have information that will enhance their ability to care appropriately for Spanish-speaking patients with pain after surgery in the hospital environment.

The study will acquire knowledge of the way Spanish-speaking patients experience and perceive pain after surgery and to analyse how their lived experiences, lack of knowledge of the language and their cultural beliefs may influence their experiences. This knowledge will subsequently assist health professionals to provide a culturally appropriate pain management plan and care for Culturally and Linguistically Diverse (CALD) patients. In this chapter I will provide an understanding of what it is like to be a person from South America who speaks Spanish, highlighting that people who speak Spanish have their own dialects and beliefs. They also often have characteristic body language and non-verbal signs which are influenced by the person's cultural background, state of mind and feelings of loneliness or being protected (Harper, 2006). Pain can be expressed through both verbal and non-verbal behaviour which may be related to the physical or psychological pain the person can be experiencing (Harper).

As the Spanish language is spoken in many countries such as Spain, all of Central America, most of South America and the Caribbean it is necessary to be aware of the possible issues, such as misinterpreting or not understanding, that may be present when

dealing with people who speak many different dialects. I will also provide a background to the study by defining cultural identity, explaining my interest in this topic, and reflecting on my personal and professional experiences as a CALD person. I will reflect also on my experiences of caring for people in pain who are from a CALD background and have very limited knowledge of English in order to communicate with staff after surgery. I will explain how the research question emerged from issues and problems I have encountered when providing pain management to CALD patients. I will also outline why interpretive phenomenology is the most appropriate approach to answer my research question. An explanation of the significance of my study will be provided in relation to the mission, values and strategic directions of the Australian State and the related health institution in which the study occurred, as well as in regards to the importance of this study to our Spanish-speaking community accessing this health service. Lastly, I will summarise the chapters in this thesis.

#### **Cultural identity**

Cultural identity is a way a person or group of people express their sense of belonging to a specific group or culture which may be conveyed in the concept of race or biological descent (Friedman, 1995). People identify themselves as belonging to a cultural group with their own beliefs and traditions which follow ancestral teachings and symbols. The resulting cultural beliefs and practices identify them as different from other people and cultures. However, as people increasingly move from one country to another in our globalising society (Germov, 2009) cultures mix together and take on some of each other's customs (Evans & Mannur, 2003; Germov). Despite the mixing of cultures, there are still some visible differences that distinguish cultures and one person from another from the same culture. These differences are influenced by the person's history, race, religious beliefs, ethnicity, language, thoughts, actions, customs, values, traditions and education (Hogan, 2005) and are passed on from generation to generation (vertically),

parents to children and from people within the same generation (horizontally) throughout the community. This helps to determine who we are and how we behave (Bammer, 1994; Evans & Mannur). Cultural identity, which can be described as ethnicity, is not practiced but inherent, not achieved but ascribed, and is constantly being remade as it is experienced by people (Evans & Mannur; Friedman, 1995).

At some level, cultural identity might be affected when other generations cannot relate uniquely to their ancestors' culture or when they are influenced by the degree to which the person internalizes their cultural definition (Evans & Mannur, 2003). This disruption to identity is apparent when families migrate to or find asylum in Australia and their family cannot identify totally with their parents' culture (Evans & Mannur). Some beliefs and practices are kept, but others are lost and some may be adopted when the person moves to a new culture. Cultural identity is not eternally fixed in the past; it is flexible, interleaved, and belonging to the future as much as the past (Chambers, 1994; Evans & Mannur) .The loss of some beliefs depends on the level of acculturation that one has experienced, the strength of these beliefs and how the person copes with the constant transformation of the cultural identity (Werkmeister-Rozas & Klein, 2009). I will now explain how my own cultural identity has been affected by my migration from Colombia to Australia around twenty years ago.

I identify myself as coming from a South American background with a very diverse and rich Indigenous and Spanish influence in relation to the folk music, food and language but I also relate very well with the Australian culture. While I am still South American at heart, I do not feel the need to listen to the music, eat the food or even speak the language as much as some compatriots who have just arrived, who leave their family in South America or who speak very little English. I have many friends who have settled in Australia but their parents and siblings are in South America and although they have become well acculturated into the Australian culture their traditions and sense of self are missing. Their identity is affected in a way that they need to feel close to others from the same culture

and beliefs. Some of my friends have decided to emotionally adopt them as their absent parents or siblings, because they feel the need to be close to those who share their beliefs. This experience seemed to help to reduce their sense of identity disruption (Evans & Mannur, 2003), as they were able to pass cultural aspects on horizontally through the Spanish community.

Ideally people should be treated as individuals and not have their care stereotyped according to their cultural or religious background. However, this stereotyping happens repeatedly, as health professionals follow cultural information labeling specific cultures. As Werkmeister-Rozas and Klein (2009, p. 6) stated, "Every encounter is bound to have different degrees of attention to the various macro social factors that shape the life of each person." Sadly, however, often in practice, cultures are described and people are grouped together, or homogenized, providing a notion that all people in specific cultures think and behave similarly. Learning about the patient's cultural background is as important as caring physically for them, as nurses need to understand them emotionally to be able to provide holistic care. This notion of knowing a patient is explained by Werkmeister-Rozas and Klein (p. 6) as they stated "More than just information, it is about taking into consideration all aspects from a person's identity and experience such as acculturation, socioeconomic status, gender, power...and personality." Therefore, the more we know about patients, especially if they are from a different culture, the easier it is to provide the best care possible.

I will now move on to explain my personal and professional experiences as a CALD person, as well as my experiences of caring for CALD patients.

#### Personal experience as a CALD person

It has been over 20 years since I migrated to Australia with my immediate family. I was in my mid 20s when my parents decided that we should leave our country in South America

to start a safer and "better" life in Australia. Although at that time, the violence, kidnapping and killings in my homeland were of a daily occurrence and our family was personally threatened, my brothers and I were very upset about leaving our relatives and lifelong friends. We eventually understood that we needed to migrate to a safer country if we wanted to live a life with a better future.

We knew we had to deal with two important issues; firstly although our education was in a bilingual (American) school, we knew we had to improve our knowledge of the English language. Secondly, we had to assimilate into a new culture with its different values and beliefs. It was very difficult at the beginning and to some extent I was depressed as I was wondering what was going to happen with my life in a totally new environment. I left my studies, my home, my extended family and my friends. The first couple of months were the hardest; although I had my parents and brothers, I felt that something was missing in my life. I felt emptiness and a sense of not having a past. I also felt as if everything I had lived and experienced in my life had gone and nothing existed before I came to Australia. Additionally, I felt that I did not belong here and that I should go back home. It has been a long time now since then but I still, sometimes, feel that way now. I can now see that this was my experience of identity disruption as explained previously by (Evans & Mannur, 2003).

Sometimes I feel nostalgic and miss my hometown immensely, wondering how life has changed for my extended family and friends, how they look now and what they are doing at present. I have always maintained telephone contact with my two best friends but it was only recently that I was able to contact a few more school friends to arrange a school reunion when I returned earlier this year to my homeland for a visit. I cannot express the deep nostalgia I felt as the plane landed in my homeland – the tears were flowing down my face. At the reunion, it was as if my past had returned and all these wonderful memories and past experiences from my hometown were coming back into my life. I enjoyed this time immensely. I was "home" – with people who shared the same culture

and spoke the same language. As Bammer (1994, p. 23) explained, "our language is like a roof over our heads".

When my parents migrated to Australia with me, it was a different story for them as they had to leave their lifetime friends, relatives (many elderly), their professions, well-paid employment and status behind in their homeland. They arrived here as nobodies and for the main part that is how they have been treated. As they have grown older, their English has deteriorated and now they need us, their children, to assist them with all health, financial and day-to-day issues. It is very frustrating for my parents and they complain of how people talk to them as if they have a low level of education simply because they have English as their second language. My parents were well educated (with post graduate degrees) and were respected in their own profession as lecturers at the university. Occasionally my father receives mail from his colleagues and friends to ask for advice and information because he still is regarded and recognised as a very knowledgeable person in his profession in our home country. My mother, who was very sociable in our homeland, now does not want to go out of the house or talk to anyone because she is afraid she will not understand what people are saying to her, or that people will not understand what she is saying to them.

My parents depend on us, their children, for their communication and decision making because their self esteem and self worth are not as they used to be. They do not want to talk to people because they are afraid of "making fools" of themselves and they would rather keep their opinions, worries or questions to themselves. When my parents have attended the hospital for medical issues or checkups they have not expressed their real concerns and feelings as they have trouble communicating and do not want to become a burden to others.

After a recent incident that happened to my father when he had a heart attack and was taken to a public hospital I realise that we still have a long way to go in providing culturally sensitive care to non English-speaking background (NESB) people. My father required

procedures that needed verbal consent and the staff went ahead with the procedures without ensuring he or one of his English-speaking relatives understood the procedures. After a recent procedure, the nurse explained to me in a patronising way that "You don't need to know [about your father's procedure] - your dad understood everything because he was nodding." Although my father was nodding, smiling and keeping eye contact it did not mean he spoke and/or understood English like other CALD patients sometimes do. I was left wondering how she knew my father better than I do. I was very upset because I was asking for information about my father's care because he had asked me to find out what they had done to him during the procedure. Although my father was present, when I spoke with the nurse, the nurse refused to tell me anything because "If he is not telling you, it is because he doesn't want you to know." She did not understand that my father neither understood what was wrong with himself nor anything that had been done to him in the procedure. She also did not appear to understand that he could not ask her himself even though he had a right to know and understand issues to do with his own health care. Sadly, my father did not want to complain formally because he was afraid that the care (good or bad) he was receiving could have been compromised.

Recently, my father had another experience in hospital where the health professional refused to allow me to attend the appointment. As it was a minor test I was advised not to stay with my father as the health professionals thought it was better for him to be there by himself. When the test was finished the health professional told me that my father had done "very well" and he had not required my presence. After the test I replied that my father had requested my presence because his level of English was not adequate to understand instructions and medical information. I wanted to attend but I did what I was asked so I would not upset the health professionals looking after my father. As my father and I were not satisfied with the outcome of this appointment, I told them that in the future I would attend all the medical appointments with him.

In the afternoon, when the doctor reviewed the test completed that morning he was confused because the earlier test did not correlate with the results he was seeing at that point. Because he was concerned about the results, he proceeded to order another scan and decided to book my father for an angiogram. He explained to me that the test done in the morning produced poor results and he wanted to ensure that there were no major problems with my father's cardiovascular health. I told him that I was unsure of the reliability of the test performed in the morning because it had been done without my presence and my father may not have understood the directions given to him. The doctor immediately discarded the test results, cancelled the angiogram and decided to have the earlier test repeated in my presence. The result showed there was no problem. However, the original refusal to allow me to be present to interpret for my father caused much distress and anxiety for my father and I when the doctor explained his concern. It also cost considerable time and money for the repeat test needed to ensure reliable results.

#### Professional experience as a CALD person

As well as my own family experience, this study is also grounded in my professional experience as a CALD person. It has been difficult for me to advance in my profession in Australia as a CALD person and a nurse. I have seen a few CALD professionals achieve their goals but they had to fight and struggle to be able to attain their status. I have felt that I have been discriminated against many times. On one occasion when I had failed to obtain a promotion at work, I was told by the chair of the interview panel, that the fact that I was from a CALD background and a NESB person did not mean I was less able to perform the job as well or better than an English-speaking person. This was never the case for me but the fact it was raised at all caused me to wonder if it had been an issue for that person. Being from another cultural background and having English as a second language never has been an issue for me and it will never be as I feel I have assimilated

into and accepted the Australian values and beliefs and speak and write English relatively well. However, sometimes I do sense a patronising attitude in others in the professional sphere of my life.

Many times I have heard staff at the hospital making racist and derogatory comments about workmates and patients just because they are from another cultural and religious background or do not speak English well. With all the literature and education provided at the hospital I wonder why people still think this way and what can be done to encourage people to be more tolerant and interested in learning about other cultures. I have shown my colleagues my considerable interest and passion for caring, learning and providing culturally appropriate care to all patients because I can relate to and empathise with them. I think this empathy helps me to understand how they feel while they are sick or in pain in an unfamiliar environment. They may possibly feel frustrated due to their inability to communicate and may also feel discriminated against because they cannot communicate or express themselves, just as my parents have on so many occasions. Many times I have encountered Spanish-speaking patients who rely on me for comfort and conversation. They are so appreciative when I am at their side caring for them. They often appear to be lonely and fearful when they are in hospital and I am grateful when I have the opportunity of helping them to feel more "at home" because of our shared culture and language.

#### Professional experience caring for CALD people

As I have indicated above, a health care professional's ability to provide culturally appropriate care to patients is an issue close to my heart. There is considerable literature and many courses available that provide cultural information for health care professionals, so it is disheartening to hear some health professionals' attitudes when caring for CALD people. In general, health care professionals appear to expect CALD people to behave in a certain acceptable way and to assimilate to their new country regardless of their history

or background. It also disconcerts me when I hear nurses making comments, such as: "They have been in this country for many years, why haven't they learned the language?" and "Why do we have to pay so much money for an interpreter, let's use their family or friends," or "We will provide an interpreter once and then they will be on their own." There are many reasons preventing CALD people from learning English or assimilating to the new culture. From my experience, these reasons include: when they have been victims of torture and trauma, coming to Australia as a refugee, or when they revert to their mother language due to their age or cognitive impairment.

An issue which I have observed frequently in the years I have worked as a nurse is when the health professionals leave the CALD person for many days and sometimes even weeks without explaining what is happening and how their treatment is progressing. The health professionals appear to find it too difficult or time-consuming to communicate with the person and to deal with the situation; they ignore it and sometimes try to pass the issue on to someone else. As an example, one of the many situations I experienced was with a French patient (who had undergone extensive colorectal surgery) who was becoming increasingly distressed and depressed, and was losing weight and refusing all tests and treatments. After several weeks I was allocated to care for this patient. I realised quickly that there was a major communication problem. The patient did not have any family and she was elderly, frightened and very upset because nobody was explaining anything to her. I was unable to talk to her due to the language barrier so I requested an interpreter be contacted to listen to her concerns and explain the situation to her. This had not been done previously. I asked the doctors, dietician, physiotherapist, social worker and other allied health professionals involved in her care to be present and meet with the interpreter after she had met with the patient. At this meeting it became apparent why this patient was losing weight. She was unable to tell staff her pain experience, as well as her concerns and fears, and staff had done little to assist her to communicate. The patient also told us that she was vegan and did not like tea or coffee

so the diet offered to her was inappropriate. The other issue of her refusal of tests and treatments was because she had undergone previous procedures without any explanation. She now felt utterly helpless, confused and alone.

This and other similar professional experiences and observations about CALD patients and the postoperative care they received, along with my own personal experiences with my parents, have caused me to wonder about the experiences (particularly postoperatively) of all CALD patients in our health care system. As I am bilingual and able to speak English and Spanish, I felt it was important for me to discover the pain experiences of Spanish-speaking patients following surgery, as a way of finding out what it may be like for people of any ethnic origin who cannot speak English when they require surgery in our health care system. Therefore, my research question is as follows –

#### **Research question**

What are Spanish-speaking patients' experiences of postoperative pain and pain management in an acute care setting?

#### Aims of the study

The aims of the study are to explore the ways Spanish-speaking patients who do not speak English experience and perceive postoperative pain and pain management and to provide knowledge that will assist health professionals provide culturally appropriate pain management for culturally and linguistically diverse (CALD) patients

#### Location of the study

My study took place in a large Queensland hospital which is one of Australia's leading academic and research health centres providing acute medical, surgical, mental health,

cancer, rehabilitation and allied health services as well as State-wide services. This hospital is nationally recognised for its expertise in trauma management and transplantation services. Between 2009 to 2010 there were 82,003 patients admitted to this hospital with 45,939 patients admitted to the emergency department. 492,859 outpatients visited the appointments department and there were 19.330 operating theatre cases (Queensland Government, 2011). The patients were recruited in the Pre-Admissions Clinic which is an outpatient area staffed by anaesthetic and surgical doctors, nurses, pharmacists and allied health professionals. In this clinic patients have a thorough assessment of their health and their current and past medical history. Patients are also provided with information about what to expect up to and following their surgery. On the day of surgery patients are admitted to the Surgical Care Unit where I work, preparing the patients for surgery, educating them preoperatively and then transporting them to the operating theatres. I had unconditional collaboration from the hospital management by supporting me throughout the recruitment and interviewing process and assisting me with study time to work on the data analysis and writing up of the thesis.

#### **Research approach**

I chose a qualitative research approach, informed by interpretive hermeneutic phenomenology. This approach was selected because it fitted with my research question as it went beyond describing the participant's experience and instead sought the meaning of the human experience i.e. how the person in pain made sense of their experiences (Gadamer, 1979; Polit & Beck, 2010).

#### Significance of the study

This study has significance for the appropriate care of CALD patients after surgery when they are unable to express their emotions and communicate their pain in an English-speaking environment. According to the Australian Institute of Health and Welfare (AIHW) (2009), 7,900,000 people were admitted to hospitals in Australia and 1,752,570 (22%) of the population were born overseas in 2007-08. As a consequence, the Australian health system provides care for a significant proportion of people who come from countries outside Australia and who may have English as their second language. This creates a challenge for the health service as health care professionals in Australian hospitals are predominantly English-speaking and this may contribute to misunderstandings and miscommunication. In Australia in 2007-08, there were approximately 4,744,061 people admitted into public hospitals and 3,129,885 into private hospital for various procedures. In Queensland 831,965 people underwent procedures in public hospitals and 780,299 in private hospitals (AIHW).

Australia has a population of over 21,000,000 people, which is an increase of 1.6% (336,800 people) from 2007 (Australian Bureau of Statistics, 2008) and it has been considered for many years, to be a multicultural society. People from all over the world migrate to Australia or request asylum. Some are forced to move escaping from violence, wars, political repression, poverty, economic deprivation and others are simply looking for a better life (Lasch, 2000; Tonbridge, 2000) . The health care system in Australia consists of public and private services granting all people the right to obtain hospital and community-based services regardless of age, gender, sexual preference, nationality, religion and culture.

Australia's immigration program accepts two groups of people, the skilled and family migrants and refugees and people with humanitarian needs. The skilled and family migrants move away from their home country for a better life or due to economic reasons, while people on humanitarian grounds come to Australia to escape persecution or

discrimination in their own country. Other reasons why people migrate from other countries into Australia relate to conflict in their native country or natural disasters (Department of Immigration & Citizenship, 2011).

The humanitarian program provides resettlement to refugees on humanitarian grounds from many countries in Africa, the Middle East, South West Asia, Europe, Asia and Central and South America. There has been a humanitarian program intake of refugees and humanitarian groups of over 80,000 people with an average of 13,000 to 14,000 people a year between 2004 – 2010 (Department of Immigration & Citizenship, 2011). Queensland received 1,432 people under the Humanitarian Program of 2005-2006, accepting 867 people (60.5%) as refugees and 565 people (39.5%) under the Special Humanitarian Program (Department of Immigration & Citizenship, 2006).

The Australian Bureau of Statistics (2008) acknowledged that from a total of 7,723 Spanish-speaking people who lived in Brisbane in 2006, 2,024 (26%) did not speak English well or do not speak English at all. Moreover, as indicated by the Australian Census (Australian Bureau of Statistics), the number of Spanish-speaking people living in Brisbane increased from 6,114 in 1996 to 6,708 in 2001 (9%) and to 7,724 in 2006 (15.1%).

Queensland Health is divided into 16 Health Districts providing health care to a large number of CALD patients. Metro South, as part of the Queensland Health Districts, provides health care to over 70% of CALD patients. The tertiary teaching hospital involved in the study cared for more than 22% of the total CALD patients accessing this district (Queensland Government, 2005). Spanish is the third largest language group of people (after Vietnamese and Chinese) to access the health services at the tertiary teaching hospital that is the focus of this study (Metro South Health District Interpreter, 2011). Since 2001 there have been approximately 3,800 admissions of Spanish-speaking patients accessing the health service at this hospital who needed an interpreter (Metro South Health District Interpreter). (Refer to Figures 1 and 2 below).

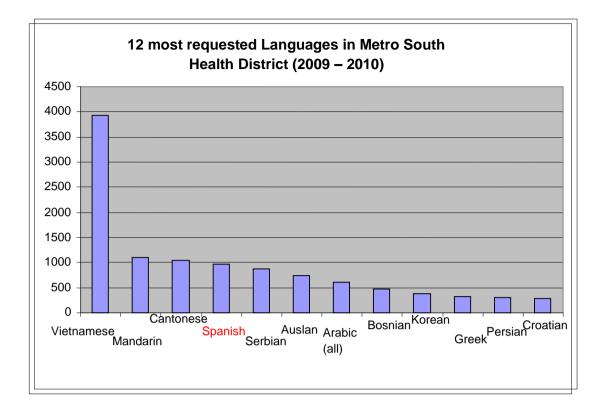


Figure 1.1: 12 Most Requested Languages in Metro South Health District (2009-2010) (Interpreter Services, 2011)

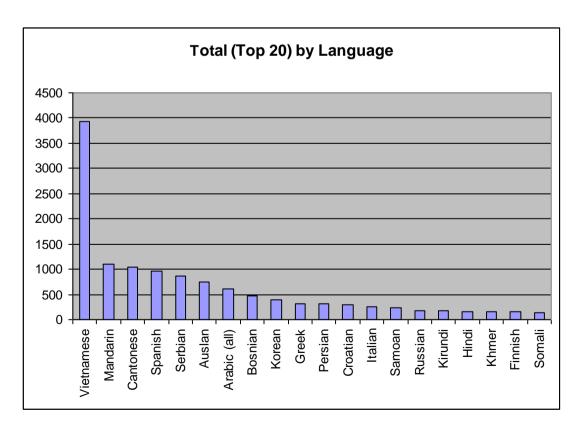


Figure 1.2: Total (Top 20) by Language (Interpreter Services, 2011)

Queensland Health states it is committed to promoting a healthier Queensland through several strategies to create dependable health care and better health for all regardless of culture and beliefs (Queensland Government, 2011). One strategy is to maintain healthier people and communities by systematically identifying people at greater risk of illness, injury or complications from existing health conditions especially due to the inability to speak and understand English (Queensland Government). Also a strategic objective is to address patients' and their family's needs to provide optimal care to achieve equitable health outcomes across the population (Queensland Government). Another strategy is to provide health professionals with culturally sensitive information regarding CALD patients' specific needs after surgery in the acute setting. The aim is to enable timely access to the right health service at the right time in the right setting (Queensland Government).

Considering the demographics outlined in this section and the health-related strategies of the hospital in which my study occurred, as well as the broader context of health-related strategies of the State in relation to CALD patients, I believe my study will provide significant information that will assist health professionals to provide a culturally appropriate pain management plan and care for Spanish-speaking patients. This study also provides important information about the care of CALD patients in general and will assist health professionals in all contexts of care to provide better care to people from other ethnic backgrounds. As our multicultural citizens age there are health issues that often will force them to access hospital care. Therefore, health care facilities may need to improve their multicultural responsiveness (Werkmeister-Rozas & Klein, 2009). Health professionals may also need to be aware of their opinions, feelings and attitudes towards people from other cultures and their beliefs so they can avoid being judgmental and being perceived as racist. Werkmeister-Rozas and Klein explain that self awareness goes beyond acknowledging one's own cultural background, stereotypes and prejudices and incorporates an understanding of the role that racism has on the worker, the client and the relationship between the two. I will now move on to provide an overview of my thesis.

#### **Overview of thesis**

The remainder of this thesis is comprised of four chapters, which makes five chapters in total. Each chapter is outlined below.

Chapter One introduced the study, provided an overview of cultural identity and explained my personal and professional experiences as a CALD person as well as my experiences of caring for CALD patients.

Chapter Two presents a review of the literature that informed my research. The literature explores major issues that are highly relevant to my research area of interest: pain perception and experience, pain assessment and ethnicity, pain management, and finally communication in pain assessment and pain management.

In Chapter Three I explain the qualitative research design used for the study, including an overview of phenomenology and an explanation of how it informed the study. I also explain the research techniques used and how I conducted the study, including the ethical guidelines that I observed. I then provide a summary of the research findings, which includes a summary of the participants' demographic details .

The research findings and discussion are presented in Chapter Four, where I present and discuss the themes that emerged from my data. I provide excerpts from my participants' stories of postoperative pain and pain management to support my findings. I also intersperse my interpretations with reflections from my reflective journal as well as drawing on relevant literature to further explain and support the data.

In Chapter Five, the final chapter, I offer further reflection and an evaluation of my research journey and the findings of my study, followed by recommendations for changes to inform best practice that will improve the care of Spanish-speaking patients and other CALD patients in acute care settings. I also discuss the strength and limitations of my study and provide the implications of my study for education, practice and future research.

# **CHAPTER TWO**

### **REVIEW OF THE LITERATURE**

#### Introduction

The purpose of this chapter is to review the literature on the experience, perception and emotional expressions of pain in people who do not have English as their primary language and who are cared for in an acute health care environment. Firstly, I will outline briefly the methods and processes I used to find and select the literature that forms the underpinnings of this study. Then I will present the literature review under four major headings as follows - pain perception and experience, pain assessment, ethnicity and pain management, and communication in pain assessment and pain management. Following the review, I will then summarise the review and pinpoint the gaps in the literature which support my research study.

#### Methods and processes

The articles for this literature review were obtained by searching a variety of electronic databases such as Medline, Pubmed, CINAHL, Health and Medical Complete and Blackwell Synergy. The key terms used to search for the literature included the following as well as combinations of the terms: *pain, acute pain, postoperative, after surgery, analgesia, analgesics, narcotics, pain relief, pain assessment, transcultural, Spanish-speaking, cross-cultural, Hispanics, communication, language barriers, interpreters, ethnic, culture, cultural, cultural competence, cultural sensitivity, ethnicity, race, non-English-speaking, English as second language, caring, nursing care, ethics, perception and experience. The terms excluded were children, chronic, cancer, palliative, mental health, and psychiatric.* 

The articles reviewed were qualitative and quantitative studies published in the English language from 2000 to 2011 although some older articles were used due to their relevance and importance to the topic discussed. The articles containing information on acute postoperative pain in people who were culturally and linguistically diverse in acute settings were used. There were numerous articles on postoperative care for people following various specific types of surgery (for example, breast surgery, hip replacement, spinal surgery). These articles were excluded in favour of literature about postoperative care generally or specifically for people of certain ethnic backgrounds. Specific emphasis was given to articles with reference to the experience and perception of pain in different ethnic groups and in relation to health professionals' abilities to assess and treat pain in minority groups. Some studies compared different ethnic groups, their willingness to request pain relief and the health professionals' readiness to provide appropriate pain management and their level of cultural competency. I will now move on to review the literature on how people from various cultures perceive and experience pain and how health care professionals assess and manage the pain experiences.

#### Pain perception and experience

The expression of pain is learned from childhood to adulthood from observing other people and the environment. The result is that pain is expressed differently by crying, cursing and moaning or simply by suppressing it depending on one's past lived experience and environment (Ramer et al., 1999). Moreover, as Ramer et al. also stated, pain and suffering have different meanings to people from different cultures so it is possible that the specific expression of pain is easily understood by people from a similar culture but not by people from other cultures. The perception and experience of pain are factors that may affect the way that CALD patients recover from their illness due to their personality and uniqueness when expressing pain. Lasch (2000) and Flowers (2004)

discuss the need to use culturally sensitive pain assessments to identify the severity of pain in all patients, considering the way they perceive and express their pain.

People with the same culture and religion may come from diverse educational, occupational and economic background which will affect the way they perceive pain, how they express it and how they employ coping mechanisms (Lasch, 2000). The observation of the participants in Greenwald's (1991) early study suggested that although ethnic minority groups assimilated to the dominant culture their specific cultural experience with pain was maintained, which in turn influenced its perception (Lasch). On the interethnic differences in pain perception, Greenwald also stated that the variation in minority groups is influenced by the interpretation of pain rather than by its perception. Therefore, it may be that whilst all people may experience similar sensations of pain in response to a specific stimulus, ethnic groups develop different emotional constructs when processing the sensation, perceiving it differently and possibly expressing it their own way. This was demonstrated in Greenwald's study where there was no difference in pain sensation but there were some differences on the affective qualities (emotions) amongst the ethnic groups.

The physiological origins of pain perception and the expression of pain and its management and the relevance they have on different cultures and races have been researched (Hama, 2001; Ray, 2002). However, pain perception and the experience of a person depend largely on the person's cultural past and traditions. This is because life experiences are recorded in the memory section of the brain in each person providing cultural influence on the perception of pain (Hama; Ray). Pain is unique for each person and it is related to their experiences with pain in the past in relation to their culture and rituals and if they endured torture and trauma or other violent events in their lives. Their pathophysiology also influences their response, interpretation and expression of pain as they react differently according to their emotions, affects and memory (Hama; Ray). On occasion, inadvertently health professionals can discriminate inadvertently against the

patient's because of the way the CALD people behave and relate to others (Lasch, 2000; Leishman, 2004). Tonbridge (2000) argues that domestic violence is seen often in refugee families due to women's vulnerability as they lack family and community support. Refugee families may also have witnessed violence to their families or have been forced to commit violent crimes, which will affect their view and experience with pain. Therefore, it is important to remember as Greenwald (1991, p. 57) stated, "An understanding of variation in the experience of pain is important for ensuring high quality medical care for patients in whom pain is part of the clinical picture".

Cole (2002) noted that there is a risk of unconscious prejudices by health professionals when they do not understand people's perceptions and expressions of pain. Flannery, Sos and McGovern (1981) reported that limited education in CALD people can cause misdiagnosis and mistreatments due to misunderstandings of different cultural expressions by health professionals. Lasch (2000, p. 18) warned against health professionals stereotyping people of different ethnic origins when he stated that "because of diversity both between and within cultures, it is important for the clinician not to make a stereotypic judgement based on a person's ethnic heritage but to conduct a cultural assessment of the patient". Madjar (1985) provided a good example of how health care professionals can have preconceived ideas of people who belong to certain cultures – stereotyping the emotionally expressive 'Mediterranean Type' (crying, moaning, and so on).

Cultural issues arise in indigenous groups as well, due to cultural differences, which are often not understood or known by Western health professionals. This is demonstrated in a qualitative study using grounded theory that was undertaken by Fenwick and Stevens (2004) who explored the postoperative experience of pain of Central Australian Aboriginal women and the interpretation of their experiences by non-Aboriginal nurses. The results encountered in this study were that Aboriginal women expected the non-Aboriginal nurses to have the same skills and cultural knowledge as the Aboriginal nurses. The study

demonstrated that non-Aboriginal nurses lacked cultural insight and appropriate knowledge and tools required to assess and manage postoperative pain. Their inadequate management was apparent when using culturally inappropriate and unreliable pain assessment strategies and when misinterpreting the traditional or folk pain relief strategies.

The CALD person's experience and behaviour when in pain in diverse ethnic groups were discussed and explained broadly in the older but highly relevant research study by Flannery et al. (1981). The authors discussed the expression and response to pain and the influence that ethnicity had on 75 women and their learned ethnic responses towards pain after episiotomy. The authors found that ethnic generalisations were often made by the health professionals in relation to culture and ethnicity. People from a Latin background such as Italians tended to be very expressive and maximise their pain, whereas Anglo Saxons and black protestants and Irish Catholic usually minimised their pain and suffered stoically, alone (Flannery et al.). On the other hand Madjar (1985) stipulated that the greatest problem with the experience of pain is that health professionals assume that behaviour and the expression of pain from a few ethnic groups can be used to understand all other cultures. There is a difference between the reported pain experienced by the first generation migrants and second and third generation as the latter two groups can become acculturated to some degree to the dominant culture (Flannery et al.). The research by Flannery et al. also determined that pain after episiotomy had a few statistically significant differences amongst the various ethnic groups. It had to be considered that 60% of the participants' mothers and 66% of fathers in all the ethnic groups studied were not generally expressive when in pain. The study concluded that keeping the medical procedure anxiety level low and attention span of the participants focussed there was no significant difference in pain response amongst the ethnic groups studied. Another factor influencing the reporting of pain was when the person understood what to do if they have pain and the importance of managing their pain

as an essential part of their care (Ramer et al., 1999). This factor may lead to misinterpretation and generalisation of the person's attitude and response to pain when the person comes from the same cultural group (Flannery et al.).

It has been noted that health professionals who learn about time orientation, different perceptions and expressions of pain (emotional, stoic), the importance of personal space and religious, dietary and diverse health practices will most likely diminish the anxiety of the CALD person who is going through a stressful situation. Religious and spiritual beliefs and practices may influence the way the person views healthcare and its outcomes and play a critical part in providing culturally sensitive care in the health environment (Davidhizar, Bechtel, & Giger, 1998). In some cultural groups, spirituality and generic remedies play a significant part in their healing process. As a culturally sensitive organisation, these practices may be accepted and acknowledged even if they are hard to understand (Cole, 2002). A strategy suggested by Cole to achieve culturally appropriate care was to incorporate folk medicine and remedies into the CALD person's treatment. As Luna (1998) discussed in her article, some ethnic groups would rather use their own healers and folk remedies before using Western medicine even though they might be harmful to their health (Green-Hernandez, Denman-Vitale, Judge-Ellis, Quinn, & Falkenstern, 2004; Luna). Spirituality and cultural healing by using religious and generic or folk remedies may be useful strategies if acknowledged by health care professionals as a means of reducing a patient's overwhelming stress and anxiety while in hospital (Cole; Pang, Jordan-Marsh, Silverstein, & Cody, 2003). Due to lack of cultural knowledge, the health care professional may encounter a dilemma between Western traditions and some ancient traditions such as Chinese in relation to truth telling (Pang et al., 2003).

I will now move on to explore the pain assessment and pain management literature under the next heading in this literature review.

#### Pain assessment and pain management

Despite advanced pain relieving strategies, it is common to see patients with unrelieved pain following surgery (Manias, 2003; Schoenwald & Rogers-Clark, 2006). The experience of pain after surgery is unique and each patient expects the nurses to consider their pain individually when providing pain relief (Rehej & Vaismoradi, 2010). Coll and Ameen (2006) highlighted the important role of the nurses to properly prepare the patients preoperatively according to the level of pain they should expect according to the procedure, the administration of analgesics and the effective assessment and management of pain postoperatively.

In the study by Davidhizar and Giger (2004), the acute pain service advocated that assessment of pain should be conducted as part of the vital signs, as this will ensure that appropriate assessment is done at the correct time. This pain assessment should be conducted by the nurses as part of their patient's postoperative care. According to Rejeh, Ahmadi, Mohammadi, Kazamnejad, and Annoosheh (2009) generally nurses believe that pain management is one of their most important and primary roles as it is considered a fundamental component of their practice.

However, pain assessment is not just the use of a pain rating scale; rather it must be an assessment of the pain experienced by a *person* – a holistic assessment conducted by a nurse who has an understanding of the person and their culture. Wylie and Nebauer (2011, p. 16) elaborated on this holistic focus on the whole person when they stated, "the pain assessment needs to reflect the whole story or at least the most complete pain account that caregivers and skilled nurses can ascertain". Although this paper referred to older residents in aged care facilities, their words are just as relevant to assessing pain in people of different ethnic and cultural backgrounds in acute care settings as these issues are only part of the whole pain story lived by the patient (Wylie & Nebauer). The pain assessment tool also needs to be suitable for assessing people from ethnic minority groups to be able to obtain an accurate record of the pain score ensuring the assessment

has been understood properly. Rejeh and Vaismoradi (2010) added a layer of culture on the complexity of pain assessment as they warn that patients respond to pain in relation to their culture, as some ethnic patients believe they should bear some pain thus this belief or view may affect the information they are prepared to provide when their pain is assessed. When assessment of a person's pain is commenced by the use of a pain rating scale, the pain rating tool needs to be suitable for assessing people from ethnic groups, who must be able to understand the scoring if the pain score obtained is to be accurate. This belief has to be taken into account as nurses usually are limited to provide pharmacological interventions and follow doctor's orders without the nurse's discretion or asking the patients for their preferences (Rejeh et al., 2009).

Perception of pain and CALD people's past experiences with pain should be taken into account when they are scoring their pain. There are many pain assessment tools available for use in clinical practice but only a few have proven to be useful for CALD people because they are purported to overcome language and cultural barriers. Using screening tools as reliable pain scales enables older residents in long term care who have difficulty communicating to identify the severity, location and intensity of their pain through pointing or marking a word, number, colour or picture (Wylie & Nebauer, 2011). The pain screening tool identifies if the patient is experiencing pain and if so the health professional then should continue on with the provision of a holistic, person-centred pain assessment (Wylie & Nebauer). However, there is no indication that the screening tools referred to by Wylie and Nebauer would be suitable for use with people from different cultures in acute care settings.

The Brief Pain Inventory (BPI) has been used in many countries with a high level of reliability and validity in relation to assessing pain level and how it impacts on people's lives (Davidhizar & Giger, 2004). For the Numerical Rating Scale (NRS) patients rate their pain 0–5 or 0–10. It is reliable, easy to score and has given good results when used in ethnic minority groups when measuring pain levels (Davidhizar & Giger; A. Smith,

Gullette, & Schnepf, 2004). This type of scale was also found to be very useful when assessing illiterate patients.

The Visual Analogue Scale (VAS) has been used in many studies to evaluate pain perception. It measures the intensity of the person's pain by making a mark on a horizontal or a vertical line colour coded slide ruler. One side of the line has the words "no pain" (colour blue) and the other side "pain as bad as it can be" (colour red) and it represents the person's intensity of pain and at the other side of the ruler it has a 100 mm scale, which quantifies the pain. Chinese patients were able to understand better the vertical line due to the way they read their native language (Davidhizar & Giger, 2004;Huber, Feser, & Hughes, 1999; Manias, 2003; Ramer et al., 1999). Another study reported that in addition to using the VAS, more experienced nurses included other modes of assessment, such as abdominal palpation, observation of wounds, inflammation and facial expressions which are examples of an holistic assessment referred to previously in this review (Manias).

The Graphic Rating Scale uses a similar method to the VAS lines with numbers 1-5 evenly spaced with words starting from 1 as "no pain" continuing with "slight pain", "moderate pain", "very bad pain" to number 5 which is "pain as bad as it can be". Clients must select the number which corresponds best with the degree of pain felt over the previous 24 hours for 7 days (Greenwald, 1991). This method was used in conjunction with the McGill's assessment tool to evaluate ethnic minority groups as in Greenwald's study to assess cancer pain.

The Face Rating Scale (FRS) is used mostly with children and adults with communication problems such as those who are unable to speak English. Similarly, there is the Oucher Scale which has real pictures with different facial expressions (Davidhizar & Giger, 2004). A face is associated with a number expressing different levels of pain, such as a crying face to indicate pain and a happy face for no pain (Ramer et al., 1999). This scale was

found to be more reliable, valid and was preferred over the VAS by CALD patients in a study comparing the use of different pain scales (Davidhizar & Giger).

The use of cards in translated languages asking questions on the level and type of pain has been found useful for literate people who have a good level of education. Audio recordings were used for illiterate patients asking the same questions (A. Smith et al., 2004). These cards ask the person to describe their pain to find the probable cause, measure the intensity and the duration of the pain, assess also the location of the pain to assist with ordering the relevant tests or procedures and it also explores the symptoms associated with the pain (A. Smith et al.). Several pain assessments have been translated in different languages according to the ethnic minority groups present in the different institutions.

The Memorial Pain Scale provides a rapid subjective pain experience assessment and it measures the pain perception. It is a printed card with VAS measure for pain intensity, pain relief and mood. Scale is 1 "no pain" to 8 "excruciating pain" (Ramer et al., 1999). This method may be too complex to explain to CALD patients if it is not translated and it may be too difficult for the CALD patients to respond if their language knowledge is too limited.

Some of the most commonly used pain assessment tools were reviewed by Huber, Feser, and Hughes (1999) and they concluded that very few tools include the patient's subjective description of pain and do not take into account the patient's perspective and experience with the pain. The tools were also lengthy, complicated and the terminology was difficult to understand (Huber et al.). Pain assessment tools have to be carefully chosen for CALD people to suit their personal needs therefore the health care professional requires sufficient knowledge about what they are and how to use them ensuring that where necessary the chosen tool has been translated into the CALD person's own language. Furthermore, as Wylie and Nebauer (2011) cautioned, following the use of a rating scale,

there is the need for a holistic and patient-centred approach to pain assessment to ensure the person's pain story ends with appropriate pain relief and comfort.

Patients need to receive reassurance from nurses that their pain is a normal part of the recovery process and that there is the need to continue to use their prescribed analgesics to improve (Williams, 2008). According to Chan, Nehme and Rennick (2010) and Rejeh and Vaismoradi, (2010) despite patients' experiences with high levels of pain or staff members' inability to completely relieve their pain, there was a general feeling of satisfaction with the pain management provided by the nurses in the study, probably due to lack of knowledge of what constitutes good pain assessment and management. In Rejeh and Vaismoradi's study, it was considered that some people regarded pain as a normal part of any surgery without expectation of complete relief while conversely; others believed they should not have any pain due to the vast array of treatments available. However, in a qualitative research study conducted by Rejeh et al. (2009) the area of pain management post-surgery was described by nurses as being an ethical challenge mainly because nurses are having to cope with considerable institutional limitations such as insufficient resources which limit their ability to manage pain, while at the same time, being exposed to many "ethical burdens" in post-surgery pain management (p. 161).

#### Ethnicity and pain management

Ethnicity and preconceived ideas about certain cultures may influence the type and frequency of pain relief that health professionals prescribe for CALD patients. The ideas of superiority and respect in some cultures may also affect the way the CALD person requests pain relief. This is noted by Elderkin-Thompson, Cohen, and Waitzlom (2001) when they state that nurses might be perceived as superior to the immigrants and this perception may influence the way the nurses interpret their narratives. Furthermore in this study it was also established that if the patient was considered substantially inferior in power and social prestige the nurse occasionally would treat the patient as a subordinate

(Elderkin-Thompson et al.). A number of articles in this section demonstrate the influence that ethnicity has on pain management and the importance of generic or folk remedies as part of this treatment. The following American research studies discuss the relationship of race or ethnicity and the decision to prescribe narcotics or opioids in emergency department and medical centres. These studies included CALD people with different types of injuries who presented to an emergency department using several variables to assess pain prescription. Todd, Lee, and Hoffman (1994) researched 69 Hispanic and 193 non-Hispanic people with extremity trauma to determine if ethnicity influenced physicians' estimation of their pain severity. This was a prospective cohort study in an emergency department in Los Angeles and a visual analogue scale was used to assess pain severity. No significant difference was found between the non-Hispanic and Hispanic patients in their pain assessment, the physicians' pain assessment or the disparity between the patients' and the physicians' pain assessment. The study concluded that the physicians' ability to assess pain did not differ between the two ethnic groups studied. It suggested that more research should be done to explain the difference in the analgesic prescription in other ethnic minorities.

In the research study by Fuentes, Kohn and Neighbor (2002), 323 patients, including 181 white Caucasian, 38 African American, 46 Hispanic and 38 Asians with long bone fractures, were assessed to determine if non whites were less likely to receive analgesics than white people. This was a retrospective cohort study conducted in an emergency department in San Francisco. The authors compared the findings from this study with Todd et al. (1994) duplicating the methodology to confirm the results produced by this study. They studied the relationship between ethnic or racial bias and the administration of analgesia in various ethnic groups. In relation to the limitations, the ability to speak English, the time of arrival and insurance status were not taken into account. They found no difference in analgesia administration between white and non-white patients.

The ethnic groups studied in the research by Ng, Dimsdale, Shragg, and Deutsch (1996) were 36 African American, 100 Hispanic and 114 Caucasians with limb fractures who needed open reduction and internal fixation at the San Diego California Medical Centre. The authors examined the influence of patients' ethnicity and the administration of postoperative analgesia. Injury severity was compared across the ethnic groups by using Chi square tests and analysis of variance. The multiple regression model using variables (covariates) such as age, gender, insurance status and number of diagnoses showed significance of p<0.005 explaining almost 7% of the variation in the total amount of analgesics. When ethnic groups were added as variants in the regression mode, the significance increased to (p<0.0005). There was no statistical significance when including the interactions between racial groups to the covariance. They concluded that Caucasians consistently received higher doses of narcotics than African Americans or Hispanics (approximately 60% of the dose of Caucasians). The study determined that there should be further research on whether or not the difference in analgesic prescription was due to ethnic differences in analgesic requirements or whether the difference reflects cultural biases in treatments. Postoperative analgesia was ordered, "as required" (PRN), therefore it depended on patients' demand and staff perception of patients' pain. Patients' perception depended on patient compliance and the staff's own ethnic and educational background and familiarity with the patients. Patients' demand has to be questioned considering each patient's assertiveness and language proficiency at the time of assessment.

Research by Tamayo-Sarver, Hinze, Cydulka, and Baker (2003) to determine if physicians were predisposed to different treatment decisions based on patients' ethnicity or race and if it changed when occupation, socioeconomic status and relationship with the primary care giver were mentioned to the physicians. The method used was survey with three vignettes designed by the authors to cover the physicians' decision-making process. Patients' ethnicity and race were included and the vignettes that were used randomly

included or excluded social information about the patients. The vignettes were sent to 5,750 emergency department physicians of whom 2,872 (53%) responded. The survey was undertaken with limited information on patients' characteristics other than their race and ethnicity. The group included in the study were Native American or Alaskan Natives, Asian or Pacific Islander, African American, Hispanic and white Caucasians. The conditions taken into account for the study were migraine headache, non-traumatic low back pain and ankle fracture. The dependant variable was the prescription of the opioid analgesic at discharge and the independent variables were the patient and physician's characteristics and the practice environment. Limitations included the lack of interaction between patient and physician, no knowledge of patient preferences or how the physician interpreted the patient's ethnicity or race. It is unknown if the physicians responded to the vignettes the same way as they would have responded to real patients. Also there was doubt on the potential bias of the 53% of physicians who accepted to be part of the study. This study concluded that it was not likely that physicians' biases were based on ethnicity or race when prescribing opioid analgesia. Recommendations were made for further research to study medical encounters to understand how treatment decisions vary by ethnicity or race and to understand the reasons and mechanisms in which patients' characteristics influence physicians' decision-making.

To determine whether there was a difference either in prescribing or self-administration of morphine post operatively when using patient controlled analgesia, Adams, Armstrong, and Erstad (2004) studied 30 Hispanic and 30 white Caucasian patients. The authors compared other studies undertaken on the same topic to explore if there were any differences in the amount of opioid prescribed and the amount of opioid self administered in white Caucasians and Hispanics post operatively. A retrospective chart review method was used at a university Medical Centre in Arizona. Data were collected from medical charts of patients from the orthopaedic and neurosurgery wards. The dependant variables were the morphine prescribed and amount of morphine administered and the independent

variable was race. The retrospective design was a limitation due to the researchers' inability to collect sufficient and accurate data. Self-administration data was not recorded clearly because estimates based on recorded syringe changes were used. Other limitations noted were the size of the sample and the language they spoke because they were not recorded in the study. The authors concluded that Caucasians and Hispanics need a similar amount of morphine for postoperative pain. There was no evidence of prescription differences between ethnicities. This research study suggests the need to assess opioid use after other surgical procedures in different geographical areas.

Predominantly, the pain assessment results in the previous research studies produced the same outcome in all ethnic groups except for the white population who were prescribed more analgesia than the minority ethnic groups (Adams et al., 2004; Ng et al, 1996; Tamayo-Sarver et al., 2003; Todd et al., 1994). Most of these studies demonstrated statistical significance (p< 0.05). Explanations for this difference in prescribing analgesics Ng et al. noted were the medical officers' and staff's different interpretation of the diverse ethnic group's pain expression from what they were expressing in reality, the fact that minority groups were not assertive enough to request pain relief or patients demand for pain medication influenced by what they expect from the health service. The lack of proficiency in speaking the language may have also affected communication between the health provider and the CALD person. As a result this issue predisposed the person to be under treated or not treated appropriately. In most of the studies described, the medical officers were advised that the study was evaluating their procedure to admit the people to the emergency department of the hospital to prevent them from managing the pain differently than what they normally would have to obtain more accurate results (Fuentes et al., 2002; Tamayo-Sarver, Dawson et al., 2003; Tamayo-Sarver, Hinze et al., 2003; Todd et al.).

One study highlights that there was an instance of increased analgesia prescription in men and for more obvious injuries (Fuentes et al., 2002). The effectiveness of the

analgesic and the decision to provide the appropriate analgesia is not specified in any of the studies therefore it needs to be researched further. Race and ethnicity had an impact on the opioid prescription on African Americans by receiving less analgesic for migraines and back pain than Caucasians (Tamayo-Sarver, Hinze et al., 2003), although the medical officers rated the pain similarly in severity being less significant in Hispanics. Medical officers' perception of minority groups as drug seeking people prevents them from prescribing the same amount of medication as for Caucasians, consequently it is deduced that minority groups may be able to receive non opioid analgesics instead (Adams, et al., 2004; R. Smith, Curci, & Silverman, 2002; Tamayo-Sarver, Hinze et al.). Research studies carried out by (Fuentes, et al., 2002; Tamayo-Sarver, Dawson et al., 2003; Todd et al., 1994) concluded that there was no significant difference between races or ethnicity when prescribing narcotics. On the other hand, Green et al. (2003) found a significant difference in the amount of opioid prescribed when doctors ordered analgesics or when they estimated pain severity. (Tamayo-Sarver, Hinze et al., 2003) noted that there was no difference in the prescription of narcotics between all races, which might mean that race and ethnicity are no longer an issue when managing an person in relation to communication problems, perception of the person by medical officer and social distance or trust.

The use of a different methodology and number of participants in each research study could account for the discrepancy in the results of all similar studies (Tamayo-Sarver, Hinze et al., 2003). In Adams' et al. (2004) study, Hispanics reported concern about taking too much pain medication and complained more of the side effects, they were also less willing to self administer opioids and exhibited an increased pain threshold.

#### Communication in pain assessment and pain management

Through several research studies it is shown that CALD people who are unable to communicate in hospital with their health professionals are more likely to require more

procedures and tests and less likely to understand the discharge information and may have their discharge delayed (Brooks et al., 2000; Davidhizar, et al., 1998; A. Smith et al., 2004). In addition, as Garret, Forero, Dickson and Whelan (2008) stated, lack of adequate communication can hinder CALD patient's assessments, treatments and in general their care may be jeopardised. A section of this chapter also reviews the literature on communication issues influencing the care of CALD people and the appropriateness of accredited interpreter usage.

Furthermore, it is also discussed how poor communication increases stress and anxiety in people (Manias, 2003; A. Smith et al., 2004) and how their acute state of illness or an emergency situation may cause a person to revert back to their native language (Brooks, et al., 2000; Chang & Harden, 2002; Tate, 2003). The experience of being in hospital and going through a surgical procedure can be a traumatic time for a person. The patient not being able to communicate and staff not assessing the patient's pain adequately may negatively affect the quality of their experience. Moreover, as Johnstone and Kanitsaki (2006) explained, the interpreters sometimes are not provided, thus the quality of care and related health outcomes can become compromised or may be inferior to that provided to the English-speaking counterparts. The consequence of this situation is that some patients may receive inadequate pain relief and support.

New migrants tend to establish themselves near their ethnic communities for support and comfort delaying their acculturation into the new country and the learning of English (Elderkin-Thompson et al., 2001). As a result adequate communication is needed between health professionals and CALD patients, especially if there is a language barrier, for a culturally appropriate assessment and management of their pain as an essential component of patient care (Kleinpell, 2008; Madjar, 1985). It has also been established by Elderkin-Thompson et al. and Kleinpell that language and cultural differences are the biggest barriers to receiving health care and may cause alterations in the information conveyed such as descriptions of patient's disease or prognosis. These issues may

directly impact on decisions about treatment preferences and decision making and may even cause adverse events (Johnstone & Kanitsaki, 2006; Kleinpell). Consequently, interpreters may be needed for people who have English as their second language to enable and facilitate effective communication with English-speaking health professionals (Dysart-Gale, 2007).

Language issues vary according to the level of the person's proficiency in English and their ability to understand instructions, diagnoses and treatments. Cultural and language issues are often intertwined and in some cases are difficult to separate; therefore they have to be dealt with differently. Cioffi (2003) stated in her study that the nurse's culture influenced the interpretation of the patient's behaviour and the nurse's response to their patients. Moreover, there is a challenge when communicating cross-culturally as the emotional and educational level should be taken into account when dealing with people from very different worldviews (Dysart-Gale, 2007). Hence, it is appropriate to suggest that healthcare staff would benefit from education on cultural awareness and the use of interpreters to help them improve their own cultural and linguistic competence. Dysart-Gale also suggested that cultural competence should be a continuing health professional development strategy undertaken by all health care institutions. Lee, Thompson and Amarin-Woods (2009) highlighted that it is difficult to represent and cater for specific communities and that their knowledge of English may be affected due to age, migration experience and length of residency in Australia. Some examples of cultural and language issues are described in the following articles where the knowledge of cultural issues and the use of interpreters may influence the health care professional-patient relationship. Language and cultural barriers present major obstacles when accessing healthcare by CALD people, consequently making it more difficult for health professionals when planning treatment for ethnic groups (Brooks et al., 2000; Davidhizar et al., 1998; Fernandez et al., 2004; Gerrish, Chau, Sobowale & Birks, 2004). Likewise, as Elderkin -Thompson et al (2001) implied, language barriers hinder the CALD patient's ability to

express their perceptions and concerns towards their illness as the doctor's main objective is only to inform of the clinical symptoms.

A relevant issue is the lack of knowledge about interpreter services by health professionals and CALD people and the services' apparent misuse. In the studies about knowledge and utilisation of the interpreter services and its perception by nurses, interpreters and ethnic groups, (Garrett, Forero, Dickson, & Klinken Whelan, 2008; Gerrish et al., 2004; Johnston & Kanitsaki, 2008) and found that knowledge about the Interpreter Service was inadequate and family members were relied upon for interpreting in particular to ask the right questions, especially after hours. Some studies have highlighted the lack of confidentiality and ethical issues arising when relying on the family and the high risk of not providing accurate information due to lack of interpreting skills (Brooks, et al., 2000; Dysart-Gale, 2007; Gerrish et al.). Nevertheless, as Gerrish et al. and Garret et al. (2008) suggest, appropriateness of using family and friends needs to be explored further but at present there is the likelihood of being used in emergencies when there is an inability to obtain qualified on site and telephone interpreters. These issues led Gerrish et al. to identify some recommendations to improve the use of the interpreter service such as by reorganising this service to ensure interpreters are available at key times, recruitment of more interpreters and multilingual staff, and establishment of a linkage of interpreters to specific wards for continuity of care. It is very important to recognise the importance of training interpreters especially in medical terminology as they might not be proficient in both languages and the capability of speaking another language does not make a person able to interpret medical information (Becze, 2007). Other authors recommend the identification and recording of information on ethnicity, language and religion and working closely with cross-cultural volunteers to utilise their assistance in a social aspect (Gerrish et al.).

When using interpreters there is a risk of causing significant misunderstandings when the specific meanings of the words get lost especially if the language has several dialects,

such as in Spanish (Davidhizar et al., 1998). Idioms have originated from folk beliefs differing from western biomedical constructs so if the interpreter does not explain the idioms (relationship between blood and hot-cold belief) the literal interpretation will not make any sense (Elderkin-Thompson et al., 2001). Another important area is misunderstanding or miscommunication when a health professional fails to recognise that some people not only interact by oral or written language but also by using facial expressions and gestures (Adams et al., 2004; Davidhizar et al.; Tate, 2003).

When CALD people are unable to communicate, misunderstanding with health professionals can become frustrating and may lead to misdiagnosis, experiences of increased pain and anxiety and may also cause pain to go unnoticed, untreated or under treated (Manias, 2003; Tate, 2003; Tonbridge, 2000). If language barriers are unable to be overcome in the health care system the person's care may be compromised. In consequence, if people do not understand their health problems and treatments it can be detrimental to their health outcomes (Gerrish et al., 2004) and some people may not comply with their treatments.

Trained interpreters should be used whenever possible so compliance and treatment orders are followed correctly and assessments are culturally appropriate enabling the provision of an equitable service (Brooks et al., 2000; Fernandez et al., 2004; Gerrish et al., 2004; Manias, 2003). Nevertheless the availability of interpreters is still a major problem (Cioffi, 2003). As Brooks et al. advise, using non accredited staff as interpreters may lead to inadequate transmission of information due to lack of knowledge of medical terminology, omission or addition of information, and condensation or substitution of terms. However, unqualified bilingual/bicultural staff may be trained and then utilised to deal with ethnic minorities to prevent labelling the staff as culturally insensitive. This will assist staff to build better rapport and communication skills with the CALD patients (Cioffi). Untrained staff usually feel overwhelmed when given the responsibility to interpret without the appropriate qualifications (Brooks, et al.) due to their lack of

knowledge on specific terminology and legal health issues. This trend is followed often by many health facilities as it is more feasible due to economic reasons than employing accredited interpreters as Elderkin-Thompson et al. (2001) stipulated. Not providing accredited interpreters will compromise quality of patient care; will affect their outcomes and possibly incur liability for negligence if there is harm to the patient (Cioffi; Flores, 2005). Quality of care may also be jeopardised when medical language is complex and the English proficiency level of the CALD person is low (Garrett et al., 2008)

Bilingual health care professionals may be educated by teaching them essential words in other languages according to their area of expertise to provide some assistance when communicating (Green-Hernandez et al., 2004; Pang et al., 2003; A. Smith et al., 2004). This process probably would be a complex task due to the reluctance or difficulty for some employees to learn other languages. Evidence suggests that hospitals could benefit from recruiting professional interpreters by providing fast and efficient on site and telephone interpreting (Gerrish et al., 2004; Green-Hernandez et al.; Lasch, 2000). Building a relationship with people from different ethnic backgrounds and their families is an important part of cultural understanding and may assist with the negotiating plan when cultural perspectives are involved in communication (Cole, 2002). Studies such as that by Davidhizar and Giger (2004) have also suggested the development of communication guidelines addressing cultural beliefs and health practices of patients and staff so they can work together. These cultural guidelines can be used to undertake an appropriate pain assessment and subsequently develop a cultural pain management plan. These guidelines are corroborated by Chang and Harden (2002) in an educational paper about cultural issues and proposed strategies to help overcome these issues. They suggest that the integral components of a cultural or transcultural assessment model are communication, time orientation, space, pain, social organisation, environmental control, biological variation, religious beliefs, taboos, dietary practices, health, family and view of death (Chang & Harden). This cultural assessment is essential to identify factors that may

influence the patient's behaviour and their response to the Western health care system and to appreciate differences between diverse ethnic community groups. By understanding all these factors health care professionals can appreciate the differences in diverse ethnic groups (Davidhizar et al., 1998) therefore, considering these for diagnosis and treatments. (Chang & Harden; Fenwick & Stevens, 2004; Green et al., 2003; Hilderley & Iwamoto, 1999; R. Smith et al., 2002; Walsh, 2004)

Psychiatrists are frequently asked to evaluate CALD patients, when the person behaves differently from the norm due to their cultural background and their inability to speak or understand English. Some authors found that factors such as, having different values and beliefs and the inability to speak the language may hinder health professionals' ability to assess appropriately and prescribe the adequate analgesia for ethnic groups due to their non-assertiveness when interacting with health professionals (Adams et al., 2004; Tamayo-Sarver, Hinze et al., 2003). Furthermore, Fernandez et al. (2004) researched physicians who self-rated their ability to communicate in Spanish and their cultural competence with CALD participants. The study provided an insight into the importance of language and cultural competence when dealing with Spanish-speaking patients. It demonstrated that health professionals who are fluent in the patient's native language can elicit problems and concerns more easily and often can solve them without frustrations. Cultural competence, language barriers and people's behaviour influence how people perceive each other and explain how misunderstandings between cultures when communicating may be caused because of generalising or stereotyping. These behaviours are learned from parents, teachers or previous life experiences (Tate, 2003). Some authors highlight the need to increase the awareness of stereotyping and bias within the health culture and emphasise the need to consider CALD people's particular cultural idiosyncrasies (Lasch, 2000; Leishman, 2004).

Green et al. (2003) collected scientific evidence and concluded that there are complex disparities among racial and ethnic minorities, which need to be addressed in further

research. There is also the need for training in cultural issues on specific communities and working with interpreters for all health professionals and for CALD people and their families on the Interpreter Service. Communication is an essential part of patient care; therefore as patient advocates, teachers and carers, nurses should ensure information is transmitted adequately especially if it is through interpreters. Cultural and religious beliefs and folk remedies may be used as part of the treatment if possible to assist the health professional decrease the CALD person's anxiety, stress and possibly pain.

#### Summary of literature review

The first section of the review focused on literature about pain perception and experience and how it is different from one culture to another. Nevertheless, pain perception and experience are factors that determine how CALD patients recover from surgery because they usually perceive and express pain differently because of past experiences that hold particular meanings for them. Therefore, the literature shows that nurses need to be aware of having unconscious, preconceived ideas about CALD patients which can lead them to stereotype patients from certain cultural groups when they assess their pain and plan their care. Nurses need to conduct culturally sensitive pain assessments, particularly when caring for people who have endured torture and trauma and other violent events in their lives.

In the next section of the review, literature relating to pain assessment and management was reviewed. Sadly, despite advanced pain relieving strategies, the literature shows that the experience of postoperative pain is still common in postoperative patients generally, and thus it is likely to be even more common in CALD patients where there may be some prejudice by staff and communication difficulties between patient and staff. For this reason, it is extremely important that postoperative pain is assessed appropriately, firstly, by use of a culturally sensitive pain rating scale, and if pain is present, then a detailed

holistic pain assessment of the patient is required, following by a plan to provide (as much as possible) a pain-free postoperative period.

The third section of the review focused on literature about ethnicity and pain management and how preconceived ideas about people from certain cultures and their language skills can influence the type and frequency of pain relief prescribed and given to CALD patients. The way the patient views the health care professionals can also determine how they attempt to communicate their pain experience, particularly if the health care professionals are perceived as being more powerful than and superior to the CALD patient.

In the final section of the review which addressed literature about communication in pain assessment and pain management, it was found that lack of adequate communication by a CALD patient is a key factor in determining their stress and anxiety while in hospital, as well as their ability to express their pain experiences to staff and in turn, their ability to understand what is said to them regarding their pain management, or lack thereof. So the space between the patient and the health care professional is where communication about pain experience and pain management occurs or fails to occur, depending upon a myriad of factors that are both staff and patient related. Staff related factors include: attitude to people from different cultures, attitude to having interpreters, a belief that CALD patients have a better understanding of English than they do, time availability, communication skills, pain assessment and pain management knowledge and skills. Patient related factors include: attitude to health care professionals as superior and powerful people, fear and a sense of alienation in the health care system, poor expressive language skills, poor English comprehension skills, previous negative pain experiences, and low self-esteem, When these factors meet in the in-between nurse-patient space, the result can be seriously jeopardised quality of postoperative care and pain management for CALD patients and undoubtedly, considerable frustration for health care workers.

Therefore, in order to understand this phenomenon better, particularly in relation to patients who speak Spanish only, the research question for this study is *"What are Spanish-speaking patients' experiences of postoperative pain and pain management in an acute care setting?* 

### Conclusion

This chapter reviewed the literature that related to the topic of this study within four main areas – pain perception and experience, pain assessment and pain management, ethnicity and pain management, and finally, communication in pain assessment and pain management. The methods and processes for selecting this literature were provided initially in the chapter. Also, a summary of the major trends in the four literature section was discussed at the end of the review, along with a rationale for selecting the research question for this research study. In the next chapter – Chapter Three – I will explain the research design for my study, including the research techniques, ethical considerations, and data collection and data analysis processes.

# **CHAPTER THREE**

## **RESEARCH DESIGN**

#### Introduction

This chapter commences with an explanation of the research design which includes a brief explanation of phenomenology, which informs this study, as both a research philosophy and a methodology (Burns & Grove, 2005). I then outline information about the participants in the study and the ethical considerations that were considered when developing the plan for data collection and analysis. I finally move on to explain the data collection methods and how the data were analysed.

#### **Research methodology**

A qualitative research approach informed by interpretive phenomenology was chosen for this study. Phenomenology is relevant because it explores human experience and its meaning (Whitehead, 2007). As explained by Flood (2010, p. 8) "issues and meanings are constructed by people as they engage with the world they are interpreting". Phenomenology as a philosophy as well as a methodology (Burns & Grove, 2005) explores the experiences exactly as they are presented to consciousness expressed as feelings, facts, concepts, sensations and thoughts. This is achieved by asking the question: what is the meaning of things of the phenomenon being studied? (Maggs-Rapport, 2001; Van Manen, 1997). Phenomenology seeks to study and explain the phenomena that has been perceived and experienced and subsequently identify the essences of these experiences. For this reason it is a valid philosophical approach to the study of nursing as a science of caring providing the means to understand the human phenomena and the patients' experiences (Flood).

According to Spiegelberg (1965) there are six types of phenomenology which are not mutually exclusive. One of these types is hermeneutic phenomenology which was introduced by Heidegger as a special kind of phenomenological interpretation, which differentiated this approach from the Husserlian rationalist and empiricist approaches to knowledge (Spiegelberg). Hermeneutic inquiry means that the major origin of knowledge is considered to be practical activity – direct, everyday, practical involvement with people, things, and so forth. This knowledge origin equates with Heidegger's "ready-to-hand" or "at handedness" mode of knowledge which provides the most direct access to human phenomena designed to unveil concealed meaning in the phenomena of study (Packer, 1985, p. 1088).

Hermemeutic phenomenology was selected to inform this qualitative inquiry. The word "hermeneutics" is from a Greek word which means 'to interpret'. It is the art of understanding the content of what has been said, the interpretation of the text and the understanding of the experiences being interpreted rather than just exploring meanings of everyday practices (Annells, 1996; Crotty, 1998; Gadamer, 1979).

Heidegger was mainly concerned with being and time, because he saw "being" as essentially temporal (Cohen, 1987). He was critical of Husserl's Cartesian subject-object relation as an adequate way to describe our relation to things or phenomena. Heidegger's interest in the way people are related to things was that we do not normally relate as subjects to objects but as people deeply involved in day-to-day problems and coping (Fleming, Gaidy & Robb, 2003). In contrast with Husserl, who saw the world as present to consciousness, Heidegger (1962) saw the world as primarily one of a practical, at-handedness or acquaintance with what surrounds us in everyday life. Hermeneutic phenomenology focuses on understanding the meaning of the person's 'Dasein' (human existence) and how this meaning influences the choices they make on their perceived world with each participant's narrative (Flood, 2010). Heideggerian phenomenology aims to understand shared meanings with no intent to generalise, theorise or predict outcomes

but to self interpret, because to live is to listen and derive meaning (McConnell-Henry, Chapman & Francis, 2011).

Heidegger suggests taking what is presented to us undeveloped and as a preunderstanding and unfolding or exposing it, bringing these phenomena to the light (Annells, 1996; Crotty, 1998). By so doing, we can have an understanding of the 'phenomena' and another's world presented to us explicitly, allowing us to discover practical wisdom and understanding and thus comprehend the meaning of "being" itself (Crotty; Polit & Beck, 2010). Heidegger believed that this search for the meaning of being human in the world could come from accounting for our actions influenced by our personal history, culture and language which are always there as part of us as a human being (Annells; Gadamer, 1979). Unlike the Husserlian approach, the Heideggerian approach focuses on the understanding that is possible through the relationship the researcher develops with the participants rather than the knowledge that can be obtained in other ways (Fleming, et al, 2003), as explained in the following Gadamerian excerpt:

Hermeneutics must start from the position that a person seeking to understand something has a relation to the object that comes into language in the transmitted text and has, or acquires, a connection with the tradition out of which the text speaks (Gadamer, 1979, p. 262)

When I reflected upon these ideas, I could see that the approach mentioned above of uncovering or exposing to the light what my participants would present about their experiences with pain following surgery, would be the outcome of my relationship with my participants' and our shared history, culture and language.

Further thinking and reflection on readings led me to explore Gadamer's and others' writings more deeply. The terms 'lifeworld' and 'being in the world' highlight that humans cannot separate themselves from the world where they share things because these are what give meaning to their lives (Lopez & Willis, 2004; Maggs-Rapport, 2001). Heidegger and Gadamer believed that understanding a phenomenon came from interpretation not

just from the phenomena itself, thus manifesting the 'being in the world' through language and speech (Maggs-Rapport).

A hermeneutic phenomenological approach is based on what the participants experience rather than what they consciously know (Solomon, 1987) and it is determined by the prejudices and knowledge that the researcher brings to the study (Gadamer, 1979). Gadamer acknowledged the importance of not stepping out of our history with all our prejudices as it is part of our knowledge and understanding. If we did step outside our own history, it would impede us looking at our past objectively (Gadamer). As a result, this connection between the participants' experiences and researcher's prejudices provides a framework that acknowledges that people are totally connected to their world (Crist & Tanner, 2003). For Gadamer, the researcher's pre-understanding or prejudice is essential to properly understanding the meaning of what people are telling them without misunderstandings or misinterpretations. Previous understanding of the phenomenon studied is the main difference between Husserl's and Gadamer's phenomenologies.

The hermeneutic circle or circle of human understanding and the 'fusion of horizons' are terms which describe what hermeneutic phenomenology is all about. A forward arc, that recognises assumptions made by the interpreter and a return arc that describes the interpretation of the phenomena, form the hermeneutic circle (Crist & Tanner, 2003; Crotty, 1998). The participants' narratives and stories are analysed inside this circle at the same time as the interpretations are emerging, keeping each participant's unique story within its own context (Crist & Tanner). The circle provides an understanding of the whole text and its parts, in terms of questioning the meaning of this text or the participants' data (Polit & Beck, 2010). Therefore, data collection and analysis occur simultaneously (Please refer to Figure 3.1).

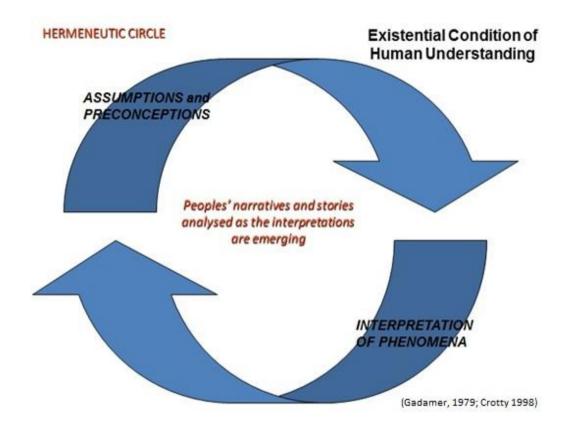
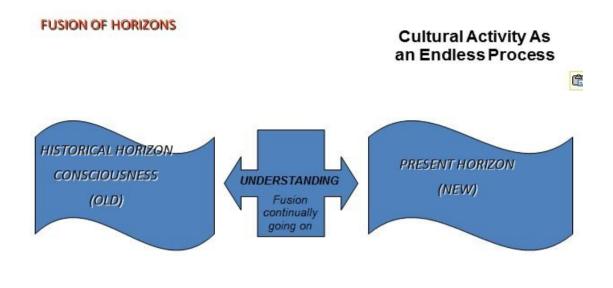


Figure 3.1: Hermeneutic Circle

The word 'horizon' means to look beyond the present to see the larger and true picture of phenomena. Hence, the researcher needs to listen to the past in a way that enables it to make its own meaning heard (Gadamer, 1979). The horizon of the present is continuously being formed therefore we have to constantly check the prejudices we bring with us. This cultural activity is an endless process of 'fusion of horizons'. The check takes place by encountering the past and understanding the ancestral beliefs of the participant and researcher and analysing them together. Thus it is important to have the encounter with the past and understand the participant and researcher's tradition to form this union. The horizon of the present cannot be formed without the past (Gadamer). The fusion of the past and present is happening continually without being able to distinguish one horizon from the other. This endless fusion of the old (historical) and new (present) leads to the

understanding of the person's experience called 'fusion of horizons' (Gadamer) (Please refer to Figure 3.2).



(Gadamer, 1979)

#### Figure 3.2: Fusion of horizons

According to Gadamer (1979), hermeneutics is the understanding of texts and oral utterances hence there is the need for an understanding between two people conversing to be able to reach an agreement about the object that is being discussed. Understanding is interpreting what the other person is saying, allowing all these interpretations to take place in the medium of language. Consequently language is the middle ground of understanding and the agreement of the discussed object between two people (Gadamer). According to Gadamer the problem with hermeneutics is not one of the correct mastery of the language but of proper understanding of that which takes place through this medium of language. In a truthful conversation each person opens themself to the other person, truly accepting their point of view and getting inside the other to such an extent that they understand, not the particular person, but what they say, their opinion.

One does not relate the other's opinion to him/her but to one's own views (in my case as a CALD and NESB person and as a nurse). According to Gadamer, for people to understand each other in a conversation they should speak the same language because each language belongs in a unique way to the process of understanding. The interpreter's own thoughts go into re-awakening of meaning of the text (the interpreter's own horizon). The text needs to be made to speak through interpretation but it will not speak if it does not speak the same language as the other person. The text has to have the language to allow it to speak.

Translators must translate the meaning to be understood within the context in which the other speaker lives. It does not mean that the translator will falsify the meaning of what is said. Meaning must be preserved and understood within a new linguistic world. When there is a translation needed, the hermeneutic process of the conversation is duplicated, and there is that between interpreter and the other as that between oneself and the interpreter. Every translation is an interpretation (Gadamer, 1979).

Gadamer (1979) also explains that linguistic tradition and cultural identity are what is handed down from one generation to the next including customs, legends, stories, and so on. It is not left-overs or remnants of the past; it is given to us, told to us as in a verbal or written tradition. This provides an historical understanding of how the text or the conversation came into being. The understanding of linguistic tradition retains special priority over other traditions; this is what is to be experienced. Hermeneutic experience is concerned with what has been transmitted in tradition, as tradition is not simply a process that we learn to know and be in command of through the experience; it is language.

I chose the philosophy of hermeneutic phenomenology as understood by Gadamer (1979) to inform my study. Drawing on key principles of hermeneutic phenomenology described above, my intention was to accurately present the Spanish-speaking patient's understanding of their experience with postoperative pain in an unfamiliar setting. Language is necessary for proper understanding of these experiences so by having a

common language and culture I feel I was better able to ascertain the participants' stories and deepest experiences, and grasp the significance of them, than would have been possible for someone from a different culture, using a different language.

#### Reflexivity

Reflexivity has been defined as, "the continuous process of reflection by the researcher on his or her values, preconceptions, behaviour or presence and those of the participants, which can affect the interpretation of responses" (Parahoo, 2006, p. 327). Reflexivity requires that researchers are aware of being part of the social world they are studying (Parahoo). Reflexivity has become an important primary methodological tool in qualitative research (Dowling, 2006). It is an acknowledgement of self and scrutiny of one's values and beliefs which is fundamental to qualitative research where I, as a researcher, impacted on the data and the critical analysis of that role (Carolan, 2003). Its use assists understanding and deeper meaning of the phenomenon being reviewed (Carolan; Dowling). Use of reflective methods in this study has enabled me to self-critique and appraise my own experience and how it has affected the research process. In this way, as an insider, I was able to identify and acknowledge my influences on the data (Barton, 2008; Dowling). I will be reflexive in my study because reflexivity involves being aware in the moment of what is influencing both my internal and external responses, while at the same time being aware of my relationship with the topic and the participants. The use of reflection, which is a component of reflexivity (Dowling), enabled me to deliberate upon my experiences as a Spanish-speaking nurse who is conversing in Spanish with Spanish-speaking patients to ascertain their pain and pain management experiences. I will do the reflecting primarily through my writing in my reflective journal, which I will explain further later in this chapter.

In summary, I believe it is appropriate to utilise a qualitative method within a hermeneutic interpretative phenomenological approach for this study as this approach will allow for the

uncovering and interpreting of hidden meanings in the data through my relationship with my participants and through our shared language and culture (Annells, 1996; Benner, 1994; Crotty, 1998; Dowling, 2004). Therefore, this approach will enable me to hear and understand participants' experiences through their narratives and their own personal stories. Understanding takes place with the fusion between the participants' and my own historical and cultural past, and through our present experiences coming from the same cultural and language background.

#### Recruitment

The participants were chosen from several surgical wards at a large tertiary teaching hospital, which has had more than 107,000 surgical events in the past five years. A purposive sampling method was employed for this research study. This enabled me to select participants who shared similar characteristics which were based on their particular knowledge of the topic and experience of the phenomenon (Streubert & Rinaldi, 2011). The participants were selected based on their Spanish ethnicity, and their first hand experience with the phenomenon of postoperative pain. Inclusion criteria will also include the following: female and male adults; age range from 30-90 years; Spanish-speaking, only able to say basic words in English such as "yes", "no", "hello", "thank you", "toilet", "pain", etc.; unable to have a conversation in English; hospitalized for more than 24 hours following any surgical procedures. People were excluded from the study if they were suffering from chronic pain, had cancer or palliative pain and also if they had organic brain disorders or psychiatric illnesses. Patients who refused to take part in the study or who had an inadequate education level to understand the study and were not able to give informed consent were also excluded from this study. The intention was to recruit up to twelve participants to achieve rich data.

#### Ethical issues

Data gathering did not commence until ethics approval was given for the study by both the university and the hospital Human Research Ethics Committees. I will now explain the processes and procedures that I followed in order to ensure that ethical principles were applied throughout my study. They will be presented under the following headings: informed consent, possible risks, unsafe or neglectful practices, and confidentiality and anonymity.

#### Informed consent

Once I was given the name of a potential participant by staff at the Pre-Admission Clinic or the Interpreter Services of the hospital, I approached the patient before their surgery to explain the project in Spanish and to obtain (hopefully) their consent. Details of the research project were explained in Spanish, and the translated (English to Spanish) informed consent form (see Appendix A) and participants' letter (see Appendix B) were given to the patient and relatives (if available) to read. The consent form was translated by an accredited translator from English into Spanish and required the participant's signature. Each participant was informed that their care would not be affected in any way should they refuse to participate or choose to withdraw from the study at any time. I explained that if they agreed to participate they would be able to withdraw their consent at any time without prejudice. I explained also that I would not be involved in providing care for them during their hospitalisation.

One week after the participants were discharged from hospital I contacted them by telephone to ascertain if they still wished to be involved in the study and, with their continued consent, established a time for the interview at their convenience. All interviews were conducted at the participant's house to allow them the privacy and freedom to talk and tell their stories at ease in a familiar environment. The home interviews reduced the

risk of the participant feeling intimidated and coerced to be involved as could happen if they were in hospital. Instead of wearing a nurse's uniform, I wore civilian clothes to the interview to reduce any further risk of intimidation by coming across as someone with "power". Prior to each interview, I asked the participant again for their verbal agreement to continue and I recorded it on my tape recorder. This was be done because consent is an ongoing process in qualitative research (Borbasi, Jackson, & Langford, 2008; Streubert & Rinaldi, 2011).

I was aware that waiting one week after discharge before contacting the participants for an interview increased the possibility of their forgetting some details of their experiences. However, I have weighed this possibility up against the possibility of the participants feeling coerced when in hospital in a vulnerable state and experiencing postoperative pain. I believed that it was more ethical to wait until I could be sure that the participants were able to give fully informed consent in an environment in which they were comfortable and familiar. I concur with Locke (1987), that whenever a researcher has a choice between gathering data that is valuable to the research, but may make the participant more vulnerable, the interests of the participant must be selected over that of the project.

#### Possible risks

There was a risk associated with participation in the study in that a participant may have become distressed or upset because of talking about their pain experience or memories of their homeland. Thus participants were observed and monitored at all times for early signs of distress and uneasiness, such as not wanting to talk about issues or appearing sad or anxious. Had this occurred I would have changed the topic of the interview or recommended a break in the session. I had also anticipated that some participants might wish to have access to a counsellor because of their distress, and had arranged for the services of the hospital's chaplains, or an independent Spanish-speaking social worker/counsellor ("Ruby") to be offered. The hospital has a number of on duty chaplains

who provide services in different religions/languages to staff and patients 24 hours a day. They agreed to provide support to the participants in this study if required. They were available via the hospital's switchboard, mobile phone number or pager. Ruby has extensive experience in counselling Spanish-speaking victims of torture and trauma and violence against women in the CALD communities. She had also agreed to provide free counselling for any of the participants if they should require it. In addition, the participants were to be given the option of rescheduling the visit or ceasing to participate in the study if they became very emotional as they remembered past experiences and were unable to continue.

#### Unsafe or neglectful practices

I had prepared for the possibility that I might become aware of unsafe or neglectful practices by any health professionals, which might cause harm to patients. In such circumstances, my duty of care was to discuss the situation in a general sense with the relevant nursing supervisor to determine if there was the need for any further action. At no time would I divulge the participant's identity, as this would have breached confidentiality and the participant would need to be removed from the study.

#### Anonymity and confidentiality

Research participants' anonymity can be protected by using invented names or pseudonyms (Burns & Grove, 2005; Polit & Beck, 2010). Therefore, to ensure anonymity, the participant's names were changed to pseudonyms after the consent form was signed and all identifying features were excluded from the interview transcripts and thesis (Burns & Grove; Polit & Beck). In case their stories gave clues to their identity, data such as gender, age, country of origin, and years in Australia were altered to reduce the risk of threat to each participant's privacy (Polit & Beck). Should a participant have wished to

withdraw from the study and wanted to extract their data at a later stage, they were asked to provide a unique code consisting of their mother's maiden name and her date of birth. This code number was placed on the participants' transcripts after each interview so that only the participant was able to link the code to their data.

The right to confidentiality was provided to all participants by ensuring the primary data (interviews), audiotapes, and my reflective journaling data were held in my house in a locked cabinet. The transcribed data were secured in my home computer, which requires a password for entry. The hardcopy of the transcripts was locked in a filing cabinet in the Principal Supervisor's office at the University. The participants' signed consent forms were kept in a second locked cabinet in the student researcher's house separate from the coded data collected to maintain confidentiality. On completion of the study, the data are being kept in a locked cabinet in the Principal Supervisor's office at the University Supervisor's office or the Co-Supervisor's office for five years in accordance with National Health and Medical Research (NH&MRC) guidelines (NH&MRC, 2007). After this period, all tapes will be erased and destroyed, the questionnaires and documentation will be shredded, and all electronic data related to the study will be deleted (Taylor, Kermode & Roberts, 2007).

#### Data collection

During the data collection process, there was a constant dialogue (back and forth) between the participants and myself to ensure feedback and discussions to provide a continuous fusion of horizons due to our common culture and language. This enhanced our mutual understanding of the phenomenon of pain and pain management (Crotty, 1998, Dowling, 2007). My own thoughts and reflections contributed to the historical understanding of the text or data and on how a mutual conversation developed between the participant and myself (Gadamer, 1979). I analysed each person's story (see Appendix C) and anecdotes to discover each participant's background to help me understand their experiences. This helped to immerse myself in their past experiences in

order to uncover the meaning of their present experience. This process was continued into the data analysis process.

#### Data collection methods

The data analysis collection methods used were interview (audio-taped), note taking and reflective journaling. I will now explain each of the methods,

#### Interviewing

Up to two semi-structured interviews with a duration of approximately 60 minutes each were undertaken with each Spanish-speaking participant to ensure the research question was discussed fully and they were able to talk freely about their experiences and feelings (Murphy & Macleod Clark, 1993). The purpose of the interview was to explore the participants' pre reflective stories, anecdotes and experiences with postoperative pain and the management of their pain while hospitalised following surgery.

All interviews took place in Spanish at the participants' homes, in a relaxed, nonthreatening environment, approximately one week after they were discharged from hospital. This assisted participants to feel comfortable and at ease to talk about their stories and their experiences of their recent surgery and postoperative pain management. Each interview commenced with the following broad, open questions to enable each participant to describe their experiences:

- Did you experience any pain or discomfort while you were in hospital after your recent surgery? If so, can you please tell me about your experiences?
- 2. Can you please tell me your stories of ways your pain was managed or not managed in hospital after your surgery?

Subsequent questions and prompts were used in response to the participant's descriptions and thoughts in order to focus the interview to the research topic. Second interviews were conducted with some participants to further explore themes that were described in the first interview, but were not explored fully at that time.

#### Audio taping

Each interview was audio taped with a hand-held tape recorder with mini tapes and was placed in front of the participant to ensure clear recording of their answers. The audiotapes were used to ensure there was a permanent record of each interview that included all the pauses and expressions of emotions which may be of great importance to the understanding of the content (Wadensten, Wenneberg, Tang, & Ahlstrom, 2008). Each audiotape was labelled with the participant's pseudonym and the date and time of the interview. I then transcribed verbatim the data into my computer which was later translated into English by an accredited translator (as explained later in this chapter).

#### Note taking

Data were also collected and recorded by my note taking in English, as I observed facial expressions, physical movements and body language for cues during or immediately after the interview (Grbich, 1999). All cultural groups express their feelings, thoughts and emotions by different body and facial expressions using it as part of the way they express what they are going through. Most pleasant and terrifying moments are usually expressed through both verbal and non-verbal behaviours (Harper, 2006). Following transcription and translation, my note taking data were interspersed with the interview data, so as to provide a further dimension to the audio taped records.

#### Reflective journaling

The process of critical thinking and reflecting on preconceptions, previous knowledge and beliefs and then writing these thoughts in a journal, assisted me to be more alert to prejudices or assumptions which may influence the way I interpreted the participants' experiences (Zichi Cohen, Khaan, & Steeves, 2000). The ideas and feelings I may have as a surgical nurse about the care and management of pain and as a Spanish-speaking person living in a different culture to my own were recorded. The journal was used also for debriefing myself in relation to thoughts and feelings provoked by the participants' stories, especially of what might be considered as poor care-giving practices by other registered nurses as told to me by my participants.

My background as a nurse and as a person from a Spanish-speaking culture allowed my reflections to be used as data and for me to express the emotions as I encountered them when interviewing the participants and hearing their stories. The reflective journal, with my thoughts, feelings and anecdotes enabled important issues to be highlighted when analysing and interpreting the data (Roberts & Taylor, 2002). As Gerrish and Lacey (2006) stated, using existing preconceived ideas in hermeneutic phenomenology allows researchers to have a way of sensitising themselves to what is missing. Similarly, Gadamer (1979, p. 358) also stated, "To try to eliminate one's own concepts in interpretation is not only impossible, but manifestly absurd. To interpret means precisely to use one's own preconceptions so that the meaning of the text can really be made to speak to us".

The reflective journal was stored in my computer which was password protected and only pseudonyms were used. When I returned home from each interview, I recorded my impressions, thoughts and feelings in it. I also used it when analysing the data to record my feelings, reactions, and responses to the data.

#### Data analysis

Data analysis or the interpretation of meanings into themes commenced during the interviews when I listened to the stories and interpreted the meanings of what was being said (Gerrish & Lacey, 2006). My aim was to obtain as accurately as possible a thick, rich description of the meaning of the participants' experiences (Zichi Cohen et al., 2000). My aim was to interpret the embodiment (relationship between body and mind) and lived understanding of the world and issues surrounding the participants' lives, which may have influenced the way they understood their experience (Benner, 1994). Pain is a total experience for the human being, because it affects the physical, psychological, emotional and spiritual parts of the person, therefore their experience needs to be interpreted as a whole (Main, Sullivan, & Watson, 2008).

The analysis process I used was that of immersion/crystallisation recommended by Miller and Crabtree (1992). This process was appropriate for two reasons. Firstly, it is consistent with Gadamer's writing in which he was critical of research methods that modelled themselves on the rigorous scientific methods of the natural sciences {Gadamer, 1979). Instead, he focused on the interpretation of texts as a way of discovering the consciousness of the people involved that is embedded in the culture and history that created them. Thus, interpreting the text involved the fusion of horizons explained previously, where I discovered how my participants' histories articulated with my own background (Gadamer). Secondly, immersion/crystallisation is claimed by the authors to be interpretive, heuristic, subjective, intuitive, context-dependent, personal, generative, and concerned with everyday existence. It required my "prolonged immersion into and experience of the text and then emerging, after concerned reflection, with an intuitive crystallization of the text." This cyclical process was repeated to enable interpretations to be reached (Miller & Crabtree, p. 19).

The analysis consisted of presenting the voice of my participants as accurately as possible and reading the text or data collected as a whole a number of times to attain the

'essence' or meaning of the participants' 'lifeworld' or sense of 'being in the world'. Clarification of the text was obtained by: moving back and forth from the data to the interpretations to find particular expressions and the 'essence' of the text and extracting the meaning; and by having to write and re-write the text several times while immersing myself in the data (Gerrish & Lacey, 2006; Moule, 2009; Zichi Cohen et al., 2000).

Subsequently, the text was divided into 'meaning units' as I searched for any changes in the meanings (Gerrish & Lacey, 2006). I was aware of the need to keep true to the text and respect what was being said. My interpretation continued until general themes arose forming the base of the study's findings (Benner, 1994). The text was analysed line by line and similar themes (thematic analysis) were recorded in the margins of the text and meaningful phrases from the text were highlighted (Zichi Cohen et al., 2000).

An audit trail is essential to establish authenticity and trustworthiness of the data collected (Streubert & Rinaldi, 2011). I employed this process to ensure that my line of thinking used in the data analysis could be followed. The audit trails ensured the analysis process was adequately documented and easily available to enable other researchers to repeat this study, thus making it auditable (Borbasi et al., 2008). I wanted to ensure that my interpretations were clear and true to the data obtained in the interviews (Streubert & Rinaldi), and thus, related closely to the phenomenon of interest.

#### Validation

In this study there were two important aspects to consider for data validation. The first one was the need for an independent bilingual social worker/counsellor (Ruby) to read and check the transcriptions and translations. Ruby had agreed to listen to random sections of the tapes, and read random selections of the Spanish transcriptions, in order to check that I had transcribed and interpreted the Spanish language correctly and accurately. This

process helped to ensure that I did not misinterpret any of the diverse Spanish dialects of my participants.

The second aspect of data validation involved "member checks" (Borbasi et al., 2008, p. 170). This meant that once the Spanish interview transcriptions were transcribed, I asked the participants to check them to confirm that the transcribed data represented an accurate record of the interview. Once the data were found to be true to what was said at the interview, the authenticity was established (Streubert & Rinaldi, 2011).

#### **Participants**

There was a total of twelve patients approached preoperatively who initially agreed to participate in the study (see table 3.1). After checking their past medical histories, two patients were excluded as they suffered from dementia and subsequently two patients refused to continue participating in the study as they had postoperative complications. Another patient was unable to meet with me because of family issues. Finally, seven patients were involved in the study, four women and three men from three Spanishspeaking countries (Spain, El Salvador, and Nicaragua).

One interview was conducted with three participants, and two interviews were conducted with four participants, making a total of eleven interviews. A second interview with some participants was necessary in order to clarify issues and questions and to obtain the richest data possible. There were no issues or difficulties when I approached the seven participants one week postoperatively to make an appointment for the interview and throughout the interviewing process. They were all prepared to have their consent reaffirmed verbally and recorded. The participants seemed eager to discuss their postoperative experiences in hospital over the past weeks. Some of the participants became emotional when telling their stories of pain and pain management, but none wished to interrupt or terminate the interviews at any stage. The only concern at the time

of interview and later when I returned to validate the data in the transcripts was that at times I needed to clarify with several participants some ambiguous and confusing terms due to the different dialects they used. The participants seemed to be extremely grateful for the opportunity to discuss their recent experiences with someone from their own ethnic background, despite the occasional difficulties with dialects. The following table illustrates a summary of the participants' demographics.

| NAME <sup>*</sup> | AGE (years) | GENDER | YEARS LIVED IN<br>AUSTRALIA | BROAD AREA OF<br>SURGERY |
|-------------------|-------------|--------|-----------------------------|--------------------------|
| Mercedes          | 81          | Female | 20 years                    | Eye surgery              |
| Maria             | 56          | Female | 21 years                    | Renal surgery            |
| Jose              | 75          | Male   | 38 years                    | Foot surgery             |
| Juan              | 60          | Male   | 21 years                    | Abdominal surgery        |
| Lola              | 83          | Female | 38 years                    | Abdominal surgery        |
| Dolores           | 67          | Female | 37 years                    | Abdominal surgery        |
| Pablo             | 67          | Male   | 37 years                    | Cardiac surgery          |

Table 3.1: Summary of Participants' Demographics

\* Pseudonyms used

#### Interpretive process

I transcribed all of the interviews in Spanish and had them checked for accuracy by the Spanish social worker from the hospital. The analysis process that I used was an inductive process of immersion/crystallisation recommended by Miller and Crabtree (1992) as explained previously. This process was challenging as it required my "prolonged immersion into and experience of the text and then emerging, after concerned reflection, with an intuitive crystallisation of the text." This cyclical process was repeated until an interpretation was reached (Miller & Crabtree, p. 19). The process was to read and re-read my participants' interview transcriptions, my notes and my reflections. My reading occupied considerable time and involved deep reflection and analysis while keeping Gadamer's (1979) theory in the forefront of my mind as I read my participants' stories and experiences. As I continued my immersion in these stories, I began to write code words and notes which merged into stories about my participants' experiences with pain, pain management, communication and a range of contextual factors as well. I also continued my reflective journaling during this process and gradually, the themes emerged. This process seemed to happen simultaneously. Guided by Gadamer's theory, I checked and rechecked the text to see if the findings were consistent with the data provided, and also with my research question. After very meticulous and thorough data analysis, it emerged that while for some, pain and its management were a significant part of their postoperative experiences, their pain experiences were often exacerbated by problems with language or communication as I have demonstrated in my research findings.

I was concerned initially to see that the data involved much more than stories about postoperative pain experiences and pain management. It involved stories about the broader context of care in which the participants experienced frustration and anxiety from trying to understand staff, and stories of being unable to communicate their pain experiences effectively with the staff. It also involved stories of being denied interpreters, of needing and wanting to have family present in order to feel safe and cared for. Additionally, the data delved into stories of the patients' experiences of feeling neglected, rejected and discriminated against by staff. However, I realised how these stories mirrored my own experiences as a migrant to Australia, and I resonated with them – they articulated with my history and culture in a fusion of horizons (Gadamer, 1979). I knew that my participants had trusted me with their deepest feelings and at times, very distressing stories, and I was determined that these stories would be told. The themes that emerged from the data were as follows –

Having your pain assessed Having your pain relieved Not understanding the medication Trying to communicate but not being understood Having no voice Not understanding what they are saying Wanting and needing an interpreter Having an accredited interpreter

The themes will be explained and discussed in the next chapter.

# Conclusion

This chapter commenced with an explanation of the research design which included a brief explanation of phenomenology as the research philosophy and methodology that informed the study. I then justified why this approach was selected and also provided information about the participants, and identified the ethical issues that were considered. Finally, I explained the data collection methods and how the data were analysed and validated, and presented the themes that emerged from my data analysis. In the next chapter I will present, explain and discuss my research findings.

# **CHAPTER FOUR**

# **RESEARCH FINDINGS AND DISCUSSION**

# Introduction

In the previous chapter I presented the research design and methodology that I used for my study and discussed briefly how I followed this research plan. In this chapter, I will discuss the resultant research findings, which were generated from my inductive analysis of the participants' stories. The stories were told in response to the questions I asked and the discussion I had with the participants. These questions were generated from my research question, which was "*What are Spanish-speaking patients' experiences of postoperative pain and pain management in an acute care setting?*" It is necessary to clarify that although an enhanced understanding of the experience of pain and the need to answer the research question was the motivation for this research, the findings revealed some unexpected results, particularly in the area of communication difficulties experienced by the participants, in relation to their communication of their pain as well as their understanding of what the nurses and other health care professionals were trying to communicate to them.

During data collection, it emerged that while pain and its management were significant aspects of the participants' postoperative experiences, their stories focused on problems with language and communication. Although I had set out initially with the purpose of exploring patients' experiences of pain and its management, what very soon became apparent, as the participants recalled their experiences, was that lack of communication and their inability to participate in their own care because of this, was a far greater concern for them. Therefore, rather than forcing participants to maintain an interview focus on pain only, I facilitated their exploration of communication issues as well.

What emerged from the analysis of the findings was a far greater emphasis on participants' experiences of communication compared to their post-operative pain management. As a consequence the findings are heavily weighted in this area.

The irony of this study is that my original intention was to understand patients' experiences of pain management whereas the patients' experiences led me to the discovery of poor communication, which appeared to significantly influence their experiences of post-operative pain

In this chapter, I will discuss in depth the main themes that emerged from the data analysis: "Having your pain assessed," "Having your pain relieved", "Not understanding the medication", "Trying to communicate but not being understood", "Having no voice", "Not understanding what they are saying", "Wanting and needing an interpreter", and "Having an accredited interpreter." The findings are presented and discussed, using direct quotes from the participants to support my interpretations. Additionally, literature that was presented and discussed in Chapter 2, along with additional literature sources to help explain and deepen the findings, is provided. Excerpts from my reflective journal are also included as they provide a rich source of data in response to my thoughts, feelings, and prejudices regarding the participants' stories and experiences.

## Having your pain assessed

This theme presents participants' stories and their interpretation that relate to their issues with having their pain assessed adequately, and how their pain was or not relieved due to their inability to communicate. This theme relates very closely to the research question, as it contains stories and interpretations about how participants' pain was assessed or in many cases, not assessed, by the nursing staff. In the instances where the participants' pain was relieved, there appeared to be an inconsistent pattern of medication administration, which created confusion and concern for some of the participants.

Participants encountered difficulties when trying to explain their pain and the inability of the health professionals to perform an appropriate and comprehensive pain assessment. Lack of communication between the staff and patients and an inability or unwillingness to understand the signs provided by the patients could condemn patients to unnecessary suffering, jeopardise their wellbeing and inadvertently prolong their recovery from surgery. After undergoing various surgical episodes at the same hospital over a period of four years, a participant (Maria) still did not understand how the nursing staff used a pain scale to assess pain even though they would have asked her many times to rate her pain. It was left to Maria to request this information from an interpreter, which resulted in Maria finally understanding how the pain scale worked. Her story<sup>1</sup> of being taught by the interpreter is presented below:

Yes, yes, think I understood because before going into surgery I had an interpreter and she sort of explained what was going to happen and with the little bit that I understand in English I could say "pain" and nothing else because I wasn't very sure. I asked her, "what did 1 to 10 mean" because I didn't know if the pain was going up or down. So the interpreter told me that day....I was able to understand then how much was my pain because many other times I was sweating trying to tell them how my pain was but I don't know if I said it wrong and they didn't understand my pain, but this time they did.... I asked the interpreter, I said, "I want you to do me a favour, I think I understand that from 1 to 10, I think it is for the pain but it is not clear to me. So can you please explain to me how it works" Then she explained it to me. "If you have very severe pain," she said, "very strong that you can't put up with, it will be from 5 to 10, but 5 and under it is less, less, less." After then I understood....It has been 4 years (since she started to be treated at the hospital). As soon as I woke up from the anaesthetic she (the nurse) was next to me and asked me if I was alright and I told her that I had a little bit of pain in my arm. Then she asked me how much and I said a 5...after the surgery I had some pain so they (the nurses) gave me an injection. (Maria)

Maria never knew if staff understood that she had pain and that sometimes this pain was excruciating and she did not have the means to express it. She could not understand why the staff did not try to explain how pain was assessed but she was never told. Even more importantly, the scale had not been explained at this hospital before any of her surgeries.

Maria became aware that she could have avoided the pain and anguish she experienced

<sup>&</sup>lt;sup>1</sup> All participants' stories are presented as spoken in Spanish – the translated English grammar has not been corrected.

for many years of repeated hospitalisations if she had understood the commonly used pain rating scale earlier. This situation indicates the importance of communicating this information to any CALD patients, especially if there is a language barrier, to ensure a culturally appropriate assessment and effective pain management as an essential component of patient care (Kleinpell, 1998; Madjar, 1985).

The distress Maria felt due to her pain and her inability to express this pain possibly went unnoticed by the staff who were caring for her. Cole (2002) noted that there is a risk of unconscious prejudices from the health professionals when they do not understand people's perceptions and expressions of pain. Flannery et al. (1981) also stated that limited education in CALD people can cause poor diagnosis and incorrect treatments due to misunderstandings of different cultural expressions by the health professionals. Nevertheless, Maria somehow knew there was a correct way to assess her pain but she was unsure of what it was. But eventually, because of the explanation by the interpreter, she was able to feel comfortable to express her pain appropriately when assessed. Sadly though, Maria had to go through many years of describing her pain as "little" or "much" as they were some of the few words she knew. Thus, her pain relief was most probably less than optimal as for many people "little" or "much" could have many different meanings.

If the staff thought that the pain rating scale used was too complicated for her to understand, considering her inability to speak English, they could have found a culturally appropriate assessment to apply. Lasch (2000) and Flowers (2004) discuss the need to use culturally sensitive pain ratings and assessments to identify the severity of pain in all patients, considering the diverse ways they perceive and express their pain. In these studies, the health professionals required sufficient information from the patient to assess their pain correctly whilst taking into account their physical and psychological signs. Because there is no biological marker for pain, its presence is totally subjective, therefore, it is vital that the nurse gets information about the pain experience from the person with the pain, as it is only the owner of the pain who can express and describe pain intensity

and its other features. Because of this, self-report of pain is thought to be the "gold standard" in pain assessment (Wylie & Nebauer, 2011, p. 12). Pain assessment is explained further by Wylie and Nebauer when they discuss the role of pain-screening tools compared with a comprehensive person-centred pain assessment. The use of a pain-screening tool is not a pain assessment – it is just the beginning. The authors stress the need for nurses to listen to and interpret the person's pain story. It is important that the assessment is broader than just a physical pain assessment. It must include not just physical aspects, but also social, emotional, environmental and functional aspects (Bruckenthal, 2008).

In an effort to ensure that pain assessment is in the forefront of nurses' minds when doing routine observations of vital signs, Davidhizar and Giger (2004)) advocated that nurses consider a pain assessment as the fifth vital sign to be assessed, along with the usual four measurements of vital signs of temperature, pulse, respiration, and blood pressure. If this were done, and followed up with a person-centred pain assessment, it would ensure that all patients, including CALD patients would receive a comprehensive pain assessment. However, there would be no guarantee of this if the nurses concerned thought that using a pain scale was a complete pain assessment, as appeared to be so in the case of Maria. Pablo faced a similar situation to Maria when staff avoided talking to him and provided him

with medication with no explanations. He explained below:

If I needed a tablet for pain I would say, "Give me another one, give me another one like this or something like this". Sometimes they would give me tablets or something until the pain stopped. To tell you the truth when they (the nurses) would come to me, they would not ask me anything, they would look at the plastics (indwelling catheter, intravenous catheter, etc) and go away. (Pablo)

The level of caring was questioned as staff did not appear to make an effort to obtain the patients' pain status. Similarly, Pablo did not feel that the staff were interested in assessing him by spending time and asking him questions in regards to his pain and general health status. Staff were dealing with physical issues but not with his holistic

needs perhaps because he was not being vocal or expressing it loudly as it is often expected from Spanish-speaking people. Ferrell (2005) explained that nurses hold an intimate place, perhaps a sacred place, in caring for a patient and family in pain. Nurses also have the opportunity to 'give voice' to pain and, thus, to the suffering of patients (Wylie & Nebauer, 2011). By ensuring that Pablo was able to describe his pain the nurses would have given him "a voice" and therefore provided him with some control over his pain. Therefore, Pablo would have received better treatment by being given the tablet he requested as he knew it would take his pain away as it had done many times before. Additionally, it was not clear if the analgesics given were the correct choice for Pablo's pain as there was no obvious assessment of his pain. In addition, nursing assessment of both Maria's and Pablo's pain required identifying the type of pain – whether neuropathic, nociceptive, and/or mixed category pain and the contributing and exacerbating factors to ensure the treatment prescribed was appropriate (Horgas, as cited in Wylie & Nebauer, 2011).

In the excerpt provided, there appeared to be no clear communication or adequate patient-nurse relationship between the nurses and Pablo as it was expected and required for an adequate pain assessment because Pablo was not able to describe any aspects of the pain assessment. Like Maria, Pablo was unaware of the correct assessment process such as being asked about the location of the pain and its severity and so on. Pablo wanted "something like that"; it did not matter to him what it was as long as it took the pain away. It appeared as if there was a "hit and miss" approach, because sometimes the nurses gave Pablo medication and sometimes they did not. There was no indication of their decision making process as they did not ever appear to assess his pain. Despite this omission, they still gave him medications, even if his pain may not have been severe enough to warrant medications.

#### Having your pain relieved

This theme describes the importance to the participants of being pain free no matter what it took or how it was done. Participants demonstrated considerable trust and faith in the nurses and accepted whatever they were given without questioning. The participants saw the health care professionals as powerful and knowledgeable people, therefore in their minds, whatever the health professionals said, should be done. The participants were unaware of the pain assessment processes therefore they did not know there were different methods of relieving pain or the different types of analgesia available. Their postoperative pain was best relieved when the nurse took a holistic approach to the person and focused not just on their physical pain, but also on their emotional pain after communicating with them.

In the following quote, Dolores described her distressing experiences with the pain relief she received after her surgery:

....when I came out of surgery, I had terrible pain and they had to give me something, I don't know what, something for the pain....after a while they (the nurses) gave me something, a liquid that was put in my mouth and they (the nurses) would ask my date of birth, and all that, because it was a stronger medicine....and they also gave me paracetemol....I had to press the button but they (the nurses) had to press it for me because I could not manage with the machine....I knew how to use it but I had too much pain and they kept on telling me to press it and I was too nervous. But I think they gave me something stronger because I had too much pain....It (the PCA) was making me very drunk,, I was dizzy and the pain was not going away but I was feeling very bad with the morphine. I did not know where I was. (Dolores)

In Dolores' story, the nurses appeared to have tried valiantly to assist her with her pain, and they obviously did some checks of her identity, and so on, before administering her medications. However, there was no evidence that they assessed her pain in a holistic way – they simply focused on her physical pain following physical signs without asking her point of view. The attempts to control her physical pain produced distressing side effects for Dolores. If they had assessed all aspects of Dolores' present existence, they may have tried interventions that focused on Dolores' emotional state. For many older people, pain can be a terrifying and isolating experience which can contribute to depression and anxiety (Bruckenthal, 2008). Unfortunately, Dolores' pain was not relieved and she was becoming more distressed and frightened as the situation was too overwhelming for her. Having to deal with the excruciating pain, the side effects of the patient controlled analgesia (PCA) and not being able to explain all these issues to the health professionals were increasing her feelings of fear and loss of control.

In contrast to Dolores' experience of pain, despite having significant pain which caused him physical and emotional suffering, Jose felt a closeness to staff who spoke Spanish as they not only understood the spoken language but also they were able to relate to and empathize with the way he was feeling when separated from his loved ones -

It (having a staff member speaking the language) doesn't affect the physical healing but it does affect in some way with a lot of force towards the sentimental pain or family pain. We feel as if we have a family member next to us. (Jose)

Jose felt comforted and his anxiety decreased when he was around people he understood and were able to communicate with him. Unlike Dolores' situation, his physical pain took second place because in his mind, as soon as his "sentimental pain" or emotional pain and fear about himself and his family were taken care of, he was at ease. As Saunders (2006) said, pain can disrupt a patient's usual communication and renew a circle of fear and tension. For Jose, having someone from the same cultural background close to him made him feel as though his family members were there in a time of loneliness. These are people who have grown up with similar rules and beliefs making him feel as if they were a part of his life and therefore a part of him. Thus he felt reassured, safe and cared for and able to cope with his sensations of physical pain. Cioffi (2003) stated in her study that the nurse's culture influences their interpretation of the patient's behaviour and their responses to their patients.

When I reflected upon Cioffi's words and Jose's experiences, I wrote the following entry in my journal:

If the staff member speaks the same language as the patient it makes the patient feel as if they are involved in their own treatment and healing process. They are then free to express themselves and negotiate their care as English-speaking patients do. Jose felt comfortable and at ease when he encountered staff who spoke Spanish as it made him feel involved in his treatment by keeping him informed and aware of his health outcomes. The concern demonstrated by staff in regards to Jose's understanding of his treatment and outcomes showed. Sometimes I feel the need to be close to people who speak my language and who can understand the way I think and feel. This seems to reinforce my identity, my sense of being a Spanish person, and sense of security. When I think of my country-people in the often alien world of an Australian hospital, I can understand how they need this same sense of being understood by someone who shares the same cultural background and experiences.

Arman and Rehnsfeld (2006) explained that when nurses show caring and compassion for

a patient, it brings forth an optimal healing environment for the patient. Not only did the

Spanish-speaking staff provide support and encouragement to Jose but also English-

speaking nurses with their caring qualities were able to relieve Dolores' pain eventually:

It was about 3 or 4 days after (the operation) because I was able to get up by myself with a little effort but I was able to do it by myself. Some nurses truly helped me very much. There was the little one (the nurse). There were two of them (who) were terrible towards me because they were not paying too much attention to me....At night time if I had a problem I would call (the nurses) except for those two who always took so long to come. The rest came and looked after me very well. If I said that I had pain they would bring me a hot pack to put on my back for the pain. They would say *"Have this, it will alleviate your pain"* and then she (the nurse) gave me the medication and cared for me very well.... (Dolores)

Dolores was very appreciative towards the staff for their kindness and thoughtfulness when they offered her alternatives to alleviate her pain. She understood very well what their intention was and how their caring and willingness to help assisted her to overcome her pain. According to the study by Brilowski and Wendler (2005), many nurses attempt to create a trusting relationship characterized by openness, sincerity, love and patience. As Dolores was recounting her experience it was clear that she experienced these caring attributes from the nurses who demonstrated their ability to overcome the language obstacles and find a way to ease her pain and provide compassion, thus making her feel special while compensating for the rudeness and discourteous behaviour of other nurses.

Pablo had a different experience to Dolores, but it was nevertheless a satisfying experience, as shown in this excerpt below:

I didn't feel anything except at night I was woken up by the cough. I couldn't sleep; I had to get out of bed. I think they (the nurses) were giving me tablets, a tablet that I am still taking every 6 hours. One time they (the nurses) gave me a suppository, twice. Ohh my God, the cough, it almost made me cry. Sometimes I had to press like this (pointing to pressing on chest) as they told me, like this with the pillow. The tablets were big and they were dissolving in a glass full of water....I told them (the nurses) that I was taking one (tablet) at 2, at 7 and at 8.30. When I have 2 it is like Panadol or something like that....because if I don't take them one day it doesn't matter. That is how they (the nurses) as well. (Pablo)

Pablo did not have problems taking the medications he was given to relieve his pain, but he was not told what they were and he did not ask what they were for, as he trusted the staff to give him what he needed. Pablo alleviated his pain by following the advice from the nurses on what to do and by taking his tablets as indicated. He trusted the nurses to the point of taking medications without questioning as in his eyes the nurses had the knowledge and the power so he did what he was told. One wonders if the nurses were aware of the power and influence they had over Pablo. It appears that some nurses may ignore or remain oblivious to the power they have over some CALD patients as some cultures see the nurses as superior due to their knowledge and skills (Tarlier, 2004). By using this power to influence the patient in a positive way and educate them appropriately and possibly assist them with their language issues it might make their postoperative pain and hospital experience a little more bearable.

In the next theme the participants communicated their feelings when given treatments and medications without any explanation. There was no evidence of medication checking or of the patient having knowledge of what they were given. This concerned some participants but not others.

#### Not understanding the medication

The participants' stories also emphasised the need to comprehend various aspects of their medication making communication an essential part of their care. This way, they can be informed on the how, why, when and side effects of their medications. Since the participants were unable to speak or understand the language adequately, staff may have thought it was a waste of time to ensure their comprehension. No matter how much the staff would explain the medications and their effects, the participants could not understand without an interpreter. Lola's experiences of pain, vomiting and medications following surgery are described in the excerpt below:

They (the nurses) just gave them (the tablets) to me. No, I didn't say that I had pain, they (the nurses) gave them (the tablets) for the pain and for the vomiting, and they didn't tell me anything. They just gave them (the tablets) to me. Yes they (the tablets) were given immediately; I think they (the nurses) would have given them (the tablets) to me anyway. (Lola)

Lola accepted the tablets without knowing what they were for; she knew they could have been for the pain or for the vomiting but she did not ask for an explanation. She took the medication administration as something the nurses had to do without needing her consultation or approval. Lola thought it was something the nurses did without needing to give an explanation. There appeared to be little connection or understanding between the two parties when interacting which precluded Lola from having the confidence to ask any questions, or trust that her questions would be understood and answered. Gadamer (1979) explained that understanding requires people to understand one another in order to agree and be in harmony with each other. Because of the lack of agreement and harmony between Lola and the nurses, clearly she did not have any understanding of the medications and their possible side effects and the nurses had no understanding if Lola had any previous problems with these medications. This could have led to possible drug reactions and side effects for Lola.

Similarly, Mercedes explained her experience when her medications were administered:

There was the gauze and the red spot and then I saw the doctor running away. After that they (health professionals) squirted a lot of drops like this (showing how they instilled the eye drops), it felt as if they put in the whole bottle.... No, no, when I told them that my eye was stinging and hurting very much, the doctor finished and I don't know what he did and ohhh! When I felt that they were squirting something, it stung, it stung too much, too much AYAYAYAY!!!! I said, I screamed "AYAYAYAY!!!!" I said "the pain! the stinging!" but I said it all in Spanish. No, he (the doctor) didn't answer me, I asked the doctor who operated on me and (he) did not want to answer me, (he) didn't want to say anything... (Mercedes)

Mercedes felt ignored and disregarded as nobody was answering her questions or responding to her distress. This lack of response made her very angry and upset as she felt dismissed and treated like an object, not like a person. Staff seemed not to be aware of Mercedes' concerns and feelings of neglect as there was no explanation or understanding for her medication and treatment. The health professionals did not respond to Mercedes' distress and pain after they instilled the eye drops. Mercedes did not indicate that staff explained the procedure or checked her discomfort or pain even though she was loudly complaining about her pain. It appeared that Mercedes perceived that staff did not display empathy or show any concern about her understanding of the medication administered or the adverse effects she might feel. Gadamer (1979) believed that people generally understand each other directly after a dialogue where they arrive at an agreement reaching at the same time an understanding about something. Therefore, with no dialogue there could be no understanding between Mercedes and the staff.

In the following quote Juan described his experience when he was given parenteral medications:

I had pain, but they (the nurses) were injecting me all the time on the leg and they (the nurses) were leaving me all bruised, No, (I didn't have much pain) because the girl (the nurse) was coming in very often, I wasn't feeling any pain. I was given injections without telling me what they were for. (Juan)

Juan was not given any information about the injections he was receiving but as he was pain free he assumed he was receiving adequate analgesia. Not understanding what he was given could have caused him some problems as he was bruised but he was unaware that frank bleeding could be a consequence as no one had informed him of this consequence. As a very timid, shy and introverted person, Juan did not feel comfortable questioning the nurses so he decided to accept what medication he was given no matter what it was. Coming from a war torn country and watching powerful people kill friends and family he did not feel safe questioning health professionals who, in his view, represented authority. Juan did not know what it was but he did not complain about the bruising caused by the injections. He was content to not have the pain and as he was not confident enough he did not want to ask and clarify any issues himself. This apprehension was probably due to his cultural upbringing and beliefs which prevented him from questioning or interacting with the health professionals. Adams et al. (2004) and Tamayo, Hinze et al. (2003) found that some factors such as having different values and beliefs and the inability to speak the language could hinder health professionals' abilities to assess appropriately and prescribe the adequate analgesia for ethnic groups. And in Juan's case, his non-assertiveness when interacting with health professionals as people in authority, along with his poor English, meant he was not able to provide the necessary information for staff to assess his pain properly.

## Trying to communicate but not being understood

This theme illustrates the frustration and anxiety some participants experienced when they were unable to communicate because of their limited vocabulary. Their distress intensified when they became aware of the health professionals' not understanding what was said regardless of their considerable efforts. This theme highlights the importance of participants' language when communicating with the health professionals as they tried to explain their symptoms and clarify their concerns after surgery. Unfortunately, the participants had to deal with recuperating from the operation and suffer their frustration as they were not understood regardless of their attempts to explain what they were feeling. In

the following excerpt, Maria explained the difficulty and considerable frustration she encountered when attempting to communicate the pain she was feeling:

After that I felt very sensitive maybe because I can't make myself understood and I fill up with nerves and also fill up with the need to cry....One time I wanted to tell the doctor what I felt because I felt pain in my stomach, it was pain, but it wasn't a simple pain but it was like cramps inside. I wanted to tell him (the doctor) what I was feeling but I couldn't, I couldn't express myself. Tell him (the doctor) this is what I feel, I feel pain from here to there and how many times I had this, so it was terrible. (Maria)

The emotional suffering Maria was experiencing at this time was unbearable as her feelings of hopelessness and inadequacy were exacerbated by the thought of the health professionals not understanding this important information. For most people pain is very difficult to describe but when a patient can give a clear explanation of their symptoms, it is possible for the health professional to recognise the type and severity of the pain and treat it adequately.

In Maria's situation, she felt sick not only physically due to her surgery, but also psychologically when the nerves and stress of explaining in a different language overcame her. Before attempting to describe what she was feeling she already had the belief that the staff would not understand her due to her limited vocabulary. Maria felt traumatised and incompetent every time she tried to explain her symptoms as she knew she had to struggle to make herself understood without knowing if they comprehended her situation.

At the same time, the staff failed to understand the high level of anxiety and distress that Maria was under every time she had to face them. As they were unaware of Maria's constant anguish, the staff did not ensure she was provided with an interpreter to improve everybody's understanding. Elderkin-Thompson et al. (2001) reported that language barriers hinder the CALD person's ability to express their perceptions and concerns towards their illness as the doctor's main objective is only to inform regarding the clinical symptoms rather than listen to the patient. This may explain in some way the reason for

health professionals not understanding how Maria was feeling and reacting. The idea of having to answer questions and make herself understood was so traumatic that she cried every time she had to communicate with the health professionals because she knew there were no interpreters available for her and whatever she had to say was going to be misunderstood or disregarded.

Similarly, Lola expressed her frustration about the same difficulties in communicating her pain experience:

...but pain, pain, I don't know how to explain it to you, but when it hurts, it hurts, and you put up with it.... (Lola)

Although Lola was unable to explain the pain she was feeling, she decided that it was best to "put up with it" since nobody knew about her pain thus nobody was concerned. She encountered many obstacles in trying to communicate and make herself understood. It was too hard and instead of intensifying her stress, hence worsening her pain, she decided to concede. Lola saw to "put up with" pain, sickness and bad health as her only option as she felt she was not understood no matter how she tried to explain herself. She decided to continue without asking questions or notifying anyone about her condition as culturally that would be the appropriate thing to do.

Many times Lola needed to explain what she was feeling but instead she thought she would just suffer in silence. Lola realised it was going to be impossible to find relief, the pain would eventually go away and she would be able to continue her life. Nurses were unaware of the silent suffering she was going through but with her innate optimism she knew she could come through this by herself without help from the nurses. It is a challenge when communicating cross-culturally as the emotional and educational level of both patients and staff and their cultural knowledge, should be taken into account when dealing with and treating people from very different worldviews (Dysart-Gale, 2007).

In contrast, Mercedes explained in the following excerpt how angry she felt at not finding relief as the nurses were not understanding what she was experiencing but she was unable to explain:

No, (I didn't have pain) It felt stinging, stinging....No, because they wanted to give me paracetemol and I didn't accept it.... Because it wasn't pain in the eye it was stinging due to the gauze....No pain, the truth is that the gauze had moved in my eye so it bothered me....it was stinging, stinging! (Mercedes)

Mercedes knew exactly what she was feeling and wanted to overcome this stinging sensation but she was becoming more frustrated by not being able to pass this information on to the nurses. The nurses were asking if she had pain but were missing the real issue which was that Mercedes was feeling uncomfortable and needed help with her eye dressing. Unfortunately, because Mercedes did not identify her uncomfortable feeling as pain she would not accept any pain relief. In turn the nurses could not understand Mercedes' attempts to explain her concerns about her eye dressing. Not understanding the reason for the analgesic in Mercedes' case and the nurses not understanding the reason for her refusal of the analgesic, demonstrated a wide untranslatable misunderstanding. Mercedes was unaware that nurses classified stinging as a type of pain and the paracetemol offered appropriate relief. The nurses failed or were unable to explain this to Mercedes so she could not understand the reason for taking the analgesic because in her opinion it would not solve the stinging sensation. Thus, Mercedes became more angry and upset as she felt they were not attending to her problem appropriately. Wilson, Williams and Butler (2009) declared, no matter how people express their pain, the use of verbal pain descriptors such as "sore", "sting", and so on, may impact positively and negatively on their beliefs about their pain experience but health professionals may or may not take these expressions into account when providing analgesics.

In the following scenario, Maria explicitly conveyed her traumatic experiences and life threatening situation in an Emergency Department as she did not understand what the nurses were doing and they did not understand what Maria was explaining:

That makes me feel, Oh God! Sometimes it does make me feel bad. The day that I was admitted the ambulance officers already had given me a tablet for the pain in my chest; they put a tablet under my tongue and because I had to arrive to (the) Emergency Department they (the nurses) wanted to give me another one tablet. By intuition I told them (the nurses), "no", because they had already given me one and if they would have given me another I could have had a bad reaction. I was scared of this so because I couldn't tell them in another way, I said, *'no, I have, I have'*. But the man and the woman said, *"What are you saying?"*, I said that I don't want them because, *"I have"* and I pointed with my finger that they had given me one (a tablet) under the tongue and then she understood. When the doctor arrived she (the nurse) told him that I didn't want one, *"She doesn't want one"*. She (the nurse) didn't explain to the doctor what I had told her that I already had been given a tablet. So I am saying there are many misunderstandings. (Maria)

In this scenario, Maria felt confused and mystified when given a medication without explanation. She misunderstood its use which could have caused complications, including her death. Nurses failed to explain the need for her to take this medication at that time and instead they understood it as Maria's refusal without trying to find out the real reason. The nurses should have tried to find out her reason for refusal and then pass this information on to the medical staff. Maria's bad experiences in the past with medications made her very wary about what was given to her as she was never able to explain her issues. Unfortunately the nurses did not make an effort to make her aware of the need to take this lifesaving medication as they did not understand what Maria was saying. Consequently, Maria tried in very limited English to let the nurses know the reason for her medication refusal which was that she had taken that tablet a few minutes earlier. Maria was very upset and frustrated when she realised the health professionals did not understand what she was trying to tell them; also the nurse did not explain her situation fully to the doctor. In another part of her story, Maria explains how when she was receiving dialysis, her fistula arm started to become inflamed and painful. Unfortunately the nurse was distracted and was not watching when this was happening. Maria panicked as she knew something was terribly wrong with her fistula but she was unable to let the staff know the situation. Maria tried desperately to communicate and explain what was happening but the nurses

were not making an effort to understand her or provide her with some means for this understanding to occur:

Ohh, my God, what can I say...I spoke little English, I understood less so I told her (the nurse)...the arm was swollen and when I put it down I felt like nails! I was telling the doctor, I was telling the nurse 'I help, I help' I didn't know how to tell them, until a young nurse asked me 'do you speak Spanish?' I said "yes" She said "I speak a little..." I didn't know how to tell the previous nurse, I've had to put up with terrible pain. When she (the nurse who spoke a little Spanish) arrived I got an injection. (Maria, angrily)

Maria was aware of her lack of English which frustrated her to the point of becoming angry with herself and others for not having been able to learn English. Maria's anguish increased as she desperately tried to let people know that she was having a problem. Spanish words came flooding back as she was becoming more frustrated at not being able to describe the issue exactly. Maria was desperately using the words she thought appropriate to alert the staff to the problem she was having with her arm as she did not know if it was normal or if she needed immediate attention. Having to "put up" with terrible pain for a while and not being able to do anything about it was making Maria more upset and distraught.

In her homeland she had fended for herself as she had been very independent and although she knew exactly what she was feeling, the words in English were not coming out. The feeling of being so dependent on others for communication was very overwhelming and distressing for Maria making her very upset every time she had to try to communicate. Burkhardt and Nathaniel (2008) explained this experience further when they said that patients tend to become angry if they believe they are not being taken seriously, are not being listened to, are being belittled, or are denied involvement in the decisionmaking process. This appeared to be the case for Maria.

In the following quote Maria again explained her unsuccessful effort to make herself understood in relation to her pain experience:

When they ask me something I try very hard for them to understand me....I mix all the easy words for me that I can understand in English but sometimes they say to me, "what did you say?" and then I don't know what to do because I already explained as much as I could and I feel bad. So many things one can feel because one can feel silly, discriminated against and all that emotionally. It is very necessary, yes because even if you say, alright, in my case, when they ask me, 'do you speak English'. I say, 'a bit', a little bit but I don't comprehend. (Maria)

Hearing health professionals talking about her health and not understanding what they were saying made Maria feel inadequate and unintelligent. She thought others had the same perception of her as being "silly" as she was unable to speak English. For someone who raised a family and was able to manage independently in her own country it was disheartening to feel like a child again and know she had to depend on others for everything. Maria was experiencing a high level of stress and feelings of hopelessness every time she had to speak to the health professionals. Although she wanted to tell the health professionals how she felt and had all her information and thoughts in her head she was not able to express them and that frustrated her greatly. Maria felt very disappointed and discouraged every time she made a valiant effort to make herself understood by trying to speak the language and then being shown by staff that it was all in vain.

It takes an immense amount of concentration and thinking to be able to speak another language so it was devastating for Maria to realise that no matter how much effort she put into her communication no one was ever going to understand her. Maria was able to say a few very common words in English but was unable to have a conversation with the staff. This was a very hard concept for the health professionals to grasp as they believed that if she was able to say *some* words in English she should be able to understand and explain her issues without hesitation.

In a similar vein to Maria, Juan explained how terrified he was by having to communicate with staff:

The other day they (the health professionals) touched my wound. That person touched me! So disgusting! And they sent the other person (physiotherapist) to take me out of bed by force. (I was) crooked, (but) she got me out of bed. I don't know if

she was a nurse or physiotherapist. But they know I don't speak another language (and) they scare you, because I know very little English and not correct(ly) - that is a problem. If I try to explain what I feel they (health professionals) will not be able to understand me and I get very scared....In my mind I didn't want to stay by myself because I was saying, "they (health professionals) don't understand me and what am I going to do here?" I had that fear of not being understood.... Well if you know they don't speak the language you get very scared. It's what you feel and if the person knows very little English, where the problem is when you can't speak the language. If I am going to explain what I feel he will not understand me I start filling up with fear....I don't want to stay by myself because they can't understand me.... (Juan)

In their homeland, Juan and his family experienced excruciating psychological pain and suffering as they saw family and friends being executed in front of them during a civil war. However, they learned to cope and view the world in a different way to other people who have not gone through terrible experiences in their past, such as war. Juan and his family had been having nightmares since they escaped together the suffering in his country which would have made it difficult for him to cope alone.

In relation to this notion, Cassell (2004) affirmed that events of the present can be checked against the past and events of the past contribute to the meaning assigned to present happenings. Juan only wanted his family with him to feel the closeness of his loved ones and to know that he and his family were safe.

Juan also felt the apprehension and fear of not being understood as for the most part he felt the information was going to be lost in translation anyway. Most of the time that Juan was in hospital, staff cared for him without speaking to him and explaining what was happening, something he did not mind as he was always terrified of staff talking to him and not understanding what had been said. There were no introductions or explanations of procedures as staff appeared to be finding it very hard to pass on the information without speaking Spanish. Also, Juan was feeling frightened to be face to face with the health professionals who would talk to him and ask him questions which he could not respond to because he felt inadequate and incompetent. The fear that Juan had was to encounter staff who were not patient or understanding and who would make him feel ridiculous or

silly. This feeling was increased by the thought of upsetting the health professionals as in his eyes they were of higher position and more educated than he was and as a refugee that was a daunting thought so he preferred to do what he was told.

The English-speaking health professionals were probably unaware of the terror and panic he experienced every time one of them spoke to him. His stress levels increased when he did not know if he was going to understand and if he was going to be able to answer the health professionals appropriately. In some cases this communication issue prevented him from having any contact with the staff which could potentially negatively influence his pain management and recovery.

The following theme also explains how the participants felt when unable to understand what the staff were saying and how insignificant they felt when not being able to communicate in any way with the staff. Frustration and distress were the main feelings as they felt as if they did not have a voice.

#### Having no voice

This theme discusses the considerable difficulty participants faced when listening to the health professionals speak and not being able to comprehend, question or participate in their own nursing care. Participants felt they did not have a voice as it described how they felt when they were unable to understand what the staff were saying and how insignificant they felt when they were not able to communicate effectively. Essentially, their lack of a voice was manifest in feelings of frustration and distress.

Participants faced considerable difficulty when listening to the health professionals speak and not being able to comprehend, question or participate in their own nursing care. The feeling of being ignored and disregarded thus not been able to express their emotions and concerns frustrated them to the point of believing they did not exist and that they had no voice.

Maria expressed her feelings in the following quote:

I feel stupid, that is the way they (the health professionals) make me feel. What I would like to do is..., suddenly, be able to talk to them and be able to explain to them and show them that I am not silly, but unfortunately it is not like that.... I feel like a little animal in the hands of neglectful doctors, a little animal who doesn't have the right to say anything to tell them what is happening with me, what have they done to me because I have never complained? Everything has happened to me and never, ever have I complained!" (Maria - crying)

Maria felt belittled and worthless for not being able to express what she was feeling and she needed especially to overcome the pain and distress. She felt insignificant and inadequate around others as she was not able to speak the language and communicate like everybody else as there was no rapport between her and the health professionals. The staff did not understand that Maria was concerned about not understanding the essence of what was said or being able to provide them with the relevant information for them to make an informed decision about her treatment. Instead, the staff only took into account the few words she knew in English without checking if it was enough for her to have a complete understanding. Gadamer (1979) explained that the interpretation of what people have said is hidden and needs to be revealed in order for everything that has been said to be understood. Maria's needs were hidden because of her language difficulties but sadly she believed nobody wanted to know her concerns thus she was overlooked and considered less valuable as a person than others. Maria was worried about appearing silly and unintelligent because she thought that was the reason why staff ignored her, and made her feel unimportant. Thus, she had no strength or confidence to ask about her health care. Maria viewed the health professionals as negligent and of an uncaring nature as she felt that the staff did not allow her to voice her concerns, issues and her many questions. This feeling of being left out and ignored in encounters with nurses is negative and does not contribute anything positive to care (Westin, Ohrn, & Danielson, 2009). Maria felt powerless and small as she sat quietly doing what she was told and letting others do things to her without questioning or being involved with her own life and

decision making. Her poignant impressions of her helplessness in the face of the staff members' offhand treatment of her pointed to significant dissatisfaction with her overall care (Hornsten, Lundman, Selstam, & Sandstrom, 2005).

The health professionals were not aware of the way Maria was feeling about herself and did not understand what she was trying to say. Maria explained further:

On some occasions I have told the doctors, *"I don't understand*", and they try to make me feel as if I do and that I speak English (laughing). And I don't speak English...it is because there are some words I know how to say but in reality I stayed the same as if I hadn't said anything. I feel like an idiot because they (the health professionals) talk and talk to me and I am picking up bits here and there, I pick one word, then another. Ahhh! I am not sure about that one, I am not sure of what I understand and what I don't understand so I make it up. I think that is not right....they have asked me something and I don't understand and I say *"sorry I don't speak English!"* (Maria)

In this excerpt, Maria was expressing her frustration and feelings of being overwhelmed as she was expected to understand and speak the language just because she knew a few key words which were not adequate for a conversation and least of all to understand health terminology. Maria felt that she was expected to nod and agree with the staff, but by doing so she was putting herself in a very vulnerable position. She was expected to deal with her health issues without understanding the language therefore not being able to respond to these issues appropriately. Maria did not feel confident especially when discussing her health issues with the staff as she was concerned about not providing the appropriate information. She felt abandoned and as though she was travelling blindly through her hospitalisation not knowing where she was going. Maria also felt the health professionals were not interested in her as she described in the following quote:

The first time was very painful, more than now, because I couldn't put up with the pain. I knew it was from 10 to 0 or from 1 to 10 and I said, *"Oh my God how can I tell them (the nurses)?"* That time I spoke less English than now and understood less as well. How could I tell them (the nurses) that this (arm) is hurting very much and my arm had swollen? When I was putting my arm down I felt like nails where going in. I was telling the doctor and nurses, *"I help, I help"*. I didn't know what to tell them.... (Maria)

Knowing a few words in English did not assist Maria to express how unwell she felt and describe her complaint of pain accurately and be able to obtain appropriate pain relief. Maria felt ignored as she was asking, requesting and even pleading for help and assistance but instead she was getting angry and irritated as she was not being able to describe what she wanted for her pain. Maria felt that the health professionals did not care about her comprehension or her knowledge of the language. They did not ensure there was a rapport between them to enhance her understanding. The staff knew what they had to do as part of the procedures but Maria was not told what was going to happen and no patient-health care professional relationship was formed. As Gadamer (1979) stated, the person with understanding does not know and judge as to who stands apart and unaffected; but rather, as one united by a specific bond with the other. Sadly, Maria was feeling frustrated and helpless as she knew her lack of relationship and bonding with the staff was a significant part of her having no voice. How could she have a voice when the staff stood apart from her and did not attempt to form a relationship with her?

In my reflective journal, when I reflected on Maria's experiences, it brought forth my own experiences as a Spanish-speaking person when I have felt occasionally that I have had no voice, and how this can affect my sense of self and belonging:

As part of the Spanish-speaking community I reflected on my, my family's and my friends' experiences on how the cultural and language issues are so significant in our lives even though we have lived in Australia for many years. Although some of us speak Spanish and English well and have taken in the Australian culture without difficulty, we still encounter problems with understanding and making ourselves understood. The accent will always be there making us aware of the differences between an English-speaking person and someone who learned English as a second language. There are days that I feel very comfortable speaking English and there are days that I struggle and feel as though I cannot express myself properly and that people are not understanding, making me feel frustrated and upset. At this time I feel as though it is frustrating and irritating not been able to make myself understood. I know what I want to say and the words flow out in Spanish but it is very hard to speak and express myself in English. When I am upset or stressed people do not understand the language I am speaking. I could see this happening with Maria's experience because the fact that she was getting more upset and frustrated about not being able to express herself was making her forget the few words she knew in English, aggravating the communication problem. Although I've settled in Australia, most of my extended family still live in South America or elsewhere in the world. It has been hard to feel that we belong to one place or another, neither in Australia nor in our country of origin. There is still a very strong

connection with the home country and there is an evident pull to return home after so many years away. Inside there is a concern of not been able to relate to my family and culture anymore in South America. It's a feeling of being displaced, without a home. Although I understand the Australian culture and history there is no feeling of being totally Australian or totally South American.

When I think further about my reflections above, I can relate to the stories of Maria and my other participants who expressed their utter frustrations about not being able to be heard because they had no voice. Having no voice positions the person in a lonely, vulnerable, frightening place because they feel they are not accepted - they do not belong. Bammer (1994) said that language is like a roof over our heads. When people have no language and no voice that is understood, they feel as if they have no roof, no home. They are caught in an in-between, unknown, unfriendly space where they are totally vulnerable and exposed to the power of others who are more powerful.

It was through the above reflections that I realised I had moved into a space where the text of my participants had merged and articulated with my own background. My history and culture had merged or fused with the horizons of my participants.

The next theme continues in a similar vein, by highlighting the frustration and disappointment of the participants when they were not able to understand what the staff were saying to them.

# Not understanding what they are saying

This theme describes the frustration and dissatisfaction of the participants when not understanding what the staff were saying in relation to health issues. It is dangerous not understanding what staff are saying because patients' health can be affected, in some cases, irreparably, due to misunderstandings or exclusion of important and relevant information. It is a problem because it can also cause high levels of unnecessary stress and anxiety as well as reduced self-esteem for CALD patients when they are unable to

understand what is being said, thus preventing them from giving voice to their concerns. It is a different process from the previous theme, but it has a similar outcome – the patient does not have a voice.

Health professionals may think the patient has the appropriate health education as this information was given and discussed but many times it is not delivered appropriately due to the participant's lack of comprehension of the English language, as explained by Maria:

The other thing that happened to me is that the doctors know that I don't speak English and I have encountered the difficulty in wanting to ask them, tell them, "doctor I have this, this and this." (I want to) make them feel what I feel but I can't make myself explain it because I never had the opportunity to have an interpreter when I have been hospitalised.... When I have been hospitalised for many days they (the doctors) come to see me and they (the doctors) talk and talk and they tell me but I don't understand. Only the little bit I understand putting two words together only putting words together, they (the doctors) want to tell me things but I don't feel satisfied. (Maria)

Maria patiently, but with increasing frustration, tried to explain in detail what she felt and what she wanted as she knew that the information provided could be essential to her health outcomes. The staff was not aware of Maria's distress at not understanding and her worry of misinterpreting the information because as Elderkin–Thompson et al (2001) and Kleinpell (2008) said, language and cultural differences are the biggest barriers to receiving health care and may cause alterations in the information conveyed, such as descriptions of the patient's disease or prognosis. Maria wanted to be able to talk with the doctors in the same effortless way as the English-speaking patients did. She was hoping to be able to converse with the doctors, tell them what was happening postoperatively but by using the few words and putting them together she knew it was a hopeless undertaking. It was overwhelming for Maria when in pain, sick and generally unwell not be able to express her symptoms to the doctors who could probably have been able to alleviate her complaints. But as she had not been able to express her concerns she had to, once again, allow the health professionals to treat her differently and be left without

understanding. In her distress, Maria could hear the doctors' talk nonstop without any regards to her understanding and queries. It was a real concern for her not to be able to comprehend her condition, treatment and also her health outcomes as everything the doctors were saying was lost. Nothing they said was understood. The doctors and nurses could have assisted Maria by providing an interpreter as they should have been aware of how much Maria was struggling to inform them about her pain and general health status. Consequently, this situation demonstrates that interpreters are needed for people who have English as their second language to enable and facilitate effective communication with English-speaking health professionals (Dysart-Gale, 2007). Maria continued to describe another situation where she felt she was left without understanding:

When they (the health professionals) discharged me, an older doctor and a new one, maybe the female doctor....That was the last time they were there. They were not going to explain anything, because they didn't explain anything to me...I don't know if they explained it to me or not, I can't remember who the doctor was with me and the other doctor as well. Then they (the nurses) said it was another doctor who came.... Maybe, they (the staff) did ask me but because I didn't know what they were asking me, I was left not knowing what they were asking me so I was left not knowing what they (doctors) were telling me... (Maria)

Maria's anguish and confusion when not understanding what the doctors were saying and not knowing if the necessary questions were asked led her to feel as if it was a hopeless situation. She did not know what was explained therefore did not know what she should ask. Maria also did not know if a pain assessment was carried out or if postoperative information was given. She thought it was not provided but as she did not understand what the doctors had said she did not know what to do. The doctors and nurses did not see or comprehend Maria's anxiety and confusion when she was provided with all the information as she did not understand it probably because the staff members' main concern was to convey the information to fulfil their duty. This interpretation is supported by Elderkin –Thompson et al. (2001) who implied that language barriers hinder the CALD patient's ability to express their perceptions and concerns towards their illness as the doctors' main concern is to deal with clinical symptoms.

In the following excerpt, Maria expresses how she thinks others perceive her as she is unable to speak the language:

Maybe they did ask me about it (pain) but because I didn't know what they were talking about I was wondering what they were asking me...and after that you become so proud and very sensitive, and I don't know, but for that same reason that people can't understand you is that you fill yourself up with nerves and there is something else, the need to cry....I feel stupid when I talk to them (staff) and they don't say anything...the problem is the language, even, for them to see that I am not as silly as they think. (Maria)

Maria felt self-conscious and inadequate because staff did not appear to be willing or able to provide her with the information she needed. They were aware of Maria's inability to speak and understand English but they continued to talk to her expecting her to talk back without any assistance. The staff did not seem to be aware of Maria's negative self-perception as she felt frustrated, angry and embarrassed for not being able to express what she wanted. She needed somehow to let staff know that the lack of English language knowledge did not make her any less intelligent or able to voice her opinions and ideas. It is possible that CALD patients in general and Spanish-speaking patients in particular, often feel as though staff think they are less educated and intelligent just because they do not speak the language. Thus, the staff failed to acknowledge the patient's past achievements and qualifications and may even have considered the patient to have inferior intelligence.

When CALD patients are unable to understand and communicate, misunderstanding with health professionals can become frustrating and may lead to misdiagnosis, experiences of increased pain and anxiety and may also cause pain to go unnoticed, untreated or under treated (Manias, 2003; Tate, 2003; Tonbridge, 2000). If the language barriers are unable to be overcome in the health care system, the person's care may be compromised. As a consequence, if patients do not understand their health problems and treatments it can be seriously detrimental to their health outcomes (Gerrish et al., 2004) and some patients may not continue with their prescribed treatments.

On the other hand, Jose described his positive experiences when the staff talked to him:

There is a great difference, one thing is when I talk to staff who have certain way of talking slow and explaining everything, they use easy words to understand that I understand easily. When I talk to a labourer well they turn their mouth and move their tongue that I can't *understand. That doesn't mean that they are different ....that happens in* Nicaragua because I would talk to someone who wouldn't speak Spanish correctly, the whole sentence, different from what we used. You never know. It is different to talk to someone who speaks correctly than talking to someone who uses slang....In Nicaragua, people who do not speak properly use slang, use the wrong words, the wrong tenses. In other words a lot of words that the language has that I don't understand.... When a person knows the language they don't have a problem how others speak but one who doesn't speak English or the little bit of English that one speaks have learned it reading books where you can find the correct words. Then you find people who talk to you who shorten the words or shorten the sentences which makes it difficult... (Jose)

There were staff that made an effort to communicate with Jose. Whatever they wanted to say, it mattered to them that Jose understood their message. Jose felt comfortable when people who spoke clearly and used correct English were able to pass on the necessary information without any misunderstandings. Jose found that he was able to understand English-speaking people very well if they spoke slowly and with good pronunciation without slang or idioms. As a Spanish speaker and with a Spanish culture, Jose not only used verbal language but he also was aided by the staff's use of gestures and sign language. When health professionals have a genuine regard for others they maintain open lines of communication, spend the time that is required to show respect, have genuine interest and patience, and listen carefully to understand (Burkhardt & Nathaniel, 2008). Jose thought that when staff made an effort to make themselves understood by speaking clearly it showed their caring quality and dedication by trying to ensure he felt at ease. Therefore, misunderstanding or miscommunication can be prevented when a health professional recognises that some people not only interact by oral or written language but also by using facial expressions and gestures (Adams, 2004; Davidhizar et al., 1998; Tate, 2003) thus helping their patients to understand their message.

Jose continued with his story of his positive experiences with understanding staff language. In the following quote Jose explained how staff made an effort to understand him and to make themselves understood:

Although I don't speak good English, I have noticed that the reason the nurses care for us so well, the patients, when there is no interpreter, might be because there are so many languages and people from different countries (here). They (the nurses) make an effort to understand the person to understand me. In this case I am very happy with this, I haven't had a problem. I have not found a nasty person just because I don't speak English. They haven't left me without understanding or that we have kept a conversation where we both understand each other and that is the truth....these people (health professionals) are prepared to talk to people like us who do not speak English very well, they try to explain with gestures....my biggest problem is that I understand less than what I can explain. (Jose)

Jose was at ease and comfortable with the way staff tried to explain his condition to him; making him feel as though the staff cared for him. The way the staff treated him gave him confidence and encouraged him to make an effort to listen and understand what they were trying to tell him in English. Nevertheless, even though Jose understood most of what the health professionals were saying he was aware that his understanding was limited in comparison with what the staff thought it was.

In Jose's perception, staff made an effort to make themselves understood and help him comprehend the meaning of what was said but it was not clear if Jose really understood because his comprehension was never checked. Even though Jose had low English proficiency his understanding was never questioned or verified by staff. Good communication skills include finding ways for the patient to understand important information and when the nurses have a genuine regard for others they are more likely to check the level of understanding (Burkhardt & Nathaniel, 2008). Considering the possibly serious implications of patients not understanding what health care professionals say to them, it is imperative that there is a way of checking to ensure that the message has been received and understood. It is not sufficient for staff to think that because they have given the information, therefore, the patient has understood all (or even a good percentage) of the message. This requirement does not relate just to CALD patients, it also relates to

older people, those who may have diminished comprehension because of medications or procedures, and those who may have some degree of cognitive impairment.

Not understanding what the health professionals are saying about their health issues was presented as frustration and dissatisfaction by the participants. This can have important consequences as not understanding what staff are saying can affect the patients' health, in some cases, irreparably, due to misunderstandings or exclusion of important and relevant information. It is a problem because it can also cause high levels of unnecessary stress and anxiety as well as reduced self-esteem for CALD patients when they are unable to understand what is being said, thus preventing them from giving voice to their concerns. It is a different process but it has a similar outcome – the patient does not have a voice.

The next themes highlight the importance of clear and thorough communication between the patients and health professionals to be able to provide good pain management

#### Wanting and needing an interpreter

This theme discusses the problems a number of participants faced when needing and wanting an interpreter to understand what was said but the health professionals refused to provide an accredited interpreter, and instead, demanded that the patient speak English. This demand caused a sense of desperation and increased stress for the participants when trying to use the basic English words they knew while trying to maintain a dialogue with the health professionals. Maria discussed her issues about interpreters in the following quote:

I feel like an idiot because to tell you the truth I don't speak English and they (health professionals) know I don't speak English. They (staff) do it to save money, but it is none of their business because that was one of the things the government told us that we would get an interpreter if we couldn't learn English. At least I know the basics, when someone tells me to sit down, stand up, breathe, and exhale. I got accustomed to listening to these words, it is not that I know them....I got used to listening to them (the health professionals) and they want me to understand....I can say "good morning", 'how are you", the basics. (I do) whatever I can, but full on medical terms, no. I would be lying to you. I was telling Dr....you are trying to

understand me and the other doctors don't, they don't wait for the interpreter to arrive, they get me in and start talking to me in English and I don't understand completely. Please give me an interpreter because I need one. I use words that I know; it's not that I speak English. (Maria)

Maria had to learn basic words in English to be able to communicate on a day to day basis with the health professionals but it was not enough for her to feel comfortable to express what she needed or wanted. Maria knew she qualified to have an interpreter present at all times but this request was always ignored or rejected perhaps due to the health professionals' ignorance about the interpreter services policy or their fear of the hospital being charged an exorbitant amount of money for the service. In studies by Garret et al. (2008); Gerrish et al. (2004) and Johnstone and Kanitsaki (2008) about knowledge and utilisation of interpreter services and their perception by nurses, interpreters and ethnic groups, the authors found that knowledge about the interpreter service was inadequate and family members were relied upon for interpreting, in particular to ask the right questions, especially after hours. The desperation was overwhelming for Maria when listening to the health professionals talking and explaining when she was not able to understand, increasing her concern about missing out on information especially on pain and its management.

There was a misconception amongst the health professionals when Spanish-speaking participants managed to speak a few words in English to suppose that they were able to understand what had been said. Maria felt a great responsibility and pressure to comprehend the health terminology given to her even though she had requested an interpreter, thus increasing her stress already felt due to her hospitalisation. Maria felt very confused about what was said, probably because health professionals usually use medical terms which are hard to understand even by English-speaking patients. Understanding and making sense of what she was told became a challenge and a very upsetting time as she felt it was too much responsibility to try to understand properly and to ensure the health professionals understood her as well.

Similarly, in the following quote, Lola described her experience:

I understand English well but technical words I don't understand, sometimes they say words that I don't understand. Using day to day words, "come on", "good morning", "thank you"....I didn't arrive young to understand, I was 45 years old. (Lola)

Like Maria, Lola found that day to day English words were within her capability to

understand and ability to communicate but when the health professionals decided to use

medical terminology she found it very intimidating and daunting. Lola recognized the

difficulty she had when learning English because as she got older the language was

harder to learn no matter how much she tried. This situation is highlighted by Lee et al.

(2009) who explained that it is difficult to represent and cater for specific migrant

communities because their knowledge of English may be affected due to age, migration

experience and length of residency in Australia. Lola knew enough English to

communicate day to day by using some basic words. But to communicate adequately with

health professionals she needed and wanted an accredited interpreter.

Similarly, Jose differentiated the use of main words in English and the need to use an

interpreter in the following quote:

At the hospital they (health professionals) have provided them (interpreters) as they realised that I don't speak English. English that one speaks is only for survival when we are dealing with official things I can't pretend in any way to be my own interpreter because I know I can't do it correctly. I prefer to have an interpreter where I can understand what they are telling me and that the answers be adequate and understood by the other person...my English is only for survival, I am not competent for an operation or to write a document or to talk about important things, thus we have to get an interpreter. (Jose)

Jose was conscious of his low proficiency in English. He understood the need for an interpreter when terminology was outside his scope of knowledge and needed assistance in ensuring he was providing the appropriate information to the health professionals. Jose also wanted to ensure that he understood accurately what the health professionals were

telling him as there was a possibility of missing out on understanding important

postoperative and pain management information.

Mercedes also was able to describe her experience without an interpreter:

I can make myself understood, I've had a good understanding with some doctors here at the hospital, so much that he (doctor) said I didn't need an interpreter ....in some cases they don't understand me. Look for example, with the thing in the eye it was very difficult. I can read (in English) well and I understand it, but I can't speak it. I don't know why...I, for example, have the dictionary and the bible with me all the time. I would read the bible in English and when I don't know the words I write the word in Spanish above the word in English using a pencil. That way I am learning the words (in English). (Mercedes)

The doctors' perception of Mercedes' English knowledge was very different from hers as

she felt that sometimes she was able to understand the language but she was not able to

speak and explain her problems with pain. Her real understanding of the language was

unclear as she was sure she could comprehend what the health professionals were saying

but she was unable to express it. The doctor believed that Mercedes could understand

English but it was not clear what was her level of this understanding; it was also

questionable how the health professionals were able to assess her need for an interpreter

without knowing how much she comprehended.

Maria again described her issue when she was not provided an interpreter:

"Interpreter! And please you put 'interpreter' for me (in my chart)' that is the only thing that I could tell her (the nurse) and she was saying, "you don't need an interpreter you speak very good English, you have to speak English". So I was telling her, "it's not that I don't understand, I don't understand everything, please!! Even in Spanish I was talking to her because she was telling me this. "I don't know, please" I pleaded with her. (Maria was very excited, emotional and loud). I wanted an interpreter especially when the doctor arrived, because I had no way I could explain to the doctor what was happening to me. That is how the whole time it's been since I've been with her (the nurse). She (the nurse) was looking and looking until the interpreter arrived and then would make them feel bad. She (the nurse) would tell me (in front of the interpreter), "you don't need an interpreter",...She asked me something and then I gave my answer to the interpreter in Spanish so she could tell the nurse and then she (the nurse) told the interpreter "I am not asking you!, I am asking her (Maria)! She speaks English",.... (Maria) Maria's desperation and anguish increased as she was concerned when not able to understand what was said by the nurses. This lead to frustration and irritation forcing her to raise her voice to ask for an interpreter as she felt that she was not listened to and she anxiously needed the interpreter to feel safe. The nurse's turning away of an interpreter when needed and wanted by Maria made Maria feel frustrated, hopeless and desperate as she saw the departure of her only possible way of communicating with the nurse. Just when Maria was feeling comfortable and at ease with the presence of an interpreter, she then suddenly felt abandoned and left to fend for herself once again. She explained that she was always worried about losing her interpreter (if one was allowed) as it had happened many times before. Maria felt that she was left alone trying to communicate her pain experience as best as she could without knowing if the staff were understanding.

Because of her behaviour the nurses could have labelled Maria as a "trouble maker" or as a "demanding patient", but what Maria perceived was the nurses' actions as regrettable and unreasonable. Possibly the nurses would have understood Maria's behaviour and attended to her request to have an interpreter had they been aware of the 'normal' Spanish culture and behaviour as they would have understood that it was something deeper. Cioffi (2003) stated that the nurse's culture influenced the interpretation of the patient's behaviour and the response to their patients. Moreover, there is a challenge when communicating cross-culturally as the patient's emotional and educational level should be taken into account when dealing with people from very different worldviews (Dysart-Gale, 2007).

Maria explained in the next quote how important language was for her and her fear of having her treatment "mixed up":

Language is the most important thing for me. I can't explain anything, like "look I feel this!" That is why last time I was admitted I said I was going to ask for an interpreter. When the nurse arrived I asked her for an interpreter, "I need the doctor to talk to me with an interpreter because I can't explain!". That is why they (staff) threw her (the interpreter) out, poor thing. They (staff) told her they didn't need her anymore. She asked me "are you sure?". And I said "she (the nurse) is the one who wants you to go", So she (the interpreter) left. The doctor told her, "we don't need you because

here we have Juan (a Spanish nurse)"...The interpreter came back and asked me if I wanted her so I said "I want (you) to stay but the doctor is telling you to go". The doctor told her three times to go...How you think I feel without English, Ayyyyy!!!! I was about to...I am very sentimental, but I was crying and the lady in the interpreter services asked me, "are you alright?" "Yes, I am alright" I said, I was crying because I was embarrassed I told her that I had the flu, but in reality I was crying because I was very nervous. I was thinking, "ayy God, those people who speak English can investigate the information properly in their computer, they get all mixed up and they are mixing me up as well and I don't have any English." (Maria)

Maria wanted desperately to communicate with the health professionals to explain what was happening with her, but found many issues with the use of staff as interpreters. Maria did not get help from anybody as she found that people were not receptive to her complaints. Hence, she did not want others to see her upset and to perceive her as a weak person and a complainer. Maria tried to hide the way she really felt from others as she was trying to make people believe she was all right when in reality she was very upset about the way she was treated.

Some cultural and language issues can be affected by staff members' lack of knowledge and the misuse of interpreters which may influence the health professionals' treatment plans. Language and cultural barriers present major obstacles when accessing healthcare by CALD patients consequently making it more difficult for health professionals when planning treatment for ethnic groups (Brooks et al., 2000; Davidhizar et al., 1998; Fernandez et al., 2004; Gerrish et al., 2004).

In the next theme the participants expressed their need to have family around them and also expressed how comfortable they felt with them. The theme also discussed how inadequate it was to have staff interpreting as most were not qualified therefore they were more likely to make serious mistakes or omit important information.

#### Having an accredited interpreter

This theme highlights the importance of having an accredited interpreter following surgery in hospital and illustrates the participants' views on obtaining an accredited interpreter as opposed to using family and friends to interpret for them. Some of the participants needed an interpreter to communicate a range of issues, including their pain experience, to the staff, and to be able to understand what treatment decisions staff had made. They felt that the use of interpreters was integral to their care; participating in their pain management.

In the following quote, Maria explained the importance of using accredited interpreters:

One time my son was going to interpret and he was told '*no*' because he did not have permission and any mistake that he could make would be on his conscience, but the accredited interpreter would be backed up. They (the staff) didn't let my son interpret but why would they (the staff) allow a young man (Pedro, a Spanish nurse) who is not an interpreter do it? I am always left in the moon because he (the nurse) interprets but he only interprets what he wants. (Maria)

Maria was left perplexed after a nurse who did not speak fluent Spanish was left to interpret, when her son was available to interpret for her. This person clearly did not have any qualifications to interpret in his native language. In Maria's mind there was no difference between using family or using a staff member who was not confident and competent to convey the correct information. Maria felt the nurse was only interpreting what he wanted, what he thought she needed to know or more likely he just did not know how to translate the words. She believed that someone, just because they belonged to a certain cultural group, is not qualified to be an interpreter. For Maria, there was no difference between having her son interpret or having interpretation done by the nurse who was not an accredited interpreter. They both had a high chance for misinforming and misguiding her as the interpreted information she was hearing was probably not accurate, which created a negative postoperative pain experience.

However, Cioffi (2003) explains that unqualified bilingual/bicultural staff such as 'Pedro' may be trained and then utilised to deal with ethnic minorities to prevent labelling the staff as culturally insensitive. This will assist staff to build better rapport and communication skills with the CALD patients. The accredited interpreters were trained and had the appropriate skills to interpret accurately in contrast to bilingual staff or family who know the language but do not know the intricacies of language such as dialect, slang and idioms. When using unqualified interpreters there is a risk of causing significant misunderstandings when the specific meanings of the words get lost especially if the language has several dialects, as is the case with Spanish (Davidhizar et al., 1998). Idioms originate from folk beliefs differing from Western biomedical constructs so if the interpreter does not explain the idioms to the health professional, for example the relationship between blood and hot-cold belief, the literal interpretation will not make any sense (Elderkin-Thompson et al., 2001)

Maria continued to highlight the need to use accredited interpreters as opposed to bilingual staff:

....they (staff) wanted to give me an interpreter because the doctor had to see me and the interpreter didn't arrive so they gave me a nurse who spoke Spanish, but it wasn't the same. He (the nurse) helped me a little....The nurses told me that they don't give me an interpreter "because 'Pedro' (the Spanish-speaking nurse) is there". He ('Pedro') doesn't interpret for me, he just says, "did you understand?". So I say, "no. no I haven't understood" because he only explains one part. I don't speak English perfectly but there are things I can understand and I can pick up that he only tell me certain things. After a while the accredited interpreter arrived and they (the staff) sent her away. I felt so embarrassed because I had asked for her. The doctor told me, "we don't need her (the interpreter) because we have 'Pedro' and he is going to interpret for you". But 'Pedro' only tells me what he wants to. I think he doesn't like to talk too much.... On some occasions when they have operated on me. the doctors say, "the interpreter can go, we don't need her anymore", the interpreter says, "but she doesn't know any English", and the doctor says, "I don't think so, I think it is enough, we are not going to ask her anything else." But in the operating room they have asked me things that I don't understand and I say "Sorry I don't speak Inglis". I think it is necessary (to provide interpreter) because in my case, they ask me if I speak English and I tell them, "a bit" but I don't understand. (Maria)

Maria was feeling very frustrated because she was not obtaining the information she

needed as she was given a nurse who was not qualified or fluent in Spanish to be able to

interpret for her appropriately. The fact that he was born in Spain and was aware of the Spanish culture did not mean he spoke the language as he only knew a few words in Spanish thus he clearly was not competent as an interpreter. Untrained staff without the appropriate qualifications usually feel overwhelmed when given the responsibility of interpreting, mostly due to their lack of knowledge on specific terminology and legal health issues (Brooks et al., 2000). Quality of care may also be jeopardised when medical language is complex and the English proficiency level of the CALD person is low (Garrett, et al., 2008). This trend of using untrained bilingual staff is followed often by many health facilities as it is more feasible for economic reasons than employing accredited interpreters (Elderkin-Thompson et al., 2001).

On the other hand, Jose described the need to have family at hand to interpret for him

when interpreters were not provided:

....They (staff) gave me interpreters and also my son knew a little English because I send him about five years to English courses in Uruguay. He was helping me a little bit with English....Ok my experience was good, my children never left my side and helped me in everything I needed like filling in forms, etc. If they don't have an interpreter they will have a very bad time. I really didn't have to talk too much and I didn't have too much trouble because I was always accompanied by my children and always one of them interpreted for me. The other times that I've had to come to hospital I was given an accredited interpreter and I haven't had a problem either to express what I felt, what I was going through or what I wanted....If I don't understand, I ask my children to explain to me what is written on the paper or the other paper and they explain it to me and then I can perfectly put it into practice with all my trust as if it was me who was understanding because they only tell me the truth.... Over there I had my daughters and my son. No they (the nurses) gave me my morphine, the morphine was what made me vomit, but they already had operated on me and next day my children came very late, my son, daughters and friends. I didn't need an interpreter I had my children with me. I decided not to ask for an interpreter because my daughters were there, they helped me as interpreters, I didn't ask for one (an interpreter) and I didn't have any problems and then later my son arrived and talked to the doctors and everything....I had like a asthma attack when I came out of surgery so I already had oxygen on so my son asked the doctor why I had oxygen so she explained that I had a small asthma attack in theatre so they had to put oxygen. (Jose)

In Jose's case he trusted his children implicitly when he needed the information translated

as he knew they would be honest and do their best to accurately interpret all the

information. However some studies have highlighted the lack of confidentiality and ethical

issues arising when relying on the family and the high risk of not providing accurate information due to lack of interpreting skills and medical knowledge (Brooks et al., 2000; Dysart-Gale, 2007; Gerrish et al., 2004). Nevertheless, Gerrish et al. and Garret et al. (2008) suggested that appropriateness of using family and friends needs to be explored further but at present there is the likelihood of them being used in emergencies. Nonetheless, there appears to be some discrepancies between various clinical settings in relation to the provision of qualified on site and telephone interpreters (interpreters obtained by the telephone anywhere in the country).

#### Conclusion

This chapter highlights the need for proper education on the patient's pain scoring and the health professional's inability to assess the patient's pain properly. According to some participants' experiences, health professionals need to take into consideration that pain may vary amongst patients from different backgrounds therefore they might be unable to make an appropriate pain assessment. Partly this is due to the varied verbal descriptions relating to physical pain which do not refer to pain explicitly, but as such expressions as "niggly," "aching," and "slight twinge" (Harper, 2006, p. 550). The participants in this chapter also viewed the health professionals as knowledgeable people and trusted them implicitly therefore did not see the need to question their procedures or worry about understanding the medications given. Non-verbal behaviour, like verbal behaviour, differed depending on whether it was physical or mental in origin. It also illustrated the frustration of the participants of not being able to express themselves or understand others and highlights the importance the participants put on communication rather than on complaining of pain. Their concern was about having postoperative complications because of their communication problems which might affect their prognosis or treatments as they worried about missing important information.

This chapter also discussed the continuous struggle that the participants had to experience when denied an interpreter and how they perceived their care when unable to express their pain. The participants wanted and needed an interpreter but disagreed with the health professionals as whether they should request an accredited interpreter or use family members. It also highlighted the patients' need to have family close for emotional support as an essential part of their recovery. Although their physical and psychological pain was described separately they often occurred simultaneously and were not managed in a timely or holistic manner as this psychological pain was seen as less acceptable and less real than physical pain (Harper, 2006).

The data analysis and findings were complemented with direct quotes from the data to support my interpretations. Additionally, literature that was presented and discussed in the literature review was provided, along with additional literature sources to help explain the findings.. My reflective journaling also provided a rich source of data to complement my participants' stories and experiences. In the next and final chapter, I will present the discussion, recommendations and conclusion of the thesis.

## **CHAPTER FIVE**

### **REFLECTIONS, RECOMMENDATIONS AND CONCLUSION**

#### Introduction

This is the final chapter of my thesis where I reflect on my research journey, on what I learned along the way, and I discuss the results of this journey in terms of my findings. These reflections are drawn from this study, which took place with Spanish-speaking participants from a large tertiary teaching hospital when I set out to answer the following research question:

"What are Spanish-speaking patients' experiences of postoperative pain and pain management in an acute setting?"

I will reflect on my journey through this research study, and evaluate how the literature review provided an underpinning to my study, and how well the data collection and analysis helped to produce findings that answered my research question. I will also explore the limitations of the study and the effectiveness of the methodology. Finally, I will discuss the significance and implications of the findings for hospital policy, practice, education and future research.

#### **Research process**

#### Literature review

The literature review occurred at the start of my study and continued throughout the research process and during the writing up of the thesis. The literature review was based on and reflected the research question and involved several concepts and topics related to the issue being researched. After analysing the literature it was clear that the literature

review needed to be divided into four main sections which reflected different, but related, aspects of my study: pain perception and experience, pain assessment and management, ethnicity and pain management, and communication in pain assessment and pain management.

The first section of the literature review on pain perception and experience focused on people's cultural backgrounds and learned behaviours regarding how differently pain can be expressed and how others can interpret pain. The literature explained how people can express their pain by crying or screaming or being silent or withdrawn depending on their past experiences or their ancestral teachings. This literature also highlighted the importance of understanding the CALD patients' background as their pain experience may have been affected if they were refugees or asylum seekers because they could have experienced torture and trauma prior to arriving in Australia. Having an understanding of these factors helped me to understand how pain is experienced holistically by patients, and particularly by patients from this kind of background. Their pain was not just the pain from their wound, but an overall experience of suffering, particularly if they were separated from their family during hospitalisation. This literature helped me to understand the holistic nature of pain, and in particular, the suffering experienced by two of the participants who arrived in Australia as refugees and expressed an intense need to have their family close by during their postoperative experience. In the second literature review section, I explored literature regarding pain assessment and pain management. The literature review showed the importance of conducting an holistic assessment of the patient's pain, which requires the use of a pain rating scale followed by a detailed assessment of all aspects of the pain, including its location, severity, and so on. While there were a number of pain rating scales reviewed, there

were only a few that were considered appropriate for CALD patients prior to the development of a culturally appropriate pain management plan. For this to occur, though, there needs to be adequate education and knowledge by the health professional and no

preconceived ideas or stereotyping of people from various cultures by the health professional. It was a strong thread in my data that there was limited or non-existent pain assessment for the study participants. Many who received pain medication did so without any prior assessment, and often without the participant having any idea of the medication they were receiving. This may have occurred because of limited language skills of the participants and inability of the nursing staff to communicate with and understand their patients' halting attempts to describe their pain and suffering. However, there is also the worrying possibility that there may be limited holistic pain assessment occurring with all patients in our health care facilities.

The third section of the literature review related to ethnicity and pain management. The literature in this section provided information about how the ethnicity of patients can influence the attitudes of nurses and doctors in relation to assessment, prescribing of pain medication and the overall management of pain. The literature also showed that CALD patients are often not assertive enough in requesting pain relief, possibly because of their language difficulties. Data analysis in my study showed that there were many issues in overall care and pain management that stemmed from staff members' ethnic biases, but one could argue that perhaps the participants who expressed these negative concerns were overly sensitive. It is difficult to say, as the perspectives and attitudes of the nurses involved were not determined as the nurses were not interviewed in this study. Nevertheless, there was significant information provided by the participants that they had many difficulties in communication and acting assertively in relation to their pain experiences, because of their language difficulties and concerns about staff as power figures. This was certainly the case for the two refugee participants and several other participants.

The final section of the literature review was communication in pain assessment and pain management. I chose this heading and associated literature because the literature in the previous sections spoke repeatedly about communication and language as the main

processes necessary for adequate and satisfactory care for CALD patients, and particularly, for those who are experiencing pain. The literature showed that communication and language skills affected: how/whether the patient interacted with the health care professionals, the quality of the information, the receptiveness of the health care professional to the patient's attempts to communicate, and the resultant care provided by the health professional. The literature stressed the need for qualified interpreters for CALD people, however their use in my study was fraught with confusing processes and lack of staff members' understanding/implementation of existing policy. The use of qualified interpreters who were often available, but disallowed by staff, could have helped to bridge the communication gulf that existed in many of the situations reported by the study participants. Participants who were not given or were disallowed interpreters struggled on their own or with the assistance of willing family members or unwilling staff members of the same ethnic background, with varying levels of Spanishspeaking ability. The results were often poor pain assessment and management and feelings of frustration, fear, confusion and low self-esteem for the study participants.

Overall, the literature provided a helpful underpinning to my study and helped to guide the research process. I will now move on to evaluate the research methodology I used for the study.

#### Research methodology

To explore my research question I used a qualitative inquiry informed by hermeneutic phenomenology. I utilised the Gadamerian approach because with the 'fusion of horizon' (Gadamer, 1979) I was able to look beyond the present to see the larger picture of the phenomena, the experience of pain, and thus was able to uncover its hidden meanings. I was able to listen to the participant's past and take into account my past in a way that enabled our mutual pasts to make their own meaning heard and allow the present to be continuously formed. This process enabled me to encounter the past and understand the

ancestral beliefs of the participant and myself to be able to analyse them together. This approach enabled me to hear and understand participants' experiences through their narratives and own personal stories. I made use of the fusion between the participants' and my own historical and cultural past and our present experiences as we came from the same cultural and language background.

The participants were very open and honest and they entrusted me with their heartfelt stories and accounts of their positive and negative experiences whilst in hospital. However, I believe that there would have been much richer data had I also interviewed the nurses. This would have added an important dimension to my data as I would have had the opportunity of ascertaining their experiences of providing pain relief for people with whom they clearly had communication and language difficulties. Polit and Beck (2010) refer to this process as data triangulation which is a quality enhancement strategy that would have enriched and strengthened my data quality. The authors describe person triangulation as a type of data triangulation strategy because it involves gathering data from different types or levels of people – the patients and the staff. This strategy would have allowed me to validate my data through the different perspectives of staff and patients on the same phenomenon (Polit & Beck).

#### Ethical considerations

The consent form and participant information letter were translated into Spanish for the participants to be able to take home, read through, discuss with their family if they chose, and then make an informed decision about participating in the study. It was heart-warming to see the pleasure experienced by the participants when they saw that the documents were in Spanish. I am sure this was a major factor in the eagerness of the participants to be involved in the study.

There were a few instances where the participants made me aware of potentially unsafe and neglectful practices by staff at the hospital (for example, failure to check the identity of patients and correctness of medication before administration). After reading my reflections in my journal a number of times and doing further reflection I made the decision not to discuss individually the practices with any hospital personnel at the time. I am aware that some people would be critical of my judgment, but I justify my decision in two ways. Firstly, I am aware that I have maintained the confidentiality promised to my participants, and secondly, I have given several research-in-progress sessions to staff at my hospital, where I have presented this information in a way that does not identify any staff or patients. I am hopeful that the information provided at these sessions has helped to inform supervisors and staff of these and other unsafe and neglectful practices so that the required staff development education and activities can be arranged for staff overall.

#### Data collection

The process of participant recruitment was problematic because I discovered that the process I had set in train, whereby I would be notified of Spanish-speaking patients' admissions for surgery, did not work well initially. The reasons were probably my research naivety in thinking my research was as important to the hospital staff as it was to me. When I became aware that there were Spanish-speaking surgical patients around the hospital about whom I had not been notified, I changed my plan to incorporate a regular acquisition of the interpreter services' patient list to check for their upcoming surgeries. This plan worked much better and I gradually made contact with the patients who agreed to be involved in my study.

Initially, my interviewing technique was stilted and nervous despite my many years of nursing experience. However, I had never before had the opportunity to be part of my patients' lives in such an intimate way, as I found I was accessing their inner thoughts, feelings and life experiences so closely. I felt it was a great responsibility and privilege to

listen to their individual stories and experiences as they conveyed their heartfelt emotions and feelings on the topic being studied. The interviewing process became easier and more relaxed in time. However, upon reflection, I think my data quality would have benefitted if I had conducted some practice interviews with family and friends before I commenced interviewing my participants (Polit & Beck, 2010). This process would have shown me that I had a tendency to not only ask closed questions but also fail to follow up on very rich interview threads that patients were moving into. Nevertheless, eventually, I found I was able to listen intently and then produce more questions from their detailed but very emotional stories. I was surprised to hear how open and willing the participants were to share their experiences and life stories and how at ease they felt with me which underlined my sense of responsibility to record accurately their heartfelt and passionate stories. I am sure the reason for their acceptance of and trust in me was because they felt connected with me by our shared language and culture and because I am a nurse who they felt would understand them and be empathetic towards their experiences. They were eager to tell me their stories as they hoped that by doing so, future patients in the hospital would benefit by having better care and treatment than my participants had received.

Interviewing the participants face to face at home and taking notes were appropriate strategies to use to obtain the rich in-depth data I needed to answer my research question. The participants felt comfortable in their own surroundings. My wearing of civilian clothing, I am sure, contributed to their sense of safety and comfort, because I noticed a difference between the participants' rapport towards me in hospital while I was wearing my uniform at the time of recruitment and when I wore civilian clothes when interviewing them later on at home. At the hospital the participants were more distant and wanted to be more respectful by not engaging in long conversations. However at their home they wanted to tell me their stories and experiences not only about their recent surgery but also about other personal experiences with the health system in Australia.

The participants also wanted to keep in touch with me inviting me to come back to visit in the future as a friend and to inform them about the results of the study.

By tape recording the interviews I was able to listen intently to the stories at the time of the interview without interruption, and occasionally and surreptitiously, take short notes which assisted me when transcribing the interviews. This strategy demonstrated to the participant that I was involved intently with them and their story. It also helped me pick up on subtle cues and develop further probing questions from their answers without making the participant feel as if I was interrogating them (Borbasi et al., 2008).

The reflective journal was a very important tool for my research as I was able to record my reflections, thoughts and experiences which were developing constantly as the participants were telling me their stories and while I was doing the data analysis. This journal assisted me to reflect on my ways of thinking and acting as a nurse and a Spanish-speaking person and also on how other staff at the hospital care for and treat their patients. This journal also made me realise how much I take for granted about my nursing, how important nurses are to the well-being of CALD patients and how deeply my behaviour and attitude as a nurse can affect not only my patient's sense of safety and comfort but also their experiences and perceptions of pain and suffering. Having the reflective journal helped me to reflect more deeply upon my past and present personal and professional experiences, and how my ethnic origins assisted me to understand at a deep level the meanings of the sometimes extreme emotions and feelings that the participants wanted to share with me.

#### Data analysis

The data analysis occurred concurrently with the data collection. Initially, once I had obtained all my data, I felt overwhelmed with the amount I had and how and where to continue with the analysis I had commenced during the data gathering process. I found

the immersion/crystallisation process (Miller & Crabtree, 1992) quite difficult at first as I felt as if I had no guidelines to follow, but after reading my data over and over and making copious notes, and discussing my data analysis with my supervisors on a number of occasions, I eventually began to see the themes emerge. I could see how the fusion between the participants' and my own historical and cultural past and our present experiences coming from the same cultural and language background, were helping in the analysis process (Gadamer, 1979). My knowledge of our shared language was the key for adequate understanding of my participants' experiences. Our common language and culture allowed not only the participants to share but also me to understand and respond to the compelling stories of their pain and pain management experiences.

#### Quality criteria framework

The quality criteria framework I have chosen to use to evaluate my study is that developed by Lincoln and Guba (1985, as cited in Polit & Beck, 2010, p. 538) which is considered to be the "gold standard for qualitative researchers." The authors suggested four criteria for ensuring the trustworthiness of a qualitative study: credibility, dependability, confirmability, and transferability. However, in 1994, because of criticisms that they were simply mimicking the positivist paradigm, the authors added a fifth criterion of authenticity (Polit & Beck). I will now use these five criteria to evaluate the quality of my own study.

#### Credibility

Credibility is seen by Lincoln and Guba (1985, in Polit & Beck, 2010) as the most important goal of qualitative research, as it refers to the ability to have confidence in the truth of the data and the way it has been interpreted. There are two aspects to credibility – firstly, conducting the study in a way that makes the findings believable and truthful for

participants and those within the study context; and secondly, making sure that credibility can be demonstrated to external readers.

In relation to the first aspect of credibility, the interviews were conducted in Spanish, and I word-processed the data in Spanish. After the transcriptions were completed, I had them randomly checked by Ruby, the bilingual counsellor/social worker, and then I gave them to the participants to read through the transcribed data and clarify, modify or approve their recorded experiences. This process is known as "member checks" (Borbasi et al., 2008, p. 170). One of the concerns I had about accuracy of transcriptions was my understanding of dialects, idioms and slang, characteristic of different countries and regions in Central America, South America and Spain. I sometimes encountered considerable difficulty understanding what a participant meant when I was gathering the data. In some cases I had to ask the participant during the interview to clarify the meaning of their words because I was misunderstanding what they were saying. Thankfully, because of her counselling work, the bilingual counsellor had vast experience with various Spanish-speaking groups hence she was able to verify the correctness of the different dialects in my transcriptions. Later, I translated the data into English, so my supervisors could read and understand my data.

In relation to the second aspect of credibility, I have had a number of opportunities to share my participants' data, and my interpretations, with members of the University community at my yearly research seminar, as well as with staff at my hospital when I have presented my study on research days. My audiences have always expressed their sense of the data being quite credible, as many staff had similar stories to share about caring for patients with pain and other issues when there were communication difficulties between staff and patients. This no doubt demonstrates the increasing numbers of patients from different countries who are migrating to Australia and at some stage, requiring care in our health care facilities.

#### Dependability

The second criterion in the Lincoln and Guba (cited in Polit & Beck, 2010, p. 539) framework is dependability, which means that the data remain stable and reliable over time and over conditions. In other words, if the study were "to be replicated with the same (or similar) participants in the same (or similar) context," would the findings be the same. I realise that the immersion/crystallisation data analysis process recommended by Miller and Crabtree (1992) that I used when analysing my data has made the issue of replication somewhat difficult, as I have not been able to explain in detail the intuitive processes that I used when developing the themes that arose from my findings. Perhaps if I had used a more step-by-step process to analyse my data as explained by authors such as Colaizzi or Giorgi (Burns & Grove, 2005), not only would it have been an easier process for me, but also it would have given me clear steps to show my data analysis process, so that the dependability of my results would be improved. However, I believe that the process I used was more in tune philosophically with Gadamer's (1979) approach than that of Colaizzi or Giorgi because, as explained in Chapter Three of my thesis, Gadamer was critical of methods that were modelled on the rigor of the scientific methods of the natural sciences.

#### Confirmability

This criterion refers to the potential for congruence, accuracy, relevance, and meaning between the data provided by the participants and its interpretations (Polit & Beck, 2010). This means that the themes I developed must relate to the participants' data excerpts that were provided to support my data analysis. Initially, I found this difficult to do, and had several meetings with my supervisors to ensure that there was congruence between my themes and the data that I provided to support my findings. On reflection, perhaps I used too many data excerpts to support the themes. However the data were so rich and gave

voice to different aspects of my participants' experiences that I decided to include the additional data excerpts. Consequently, I believe that I have confirmed the data and my interpretations and this confirmability is demonstrated in the rich voices of my participants that support my decisions regarding the themes.

#### Transferability

The criterion of transferability relates to the extent to which the findings can be transferred or applied to other groups and settings (Polit & Beck, 2010). In order for a reader to be able to make a decision regarding this criterion, the researcher must provide sufficient descriptive rich data so that the reader can evaluate if the data apply in other contexts (Polit & Beck). I believe the data from my participants are sufficiently thickly and richly described to enable a reader to make this decision about transferability to another setting.

#### Authenticity

The last criterion, developed by Lincoln and Guba in 1994 (Polit & Beck, 2010), is authenticity, which is the extent to which data show a range of different realities. Authenticity emerges when the data convey the feeling tone (mood, feelings, language, and context) of the lived experiences of the participants' lives. The data need to provide for the reader a vicarious experience of the experiences and the lives being described in the text (Polit & Beck). The data excerpts provided in my study showed a range of realities from staff who were caring and professional to others who were offhand and possibly even negligent. Some of my participants described deeply passionate experiences with numerous strong feelings tumbling over each other in their excerpts, while others described experiences in a more measured, more objective manner. I believe that this range of realities and feeling experiences of my participants helps to provide a sense of authenticity to the data portrayed in my study.

#### **Research findings**

In this section, I evaluate the research findings under each of the themes and relate them to the research question, *"What are Spanish-speaking patients' experiences of postoperative pain and pain management in an acute care setting?"* 

In the reported themes, Spanish-speaking patients' experiences were marked by difficult communication with health care professionals and often, by an inability to express their pain experiences thus not being understood by the staff. The participants were unable to understand that pain could be described in many different ways, such as an uncomfortable feeling or as a stinging or hurting sensation. As the participants were unable to speak or understand the English language adequately, health professionals appeared unable to ask them about their pain or to assess them holistically in any meaningful way. The communication problems affected the health professionals' decisions regarding the patients' need for pain relief and the most appropriate type of analgesic. Consequently there was only an occasional cursory attempt to rate patients' pain, and no attempt at all to conduct a holistic assessment of the patient with pain. Because of the lack of understanding of the patients' level and type of pain and the appropriateness of analgesics, there was no consistency with analgesic administration, since no matter if the word "pain" was mentioned or not, the patient was given the medication without appropriate medication safety checks. This happened consistently no matter if the patient had severe pain or not - they were not asked about their pain and it was difficult for the patient to express their concerns. Some of the participants were able to describe their pain with their limited knowledge of English but others would have benefitted from having an available, but rarely used, interpreter to convey their needs. The most alarming issues were when the nurses, with no prior pain assessment, provided analgesics without asking or explaining the indications and side effects and checking for reactions and allergies. It was also worrying that the patients took the medication without questioning. It was acceptable to the participants to do this as they were resigned to

tolerating these actions so they would have their pain relieved as they could neither express nor understand English adequately.

Postoperative pain and pain management took second place in the participants' priorities as they resigned themselves to trusting their health care professionals to provide them with the necessary pain relief. However their main issue was communication. The postoperative experiences of the participants were marked by frustration, anger, insecurity, fear and anxiety when they found they could not communicate their pain to the staff because of their limited vocabulary. This communication difficulty caused considerable emotional suffering along with feelings of hopelessness and inadequacy. Eventually, some patients decided they simply had to "put up with' the pain, as they could not get their message across to the staff. Their lack of voice to express their fears and concerns affected their sense of self and worth.

The main concern however, was that because a participant could say a few words in English, staff believed their English comprehension was much better than it actually was. Staff provided the information to the patients that their duty of care demanded, however they did not check to see how well the participants understood staff communication to them, as explained by Jose – ".....my biggest problem is that I understand less than what I can explain." Sadly, Jose's low English proficiency and comprehension were never checked by staff. Neither was the English comprehension of other participants' checked by staff. There are serious implications of patients not understanding what has been said to them, whether they are CALD patients, patients with high anxiety levels, patients with some degree of cognitive impairment. It is extremely important that staff understand what patients are trying to communicate to them. However, it is just as imperative that staff check that their message has been received and understood by the patient.

It was apparent that the experiences of participants with communication issues were a more significant factor in their postoperative care than the way they perceived their pain

management. The use of qualified interpreters would have considerably improved communication between staff and patients and therefore, the patients' perceptions of their postoperative care. It seems that if patients could speak a little English, staff appeared to think that their English would improve if staff demanded that the patient speak more English, which was outside their limited language capabilities. Staff made this demand, despite the availability of interpreter services, the use of which was encouraged as part of hospital policy. The refusal to provide interpreters increased the anxiety, stress and a sense of desperation experienced by the participants who were worried about missing out on important health-related information, as well as being frightened about having to communicate their pain and other concerns to staff in their very limited English. One of the participants was satisfied to have his family interpret for him, but others were not satisfied with this arrangement because they felt that errors could be made and interpretations could be made selectively, based upon the informal interpreter's lack of knowledge of specific terminology and health issues. Family interpreters can create confidentiality and ethical issues and lead to inaccurate information (Brooks et al. 2000; Dysart-Gale, 2007; Gerrish et al., 2004). Although most participants believed that qualified interpreters were essential to their pain management and standard of care it was also highlighted that being cared for by health professionals who spoke their same language was a great relief. Emotionally, the participants felt safe and at peace when able to relate and understand the health professionals under this stressful situation.

Perhaps because of the fear and anguish engendered by language difficulties, most participants felt that their family's presence was essential for their safety and sense of comfort while in hospital. This was particularly the case for patients who came to Australia from backgrounds of war, oppression, and torture.

When patients have a negative perception of the postoperative care being provided, it is not likely to encourage their attempts to communicate their pain, and other experiences, fears and concerns to staff. While most participants described their feelings of loneliness

and hopelessness as they felt that staff constantly ignored them to the point of affecting their self-esteem, all was not negative. In some cases, the staff tried hard to communicate with the participants, treated them with empathy, and made efforts to make them feel understood and comfortable.

#### Further reflections on the data

As health professionals we need to be aware that in some situations due to violent pasts and when patients have lost family and friends, the person may want to be close to their loved ones for emotional support. It is advisable to assess each case individually and be more flexible with visiting times as it might assist us to provide much better nursing care by being compassionate. We take for granted people's lives and their past experiences and even though they are not able to express their feelings to us we should be able to obtain this information in sensitive ways for our comprehensive plan of care. People are human beings with many different stories to tell, some terrifying, some mundane, and some very exciting. As nurses, it is our responsibility to investigate relevant issues in patients' stories so we can provide appropriate person-focused care to everyone, regardless of their personal circumstances and their cultural and language background.

Listening to all the stories I realised that there are many ethical issues that are not addressed such as not obtaining informed consent when examining a patient or when giving medications or proceeding with treatments. Another issue that has become apparent is providing inadequate patient education on participants' health issues and medications because interpreters were denied access or sent away as decided by the health professionals without consulting with the patient. This situation highlights the participant's willingness to believe and trust the health professionals even though the person does not receive the appropriate information while in hospital and on discharge. It also demonstrates how important it is to provide all the necessary information needed for a person to understand fully their specific situation so they can give informed consent

regarding taking medications and having treatments. It is particularly important that nurses find ways to bridge the gap created by patients' language difficulties, because when patients are in pain and when they cannot communicate, they are at their most vulnerable. In my study, sadly the participants' aim seemed to be to please or appease the health professionals by not complaining and asking questions as they were very grateful for whatever care they were given, especially when they came from an oppressed war-torn country with very limited health care facilities and poor standards of care.

After listening to the stories I realised that the patients who underwent minor surgery did not have an issue with pain and found that staff were very helpful and caring. On the other hand, patients who had complex surgeries or had many admissions expressed more issues with pain and communication. This indicated that probably the shorter the admission the easier for the patient to cope with what they saw as non caring staff and their own inability to speak English, as it was shown that misunderstanding and misinterpretation happened on a day to day basis. All these issues contributed to the participant's bad experiences in hospital because, according to some participants, sometimes staff tried to avoid having any contact with them as they found them difficult to deal with because of their limited English-speaking abilities. The patients needed to be listened to and staff needed to really understand what they were being told. The participants felt that the staff did not have the time, the patience or the desire to make an effort to understand them when they were trying to speak English. It was obvious that the participants felt as if they were disregarded and overlooked as being too hard to deal with. Inadvertently this may cause serious harm or damage to the patient as they may feel frustrated and try to do things for themselves prematurely if they do not feel understood or heard. There was also considerable danger for the participants when nurses thought that the patient had understood the explanation given to them, and therefore the nurse did not check their understanding.

Being admitted to hospital is one of the most stressful experiences that people may have to endure in their lifetime as they can feel helpless, powerless and even feel that their dignity has been compromised. As nurses we have to be aware that people may or may not have experienced hospitalization in their past and these experiences may not have been positive. It is possible that previous negative experiences can leave a lasting negative impression which may lead to suffering every time the patient is hospitalized. Consequently, because nurses do not know the patient's individual circumstances and past experiences, it is essential that nurses demonstrate human kindness and compassion to all patients. This approach may help to alleviate the patient's suffering and give them a hospital experience much more conducive to their overall health and healing. Most of the participants expressed their satisfaction with the Australian health system and in general with the health care workers' professionalism. However there were many and very significant issues in relation to what some perceived as indifferent care from the doctors and nurses when the participants were experiencing their most vulnerable time. However, many times throughout the participant's stories nurses forgot or chose to ignore the patients' feelings and their need to be treated as human beings. Nevertheless, there were some nurses who respected and established trust with the patient and even found health professionals who spoke Spanish to communicate with them. There are exceptions in nurses' behaviors as in the study by Jensen and Lidell (2009) where they state that nurses regarded patients and their next of kin as vulnerable and were aware of the patient's frailty as a person. The nurses expressed that being present for the suffering of the person transformed their hopelessness into consolation. This indicates that there are times when nurses who really care for others promote trust, rapport and accept individuals as they are and establish a relationship that creates a caring environment. In addition to telling me their stories while they were hospitalised, the participants also wanted to share their family experiences by talking about their children, husbands, past medical experiences and their lives in their home country. It was overwhelming to hear

how they coped and have tried to make the best of their lives in this country. They are very grateful for what Australia has given them and what they have been able to achieve. However, the constant thread of lack of communication and interpreters was overwhelming. Nevertheless, although the participants expressed very negative experiences they also clarified that some of the staff were very caring and compassionate which made up for their bad times in hospital. They also said that some health professionals did their best and made their stay in hospital as bearable as possible.

Another issue that became apparent was the participants' complaints of nurses' behaviour as they left their nursing care to attend to personal conversations with other staff. Some participants said that they were left waiting and even felt discriminated against when the nurses ignored them to talk to other staff. Most staff would not be aware that while they have a conversation with their colleagues they might be offending a CALD patient by unconsciously ignoring them and leaving them to wait. Although it is important that nurses relate well to their colleagues there is also the need to be aware that patients are very sensitive to what we say or do as it can be a very vulnerable, lonely, and even frightening time for them and they deserve the full attention of their nurse. For CALD patients, not understanding what the nurses are saying and hearing them laugh while they were waiting was very upsetting. The need for nurses to talk about their personal lives while caring for patients is not appropriate while performing procedures and caring for patients. As I reflected on the participants' stories it was sometimes challenging to hear about the nurses and doctors who sometimes try to avoid patients who, to them, were a burden or were too difficult to understand. It is challenging when the patient is from another cultural or religious belief or does not speak the language but there are resources and people whose jobs are to assist staff in these circumstances. The issue of dealing with patients from different Spanish-speaking countries with their own slang and dialects can make it difficult for staff and interpreters to understand properly what they really mean or what they want to say. It can be difficult to prove if the accredited interpreter is understanding

and comprehending what the patient is saying and if they are interpreting correctly the meaning of what has been said. The interpreters may be able to understand all dialects and idiomatic idiosyncrasies if they are trained properly as accredited interpreters. Languages can be very complex and information can be misunderstood even if we think we speak the same language as our patients. Therefore, the use of qualified interpreters is critical to quality patient care.

In addition, after treatment is initiated, most hospitals in Australia are following the trend of discharging patients earlier by ensuring there is family support or community service available for follow-up care from the patient's own home. At discharge, information on medications, follow up instructions and the condition of the patient should be discussed to ensure full understanding of the information by the patients and their family (as appropriate). In this study there was no evidence that the participants had appropriate inpatient or discharge education. Also, there was no proof that they understood their medications or follow up care-giving and participants were sent home without explanations which may have led to significant misunderstandings.

#### Limitations of the study

As a novice researcher I found qualitative research, especially the philosophy of phenomenology, very challenging. Immersing myself in the participants' stories and interpreting what they really were saying was painstakingly difficult. I felt the responsibility of taking all these heartfelt experiences and providing an accurate and precise interpretation of these experiences with pain in hospital without being able to speak English. The main problem I had was to interpret, not to describe what the participant was saying as I needed to be part of the participant's lifeworld and utilise the 'fusion of horizons' staying true to the Gadamerian approach.

Although there were only seven participants the length of the interviews was long and four of the participants had a second interview to ensure I obtained the necessary rich, in depth data. Also even though the study was performed only with Spanish-speaking patients it represented a large group that consistently requires the health services of this tertiary hospital. There are also the variables of gender, educational level and migration type to consider when analysing the experiences as this might influence their responses to the pain experience and their communication issues. However in relation to gender, four of the participants were women and three were men and as for their education level and migration type five were of a middle to high education level and two migrated to Australia as refugees. It is shown that the group was diverse and provided me with a range of very interesting past and present experiences from patients of different Spanishspeaking countries. The diversity of nationalities demonstrated the complexity of language and the challenge it represents to be able to understand what people are really saying due to the many dialects and slang which can limit the understanding. To prevent this from happening there is the need to use accredited interpreters who should be adequately trained to understand all dialects and idiomatic idiosyncrasies.

Other limiting factors were that the study was conducted only within the Spanish-speaking community and it was conducted in only one hospital, therefore the findings may not be representative of Spanish-speaking patients' experiences in other hospitals in Queensland and also it may not be relevant to other cultural groups. A further limitation that was mentioned previously was that data were gathered only from the patients. It would have added significantly to the quality of my data if I had included the nurses in this study also.

# Recommendations and implications for education, practice and research

- 1. Recommendations for education and practice are as follows -
  - There is the need for nursing staff to be aware of policies, procedures and guidelines to improve nursing practice to properly care for NESB and CALD patients. This would enable staff to provide the support and the necessary understanding and empathy to CALD patients. This makes patients feel important, valuable and worthy of the care offered by the institution in the same way as their English-speaking counterparts.
  - Staff need sufficient knowledge on cultural issues and to understand the reasons that people migrate to Australia. They also need to have information about refugees and the special needs that they have. This information is necessary to understanding some cultural problems as it can assist staff to be more open minded and tolerant. Refugees may need more emotional support and encouragement to follow medical orders due to their past experiences. They would be more vulnerable as they might have experienced violence previously, and perhaps been victims of torture and trauma. Negative experiences in our health care system may bring back memories of their violent past and they may not cope well with authority and orders.
    - Staff need to use adequate communication skills (verbal and written) to convey information to CALD patients. It is advisable to organise preoperative and postoperative translated information to cater for the largest language groups in the different areas of the institution to reinforce the information given to the patients and their relatives at admission and

before discharge. This will reduce the risk of misunderstandings with medications, treatments or diagnosis.

- Hospitals need to provide staff with regular updates and reviews on the use of interpreters' policies and cultural information, as there was some limited evidence in this study to indicate that the use of interpreters can enhance equitable care to all patients. These updates will avoid situations where health professionals might cancel or refuse to provide interpreters when patients or other health professionals have requested them.
- It is important that staff are aware of the need to conduct comprehensive pain assessments for each patient in the post-operative period. There may be a requirement for inservice sessions regarding difficulties experienced by CALD patients pre and post-operatively, particularly in relation to their experiences of pain and the various ways that their pain can be adequately assessed and relieved in an holistic manner.
- It is also advisable to employ staff from different cultural backgrounds to ensure there are people on hand who can understand and relate to CALD patients because of their common ethnic background. These staff can advocate for their CALD patients to other staff and advise them about cultural issues. At the same time, their presence provides a sense of safety and security for the CALD patients.
- 2. Recommendations for research are as follows -
  - There is the need for more qualitative research on the experience with pain and communication issues by other cultural groups to establish if the issues highlighted in this study are similar to those experienced by patients from different and diverse ethnic groups.
  - There is also a need to do a larger quantitative study on Spanish-speaking patients' experiences in multiple acute care sites to determine the exact

nature of their experiences and needs, as well as how the health system can support and assist them with their pain relief and recovery.

#### Conclusion

This thesis has found that Spanish-speaking people who experience postoperative pain and pain management have a range of issues that impact on the quality of care and pain relief they receive from nurses and other health care professionals while in hospital. The findings show the struggle they have in: trying to communicate their pain levels; in understanding what is said to them by staff, and in having staff understand what the patients say to them. Apart from often leaving the patients in unrelieved pain, this poor communication leaves patients feeling confused, angry, frustrated and unworthy.

Given the increasing numbers of patients from other countries who will be admitted to our hospitals in future years, it is imperative that hospitals work to improve staff members' skills in sensitivity and understanding regarding the vulnerability and special needs of people from other cultures. As nurses, it is our duty of care to ensure that Spanish-speaking patients, or indeed, patients from any ethnic background, are treated with respect and understanding when they are admitted to our hospitals. Many of these people come from backgrounds of fear, pain, torture, loss, and alienation. Many of them are old and have lived difficult lives in their own country. It is appropriate and fitting that, when they move to our country and at some time find themselves with health problems that require hospitalisation, they feel they have not simply moved from one place of oppression, fear, alienation to another. Indeed, they deserve to feel that being admitted to one of our hospitals is akin to reaching a safe harbour where they will be safe and well cared for. As human beings of inestimable worth, they are owed nothing less by our Australian society.

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### **APPENDIX A**

# **INFORMED CONSENT**

# (English and Spanish Version)





#### Australian Catholic University Limited

ABN 15 050 192 660 Brisbane Campus (McAuley at Banyo) 1100 Nudgee Road Banyo Queensland 4014 Australia PO Box 456 Virginia Queensland 4014 Australia Telephone 3623 7276 Facsimile 3623 7242 www.acu.edu.au

#### **CONSENT FORM**

Participant No\_\_\_\_\_

# **PROJECT TITLE** A phenomenological study of Spanish speaking patients' experiences with pain after surgery in an acute setting

SITE Princess Alexandra Hospital Health Service District

#### NAME OF STUDENT RESEARCHER AND CONTACT PERSON

Mrs Nelly Beatriz Bruinsma Registered Nurse Surgical Care Unit Princess Alexandra Hospital Phone: Email:

(07) 3240 7775 or 0414 271 878 nelly\_bruinsma@health.qld.gov.au saskiae@bigpond.net.au

#### NAME OF SUPERVISOR

Dr Monica Nebauer RN PhD Undergraduate Courses Coordinator Postgraduate Courses Advisor School of Nursing and Midwifery Australian Catholic University (Banyo Campus) Phone: (07) 3623 7216 Email: m.nebauer@mcauley.acu.edu.au

I \_\_\_\_\_\_ (the participant) have read or have had read to me in my first language the letter to participants and understood the nature and purpose and any possible risks involved. All questions I have asked have been answered to my satisfaction.

I freely agree to participate in this research project realising that I can withdraw at any time. I acknowledge that my involvement in the study may not be of benefit to me. The opportunity has been given to me to have a friend or relative present when the study was explained. Several interviews each lasting approximately 1 hour with note taking and audio taping will take place over a period of a few weeks. The first interview will be conducted approximately one week following discharge from hospital. A second and possible third interview may be conducted at a later date to validate information and clarify further (if necessary) themes that were raised in earlier interviews.

I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify me in anyway. I also understand that my participation in this research is voluntary and I may withdraw at any time and this will not impact on my clinical management or relationship with the Princess Alexandra Hospital.

I will be given a copy of the Participants Information and Consent Form to keep.

| NAME OF THE PARTICIPANT (Printed)  |      |
|--|------|
| SIGNATURE  | DATE |
| NAME OF WITNESS (Printed)  |      |
| SIGNATURE  | DATE |
| SIGNATURE OF PRINCIPAL SUPERVISOR  |      |
| DATE   |      |
| I confirm that, to the best of my knowledge, the par<br>and purpose of the study and I have answered all t |      |
| STUDENT RESEARCHER'S NAME (Printed)  |      |
| SIGNATURE  | DATE |





### FORMULARIO DE CONSENTIMIENTO

Participante No\_\_\_\_\_

TITULO DEL PROYECTO

Un estudio fenomenológico relacionado a la experiencia de control del dolor postoperatorio durante el período de hospitalización, entre pacientes de habla hispana.

LUGAR

Hospital Princess Alexandra Health Service District

#### NOMBRE DE LA ESTUDIANTE INVESTIGADORA Y PERSONA DE CONTACTO

Mrs Nelly Beatriz Bruinsma Enfermera Registrada Unidad de Cuidado Operatorio Princess Alexandra Hospital Teléfono: Email:

(07) 3240 7775 or 0414 271 878 <u>nelly\_bruinsma@health.qld.gov.au</u> saskiae@bigpond.net.au

#### NOMBRE DE LA SUPERVISORA

Dr Monica Nebauer RN PhD Coordinadora de Cursos de Licenciatura Asesora de Cursos de Postgrado Facultad de Enfermería y Parto Universidad Católica Australiana (Banyo Campus) Teléfono: (07) 3623 7216 Email: m.nebauer@mcauley.acu.edu.au

Yo \_\_\_\_\_\_ (nombre del participante) he leído o me han leído en mi idioma natal la carta de información para los participantes y comprendí la naturaleza, el propósito y los posibles riesgos involucrados. Todas las preguntas realizadas han sido contestadas a mi satisfacción.

Yo escojo participar de este proyecto de investigación y estoy informado de que puedo retirarme en cualquier momento del mismo. Yo comprendo que mi participación en el estudio puede no tener ningún beneficio para mí. Se me dio la oportunidad de tener a un amigo o pariente presente cuando se me explicó el estudio.

En un período de algunas semanas, se realizarán un número de entrevistas de aproximadamente una hora cada una, durante las cuales se tomarán notas y se harán grabaciones de audio. La primer entrevista será realizada aproximadamente una semana después de haber sido dado de alta del hospital. Puede llegar a ser necesario conducir una segunda y tercera entrevista para validar información y clarificar (en caso que sea necesario) temas que fueron identificados en las entrevistas anteriores.

Yo estoy de acuerdo que los datos de investigación coleccionados para el estudio pueden ser publicados o pueden ser proporcionados a otros investigadores de tal manera que no exista ningún modo de identificarme. También comprendo que mi participación en esta investigación es voluntaria y que puedo retirarme de la misma en cualquier momento y que el hacerlo no tendrá ningún impacto sobre mi tratamiento clínico o mi relación con el Hospital Princesa Alexandra.

Se me entregará una copia de la Información para los participantes y del Formulario de Consentimiento.

| NOMBRE DEL PARTICIPANTE (Letra imprenta)  | )                   |
|---|---------------------|
| FIRMA   | FECHA               |
| NOMBRE DEL TESTIGO (Letra imprenta)   |                     |
| FIRMA   | FECHA               |
| FIRMA DEL SUPERVISOR PRINCIPAL  |                     |
| FECHA   |                     |
| Yo confirmo de buena fe que, el participante ha del estudio y he contestado todas sus preguntas |                     |
| NOMBRE DE LA ESTUDIANTE INVESTIGADO   | RA (Letra imprenta) |
| FIRMA   | FECHA               |

### **APPENDIX B**

# **PARTICIPANT'S LETTER**

# (English and Spanish Version)



# ACU National

#### Australian Catholic University Limited

ABN 15 050 192 660 Brisbane Campus (McAuley at Banyo) 1100 Nudgee Road Banyo Queensland 4014 Australia PO Box 456 Virginia Queensland 4014 Australia Telephone 3623 7276 Facsimile 3623 7242 www.acu.edu.au

#### **INFORMATION LETTER TO PARTICIPANTS**

**PROJECT TITLE** A phenomenological study of Spanish-speaking patients' experiences with pain after surgery in an acute setting.

#### **SITE** Princess Alexandra Hospital Health Service District

| STUDENT RESEARCHER | Nelly Beatriz Bruinsma |
|--------------------|------------------------|
|                    |                        |

Name of programme in which enrolled MASTER OF NURSING (RESEARCH)

You are invited to take part in this research project. This participants' letter contains information about the research project and its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.

Please read this information letter carefully. Feel free to ask questions about any information in the document and to discuss the project with a relative or friend or your local health worker.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign a Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give consent to participate in the research project.

You will be given a copy of the Participant Information Letter and Consent Form to keep as a record.

#### PURPOSE, AIM AND DESCRIPTION OF THE STUDY

#### Purpose

The purpose of this study is to investigate Spanish-speaking patients' experience of pain after surgery in an acute setting.

#### Aim

To acquire knowledge of the way Spanish-speaking patients experience and perceive pain after surgery and to use this knowledge to develop a culturally appropriate pain management plan for other Spanish-speaking patients.

#### Description

To obtain the necessary information for this study at least 6 Spanish-speaking patients will be invited to participate in the project. Several interviews each lasting approximately 1 hour with note taking and audio taping will take place over a period of a few weeks. The first interview will be conducted approximately one week following discharge from hospital. A second and possible third interview may be conducted at a later date to validate information and clarify further (if necessary) themes that were raised in earlier interviews.

#### PRIVACY AND DISCLOSURE OF INFORMATION

Confidentiality will be maintained at all times. All information obtained in connection with this project that can identify you will remain confidential. The research report will use a code number to ensure that you as the participant cannot be identified. The list that contains your name and code number will be kept in a locked file in the Principal Supervisor's office at the Australian Catholic University. All information will be kept in a locked cabinet for 5 years at the Principal Supervisor's office and then it will be destroyed by shredding and deleting the electronic information and erasing the tapes. If you give me, the student researcher, permission by signing the Consent Form the information will be shared and results will be discussed only with my, Principal Supervisor and Co-Supervisor. In addition, an independent bilingual social worker/counsellor may see your transcribed data when she selects random pages of transcribed participant data to check the validity of my translations from Spanish to English. However, your confidentiality will be ensured as your name will not be recorded anywhere in the transcribed data.

#### POSSIBLE RISKS TO THE PARTICIPANT

There are minimal risks anticipated from your taking part in this study. However, if you find that being interviewed or the questions asked are stressful or upsetting, I, the student researcher, will stop the interview and you will be given the opportunity to see a Spanish-speaking counsellor or chaplain. You will be given the option of rescheduling the visit or ceasing to participate in the study if you become very emotional and unable to continue as you remember past experiences.

#### POTENTIAL BENEFITS TO THE PARTICIPANT

It is the intent of the Princess Alexandra Hospital that adequate cultural and religious pain management is provided to all individuals following surgery and that equitable care is provided to all.

You are invited to participate in this research project because of the valuable information that you can provide in relation to your experience with pain after surgery and your inability to communicate in English. The study will assist the hospital staff to prepare an appropriate pain management plan that will assist in achieving our aim of providing excellent care for all culturally and linguistically diverse people and specifically for Spanish speaking patients whilst in hospital. I, the student researcher, Nelly Beatriz Bruinsma, am undertaking this research project as part of a Master's degree in Nursing.

You (the participant) are free to choose not to give your consent to participate in this research study without having to justify that decision. You are also free to withdraw your consent and discontinue participation in the study at any time without needing to give a reason. It is important to emphasize that if you (the participant) do withdraw from the research study, this will not prejudice your current or future care in any way.

#### **RESULT OF THE PROJECT**

The results of this project will be used to set up educational programs at the Princess Alexandra Hospital for all staff. An executive summary with the findings will be given to the hospital's management and the participants will also be offered a translated copy of the summary. The aim is also to have the findings published in peer reviewed publications and presented at nursing conferences.

#### FURTHER INFORMATION OR PROBLEMS

If you (the participant) require further information or if you have any problems concerning this project, you can contact me, the student researcher, Nelly Bruinsma, the Princess Alexandra Hospital or Australian Catholic University Human Ethics Committee.

#### **MY CONTACT DETAILS**

Nelly Beatriz Bruinsma Registered Nurse

#### WORK

Surgical Care Unit Princess Alexandra Hospital Phone: 3240 7775 Email: <u>nelly\_bruinsma@health.qld.gov.au</u>

#### HOME

| Mobile: | 0414 271 878           |
|---------|------------------------|
| Email:  | saskiae@bigpond.net.au |

#### OTHER ISSUES

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact the Ethics Manager at the Princess Alexandra Hospital – 3240 5856 or Australian Catholic University – 3623 7294

#### PARTICIPATION IS VOLUNTARY

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with the Princess Alexandra Hospital.

Before you make your decision, I, the student researcher will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

#### ETHICAL GUIDELINES

This study has been reviewed and approved by the Princess Alexandra Hospital Health Service District Human Research Ethics Committee and the Australian Catholic University Human Research Ethics Committee. Should you wish to discuss the study with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or should you wish to make an independent complaint, you can contact:

Princess Alexandra Hospital Health Service DistrictEthics ManagerHuman Research Ethics ServicesCentres for Health ResearchPhone:(07) 3240 5856Fax:(07) 3240 7667Email:pah\_ethics\_research@health.qld.gov.au

Australian Catholic University Ethics Manager Mrs Kylie Pashley Human Research Ethics Services McAuley Campus Phone: (07) 3623 7294 Fax: (07) 3623 7328 Email: qld.ethics@patrick.acu.edu.au

#### **REIMBURSEMENT FOR YOUR COSTS**

You will not be paid for your participation in this project.





#### CARTA DE INFORMACION PARA LOS PARTICIPANTES

**TITULO DEL PROYECTO** 

Un estudio fenomenológico relacionado a la experiencia de control del dolor postoperatorio durante el período de hospitalización, entre pacientes de habla hispana.

LUGAR

Hospital Princess Alexandra - Health Service District

#### ESTUDIANTE INVESTIGADORA PRINCIPAL Nelly Beatriz Bruinsma

#### NOMBRE DEL CURSO DE ESTUDIO

Master en Enfermería (Investigación)

Usted está invitado a tomar parte de este proyecto de investigación. Esta carta para los participantes contiene información respecto al proyecto de investigación con el propósito de explicarle lo más abierta y claramente posible todos los procedimientos involucrados en este proyecto para que usted pueda decidir si quiere participar del mismo.

Por favor lea la información de esta carta cuidadosamente. Sienta confianza de hacer preguntas respecto a cualquier información contenida en este documento y de conversar del proyecto con un pariente, amigo, o con su médico de cabecera.

Una vez que usted tenga claro cual es el objetivo del proyecto y en caso que decida tomar parte del mismo, se le solicitará firmar un Formulario de Consentimiento. Al firmar el Formulario de Consentimiento, usted indica que comprende la información y que otorga su consentimiento para participar en este proyecto de investigación.

Se le otorgará una copia de la Carta de Información para Participantes y del Formulario de Consentimiento para su referencia.

#### PROPOSITO, OBJETIVO Y DESCRIPCION DEL ESTUDIO

#### Propósito

El propósito de este estudio es investigar la experiencia de pacientes de habla hispana en relación al dolor postoperatorio durante el período de hospitalización.

#### Objetivo

Obtener conocimiento de la forma en la cual los pacientes de habla Hispana experimentan y perciben el dolor postoperatorio y utilizar este conocimiento para desarrollar un plan de control del dolor que sea adecuado a dicha cultura para aplicar a futuros pacientes de habla hispana.

#### Descripción

Para poder obtener la información necesaria para este estudio se necesitará la colaboración de por lo menos seis (6) pacientes de habla hispana.

El proceso será realizado durante un período de dos semanas conduciendo una serie de entrevistas grabadas de aproximadamente una (1) hora de duración, durante las cuales también se tomarán notas. La primera entrevista se realizará aproximadamente una semana después de haber sido dado de alta del hospital. Una segunda y posiblemente tercer entrevista serán realizadas más adelante para validar la información y en caso que sea necesario clarificar temas que fueron mencionados en las entrevistas previas.

#### PRIVACIDAD Y REVELACION DE INFORMACION

Su privacidad será mantenida en todo momento. Toda la información que pueda identificarlo será mantenida confidencial. El informe de investigación utilizará un número de código para asegurar que usted como participante no pueda ser identificado. La lista que contiene su nombre y su número de código será archivado en un fichero con llave en la oficina del Supervisor Principal en la Universidad Católica Australiana. Dicha información será mantenida en un fichero bajo llave por cinco (5) años en la oficina del Supervisor Principal y luego será destruida mediante una desfibradora y se borrará toda la información electrónica y los casetes. Si usted me autoriza a mí, la estudiante investigadora, firmando el Formulario de Consentimiento su información será compartida y los resultados serán discutidos solamente con el Supervisor Principal y el Supervisor Asistente. Además una trabajadora social/consejera bilingüe e independiente puede llegar a ver su información cuando seleccione indiscriminadamente cualquier página de los datos transcriptos de los participantes, con el propósito de validar mis traducciones del español al inglés. De cualquier manera su privacidad está garantizada pues su nombre no estará registrado en ningún sitio de los datos transcriptos.

#### POSIBLES RIESGOS DEL PARTICIPANTE

Se anticipa que los riesgos de participación en este proyecto son mínimos. Sin embargo si usted encuentra las preguntas realizadas estresantes, yo – la estudiante investigadora- me comprometo a detener la entrevista y a usted se le brindará la oportunidad de ser atendido por un consejero de habla hispana o a un párroco. En ese caso podrá establecer otra cita o dejar de participar en el estudio en caso de no poder continuar debido a emociones relacionadas a sus experiencias pasadas.

#### POTENCIALES BENEFICIOS DEL PARTICIPANTE

El Hospital Princess Alexandra tiene como objetivo proporcionar control del dolor postoperatorio de la forma más adecuada a la cultura y religión de cada individuo y que todos los pacientes reciban un cuidado igualitario.

Usted está invitado a participar en este proyecto de investigación por la valiosa información que puede suministrar en relación a su experiencia de dolor postoperatorio y sus barreras de comunicación debido a su desconocimiento del idioma inglés. El estudio ayudará al personal del hospital a preparar un plan de control del dolor adecuado que nos ayudará en lograr el objetivo de brindar excelente cuidado a todas las personas de diferentes lenguas y culturas y específicamente a pacientes de habla hispana durante su internación en el hospital. Yo, la estudiante investigadora, Nelly Beatriz Bruinsma, estoy ejecutando esta investigación como parte de mi Master en Enfermería.

El participante tiene la libertad de no aceptar ser parte de este proyecto de estudio sin tener la necesidad de justificar su decisión. Usted también tiene el derecho de retirar su

consentimiento y descontinuar su participación en el estudio en cualquier momento sin necesitar dar ninguna explicación al respecto. Es muy importante enfatizar que si usted (el participante) se retira de este proyecto de investigación este hecho no perjudicará de ninguna manera su cuidado actual o futuro.

#### **RESULTADO DEL PROYECTO**

Los resultados de este proyecto serán utilizados con el propósito de establecer programas educativos para todo el personal del Hospital Princess Alexandra. Un sumario ejecutivo conteniendo los resultados será entregado a la gerencia del Hospital y los participantes serán también ofrecidos una copia traducida del sumario. Otro objetivo de este proyecto es compartir los resultados en publicaciones para colegas y presentarlos en Conferencias de Enfermería.

#### MAYOR INFORMACION O PROBLEMAS

En caso que usted (el participante) requiera mayor información o si tiene algún problema relacionado a este proyecto, puede contactarme a mi, la estudiante investigadora, Nelly Bruinsma, o al Comité Ético de la Universidad Católica Australiana.

#### MIS DATOS DE CONTACTO

Nelly Beatriz Bruinsma Enfermera Registrada - Registered Nurse

AREA DE TRABAJO Unidad de Cuidado Operatorio - Surgical Care Unit Princess Alexandra Hospital Teléfono: 3240 7775 Email: <u>nelly\_bruinsma@health.qld.gov.au</u>

#### PERSONAL

Mobil: 0414 271 878 Email: saskiae@bigpond.net.au

#### OTROS PROBLEMAS

Si tiene alguna queja relacionada a algún aspecto del proyecto, la forma en la que es conducido o cualquier pregunta respecto a sus derechos como participante de una investigación usted puede contactar al Gerente de Ética - Ethics Manager en el Hospital Princess Alexandra Hospital – Teléfono 3240 5856 o en la Universidad Católica Australiana – Teléfono 3623 7294.

#### PARTICIPACION VOLUNTARIA

La participación en cualquier proyecto de investigación es voluntaria. Si usted no desea tomar parte del mismo no está obligado a hacerlo. Si decide participar pero más adelante cambia de opinión usted puede retirarse del proyecto a su discreción.

Su decisión de tomar parte del mismo o de no hacerlo, o de comenzar a tomar parte y luego retirarse, no afectará su tratamiento de rutina, como así tampoco su relación con el personal médico ni con el Hospital Princess Alexandra.

Antes de tomar su decisión, yo la estudiante investigadora, estaré disponible para contestar cualquier pregunta relacionada a este proyecto de investigación. Usted puede averiguar toda la información que considere necesaria. Voy a solicitarle que firme el Formulario de Consentimiento solamente después que haya tenido la oportunidad de hacer preguntas y de encontrarse satisfecho con las respuestas.

#### PARAMETROS ETICOS

Este estudio ha sido revisado y aprobado por el Comité Ético de Investigaciones Humanas del Hospital Princess Alexandra y de la Universidad Católica Australiana. Si desea conversar sobre el estudio con alguien que no se encuentre involucrado directamente, en particular las cuestiones relacionadas a las normas, la ejecución de este estudio o sus derechos como participantes o si desea hacer alguna queja independiente, usted puede contactar:

Princess Alexandra Hospital Health Service District Ethics Manager Human Research Ethics Services Teléfono: (07) 3240 5856 Email: <u>pah ethics research@health.qld.gov.au</u>

Australian Catholic UniversityEthics ManagerSra. Kylie PashleyHuman Research Ethics ServicesMcAuley CampusTeléfono:(07) 3623 7294Fax:(07) 3623 7328Email:qld.ethics@patrick.acu.edu.au

#### REEMBOLSO DE COSTOS

No existirá pago alguno por su participación en este proyecto.

#### PARTICIPANTS' DEMOGRAPHICS AND BACKGROUND

#### Participant 1 – Mercedes

Mercedes was a widow who was born in Spain, eighty one (81) years ago. She lived with her son and his family and took care of the housework and cooking duties for the whole family while they worked and studied. Due to her low to medium socio-economic status in her country she had minimum education however; she was able to read basic Spanish and English but spoke only a few essential words in English. Mercedes liked to read in English and understood quite well, especially the Bible, but had great difficulty speaking the language and understanding spoken English. Mercedes was taken to the hospital by her son and then sent with an interpreter to the surgical ward to prepare for the operation. The doctor and nurses were able to prepare Mercedes for her surgery and explain the preoperative process through her interpreter.

Mercedes had lived in Australia for 20 years and has been very healthy since she arrived in Australia and had only been hospitalised for eye surgery. This hospital admission was once again for cataract surgery, but it was a stressful experience due to language misunderstandings. When Mercedes was in surgery she complained to the health professionals about the uncomfortable, stinging feeling in her eye but nobody responded to her questions or tried to reassure her. Also without warning they sprayed cold water in her eye which stang so much that she screamed in Spanish due to pain. As staff were returning her to the postoperative care ward Mercedes asked about the stinging in her eye and a red dot she could see, but once again the staff did not respond. All night she felt that her eye was stinging and the red spot was getting worse. Mercedes felt that the nurses in the ward were not taking her complaints seriously as the only thing they were telling her was that it was normal and that it would go away with paracetemol. The nurses explained the reason why they were offering paracetemol but as Mercedes did not

consider stinging as pain, she refused it. An interpreter was never called to clarify the protocol so Mercedes did not accept this explanation in English. She decided to take matters into her own hands despite the explanation from the nurses about the risks of moving the eye pad and damaging the sutures in the eye. Mercedes put her finger under the dressing and moved the gauze underneath alleviating the stinging in her eye. Fortunately there was no damage to the eye or the healing process allowing her to recover from the surgery without any physical problems.

#### Participant 2 – Maria

The second participant was Maria, a refugee from El Salvador who arrived in Australia with her son to provide him with more opportunities and advantages than what he would have had in their home country. She lived in a war torn country and received an inadequate education and no possibilities for an improved life. A few years after she arrived in Australia she became very ill and was diagnosed with renal failure. The task of learning English was very challenging and arduous as she was very stressed and concerned about her illness and had to stop undertaking English classes. Due to many hospitalisations and treatments she was only able to learn very basic words in English. This presented her with considerable difficulties when understanding people. There were many times when medication instructions, assessments, reviews and appointments were misinterpreted or misunderstood. Most of the time there were no explanations or discussions on what the problems were or how the issues could have been addressed or if there was a need for an interpreter.

Maria was fifty six (56) years old and had remarried a Spanish-speaking man in Australia. They live by themselves as her only son who is now divorced lives away but visits often with her grandson whom she adores. After diagnosis, Maria commenced her dialysis and consequently required many surgeries for insertion of fistulas which failed constantly.

After a few years of marriage, her husband donated Maria his kidney to provide her with a better quality of life and to help her cope with the disease.

Everything was going well until one day she developed an illness, which was suspected to be food poisoning from seafood ingestion. After tests and many appointments the doctors diagnosed rejection of her donated kidney. At the interview she told me that she did not agree with this diagnoses and that she felt that she was not told the truth. After this Maria had many more tests, appointments and surgeries for more fistulas, most of them without an interpreter. She also had to continue with her dialysis which she described in her stories as the worst experiences in her life. Most of her issues were related to her inability to speak English and not being able to express what she was feeling and wanting. These issues were mostly due to staff refusing to provide interpreters since they were sending the interpreters away as the health professionals stated that she knew sufficient English. Maria also had feelings of being discriminated against as she believed she was not treated the same as the other patients. Moreover, the staff told Maria that it was time she learned to speak English properly as she had lived in Australia for many years and she had been provided interpreters for long enough. Maria was aware that she knew limited English and she was not capable of understanding medical explanations or expressing her signs and symptoms adequately to be cared for correctly. Several times Maria broke down crying throughout the interviews expressing how frustrating and stressful it was for her to attend the appointments. This was mainly due to her lack of English, the staff refusal to provide interpreters and the discrimination she felt. Maria felt that she was treated differently from other English-speaking people and this made her very upset. Maria was a very outgoing and positive person who had endured many years of illness, infections and gruelling treatments due to renal failure which lead to a failed renal transplant. She told me her very sad experiences with her illnesses and the apparent lack of proper medical and nursing care which drove her to tears as she was describing her experiences.

#### Participant 3 – Jose

Jose was born in Nicaragua seventy five (75) years ago and arrived in Australia thirty eight (38) years ago; he is happily married with three children and many grandchildren. Jose is retired and lives with his wife and looks after his grandchildren when his daughters and son are at work. He has a close family and they all look after each other especially when Jose or his wife need medical attention. Jose worked in the construction industry most of his life and did not need to learn to speak English well as most of his work mates were Italians and Spanish-speaking people therefore they were able to communicate with each other.

Jose talked about his experience with the Australian Health Care System when his wife was diagnosed with breast cancer and his son had an emergency operation. Jose had a foot injury at work, which was operated on and later developed an infection which eventually turned necrotic so he was told that his toe needed to be amputated. Jose emphasised that in his opinion, his medical and nursing care was exceptional and he had no interest in complaining as other people do because although he had to wait for appointments and for the operation he knew he would receive the best care. He had the attitude that he could wait as everybody else did because he was not any more important than the other patients and he knew that if it was an emergency he would be seen immediately. Jose explained that as a person coming from another country with a different culture and language he has been welcomed and respected always and his children had the opportunity to have a great future.

Jose considered the pain he suffered after surgery as two different types, the external or physical pain and the internal or emotional or sentimental pain. He clarified that the physical pain was able to be managed with regular medications and other treatments thus it was not an issue for him. Jose was not worried about it and he could overcome it as he had done before. On the other hand, the emotional or sentimental pain was not able to be relieved as easily. In his opinion, all people who leave their home country and are away

from their families and friends are at a disadvantage as they do not have them for support. He said that this type of pain made him very upset as he was constantly thinking that if anything would happen to him in the surgery, his wife and children would not have the support from his relatives and friends from their homeland. This is the pain which affected him the most and he thought it probably would affect other foreigners as well. Jose said there was nothing they could give him at the hospital to take this type of pain away. Interpreters were always provided including after hours and even when the children were there. He was able to point or use the few words in English he knew to let the medical and nursing staff know what he needed or wanted. He mentioned that the nurses and doctors would also use gestures and basic English for him to understand without using slang. Jose mentioned that a few times Spanish-speaking nurses cared for him which made his stay in hospital much easier. He thought that having someone who spoke his own language and understood his culture might be able to appreciate and comprehend some of his reactions and behaviours better.

#### Participant 4 – Juan

The fourth participant was Juan, a sixty (60) year old refugee from EI Salvador who arrived in Australia twenty one (21) years ago with his wife and five (5) children. Juan was from a low social economic background and lived in the country side and worked in the cane fields. He never had the chance to go to school and did not attend English classes in Australia when he arrived, consequently, he did not speak or read English. Juan and his wife described how they witnessed the most shocking and horrifying killings perpetuated by the guerrillas in his country. Juan had to flee with his wife and children before they were killed as his family, friends and neighbours were murdered in front of them. He described in detail how his family was targeted and killed for the land and how men and teenage children were murdered because they were seen as a threat to the guerrillas' future. Juan also explained how they fled their country to provide their children with a safe

future and a better education and how happy they were because Australia had provided them with a job and safe haven for him and his family.

Juan also gave details on how he felt when he was in hospital surrounded by people who spoke another language, and how distressed he felt at not being able to understand or explain. Juan was a very quiet and introverted person who allowed his wife to talk for him only adding information after his wife had finished explaining the issues. At the hospital Juan did not talk very much and did not notify the nurses of his pain as he did not want to inconvenience the staff. His children, who speak English, were at his side most of the time to interpret for him and the nurses gave him regular analgesics even though he was not requesting them. Juan also had a very close knit family and they were always there for each other, taking turns accompanying him to provide him with the necessary emotional support while in hospital. His wife stated that at one stage while in hospital, Juan was not being honest about his pain and nausea because he wanted to go home. He did not want the health professionals to know he was not well so he could go home and be looked after by his family where he felt safe and happy. Although he did not have a bad experience he found that not speaking the language was a hindrance except when a nurse who spoke Spanish cared for him. Juan and his wife also described some situations in his work where they thought they were taken advantage of due to their naivety and lack of English. It was very frustrating for him to be unable to understand and explain the issues at work and this experience increased his shyness towards other English-speaking people.

#### Participant 5 – Lola

Lola is eighty three (83) years old and lives with her husband and forty (40) year old unmarried, unemployed son. Lola was from a low socio-economic status and lived in a housing commission home but she still managed to play Bingo every week at the local club. She said she liked to be around people even though they might not understand her. Lola also attended hydrotherapy where she made several Spanish-speaking friends who

she met every week to socialise. She was born in El Salvador and migrated to Australia in 1976 but as a child her family moved to Russia where she lived for twenty (20) years due to the war in Spain returning to her country of birth where she married. She spoke Russian fluently as she learned it when she was younger, but English had been more difficult because she had tried to learn it when she was in her sixties.

Lola was a very extrovert and gregarious person who was liked by everybody who knew her. She was very happy with the hospital care because has been given an interpreter every time she had needed one and she thought the care has been exceptional. Lola had a very good relationship with the interpreters as she had always been given the same ones. She mentioned that although interpreters were provided, most of the time, doctors did not explain much at all leaving her with little understanding of what was happening with her treatments. Lola knew a few basic words in English which she stated had helped her to communicate whilst in hospital. Also the caring nature of the staff had helped her feel at ease and assisted with her recovery. Most nurses did everything they could such as use gestures and signals to help her understand. Something she did not agree with was when she was given an interpreter and before her appointment was finished, the interpreter had to attend to another patient. Lola found this too rushed and uncomfortable.

The abdominal operation was not a success as it was more extensive surgery than first thought and she had not consented to it. Lola was upset because she said that she had told the doctors via the interpreter that they could do whatever they thought necessary and they had not done it. Although all this was explained to her with an interpreter she was angry with the explanation given to her and said she was left unsure of what really happened. After the operation she had issues with nausea and pain but was quickly attended to with oral medications. In this hospital admission nursing staff never explained anything to her or advised her on the medications she was given. She said she worked

out the purpose of the medication for herself because it had taken her nausea and pain away.

An issue which made her upset was when English-speaking and non English-speaking patients in her room were calling for a nurse, the nurses took a long time to arrive although she could hear them talking and laughing in the nurses' station. Even thought she could not understand what they were talking about she thought patient care came first.

#### Participant 6 – Dolores

The sixth participant is also from El Salvador, sixty seven (67) years old, married with children from a middle socioeconomic status. Dolores and her husband were Jehovah Witness and they lived comfortably in their own home attending their weekly religious meetings with Spanish-speaking friends. Dolores worked for many years as a cleaner in an Italian nursing home and described in the interview her work and the close relationships she made with some residents and staff.

Dolores had a very large abdominal surgery which kept her in hospital for two (2) weeks where she had a very stressful and upsetting time due to the lack of English language and feelings of religious discrimination. Dolores explained that she felt that she was badly cared for as some nurses were avoiding and ignoring her. A nurse left her waiting for a long period of time in the shower chair after this major operation while the nurses were conversing on private matters. She felt that staff were treating her as if she was "contaminated" because the nurses would not talk to her when attending to her cares and at one point did not even look at her while giving medications. Dolores was adamant that as soon as nursing staff knew she was a Jehovah Witness they started to behave this way. On the other hand, there were some staff who tried their hardest to communicate and explain everything and to find other ways to reduce her pain such as using hot packs.

Due to her past work with immigrants and people from non English-speaking background she said that she felt discriminated against by some nursing staff because she was left alone. Her husband and son would come often to see her but most of the time she was by herself unable to explain what she needed and she felt that staff were avoiding having any type of contact with her. At one point she said she was desperate because nurses wanted her to mobilise and be independent with her cares but she could not tell them that she was in too much pain due to her constant coughing. She was told she was lazy. Dolores was feeling unwell and tried to explain with basic English words what she felt. It was possible the nurse immediately suspected a urinary tract infection so she asked Dolores to provide a urine sample. Dolores was amazed to see her bed pan in the patients' bathroom a week later without being touched. The cleaners, nursing staff and patients had been in the bathroom many times and nobody had done anything and the smell was putrid. Another appalling incident that Dolores experienced was when she asked the tea lady if she could help her to pour some water in her glass because she could not reach it. To this, the lady responded that she could not do it because it was not her job.

In the interviews Dolores also talked about her difficult time when the nurse taking her for the shower suddenly started to cry and without an explanation left her half way out of bed and never came back. She tried to get back to bed by herself but was unable due to pain so she asked another nurse who was looking after the patients across from her but she responded that she could not assist her because she was not her patient. Dolores did not see her nurse again so the supervisor had to come a few hours later and care for her without any explanation. These events made Dolores feel as if this had been her fault, by upsetting the nurse and making her stop caring for her.

#### Participant 7 – Pablo

Pablo is a sixty seven (67) year old from Nicaragua who lived with his partner of many years whom he met in Australia. He arrived in Australia thirty seven (37) years ago from Germany where he lived for two (2) years. Pablo said he sometimes regretted leaving Germany because he had a very good pension and he was receiving more money than here. He was from a low social economic status and lives from the pension and carer allowance. Because of his heart condition he was unable to work on his trade. His children lived overseas but he cared for his wife's teenage stepson who was mentally and physically disabled. Pablo had heart problems which needed urgent surgery and he had few visitors because of his partner's commitments with her disabled child. Pablo tried many times to communicate with the nurses and doctors in English but due to his very strong accent and limited English they were unable to understand what he was saying. He thought staff understood everything he was saying but the staff stated that they never understood what he was trying to say in English.

Pablo was a quiet person who liked to be by himself so he did not mind not being able to speak or understand English. He was not interested in speaking with other patients and spent most of the time watching television. He said that it was very easy to use gestures and key words to communicate his needs to the staff therefore there was no need to be fluent in English. The pain was well controlled as he was given regular pain relief while in hospital but he was unable to explain what procedures they did or what medications they gave him because no one explained anything to him. He was given an interpreter for most of his appointments and for pre and post operative care but there was limited contact with the staff. Pablo wanted to go home because he did not like the food offered by the hospital; he wanted home cooked meals and he also wanted to be by his wife and stepson's side for comfort and support.

### APPENDIX D

# **Research Ethics Approval**

# Australian Catholic University

# ACU National

#### Human Research Ethics Committee

#### **Committee Approval Form**

Principal Investigator/Supervisor: Dr Monica Nebauer Brisbane Campus

Co-Investigators: Prof Paul Fulbrook Brisbane Campus

Student Researcher: Mrs Nelly Bruinsma Brisbane Campus

Ethics approval has been granted for the following project:

A phenomenological study of Spanish-speaking patients' experiences of pain after surgery in an acute setting.

for the period: 1<sup>st</sup> October 2007 - 31<sup>st</sup> October 2008

Human Research Ethics Committee (HREC) Register Number: Q200708 3

The following <u>standard</u> conditions as stipulated in the *National Statement on Ethical Conduct in Research Involving Humans* (1999) apply:

- (i) that Principal Investigators / Supervisors provide, on the form supplied by the Human Research Ethics Committee, annual reports on matters such as:
  - · security of records
  - compliance with approved consent procedures and documentation
  - compliance with special conditions, and
- (ii) that researchers report to the HREC immediately any matter that might affect the ethical acceptability of the protocol, such as:
  - proposed changes to the protocol
  - unforeseen circumstances or events
  - adverse effects on participants

The HREC will conduct an audit each year of all projects deemed to be of more than low risk. There will also be random audits of a sample of projects considered to be of negligible risk and low risk on all campuses each year.

Within one month of the conclusion of the project, researchers are required to complete a *Final Report Form* and submit it to the local Research Services Officer.

If the project continues for more than one year, researchers are required to complete an *Annual Progress Report Form* and submit it to the local Research Services Officer within one month of the anniversary date of the ethics approval.

Research Services Officer, Melbourne Campus) Signed: ....

### **APPENDIX E**

# **Research Ethics Approval**

# **Princess Alexandra Hospital**





Princess Alexandra Hospital Health Service District

Office of the Human Research Ethics Committee

Enquiries to: Phone: Fax: Our Ref: E-mail

Date

Ethics Manager (07) 3240 7672 (07) 3240 7667 2007/099 PAH\_Ethics\_Research@health. qld.gov.au 12 July 2007

Queensland Health

Mrs Nelly Bruinsma Princess Alexandra Hospital Ipswich Road Woolloongabba 4102

#### **APPROVAL LETTER**

Dear Mrs Bruinsma

Research Protocol: 2007/099

A phenomenological study of Spanish-speaking patients experiences of pain after surgery in an acute setting.

(Spanish-speaking patients experiences of pain after surgery)

NEAF: Patient Information and Consent Form:

Version 1.1, Dated 18 May 2007 Version 1, Dated 18 May 2007

At a meeting of the Princess Alexandra Hospital Human Research Ethics Committee (PAH HREC) held on 5/06/2007, the Committee reviewed the above research Protocol. The Princess Alexandra Hospital Human Research Ethics Committee is duly constituted, operates in accordance and complies with the current National Health and Medical Research Council's National Statement on Ethical Conduct in Research Involving Humans.

On the recommendation of the Human Research Ethics Committee approval is granted for your project to proceed. This approval is subject to researcher(s) compliance throughout the duration of the research with certain requirements as outlined in the *National Statement on Ethical Conduct in Research Involving Humans*. (www.nhmrc.gov.au/publication/humans/contents.htm; www.nhmrc.gov.au/funding/policy/researchprac.htm) Some requirements are briefly outlined below. Please ensure that you communicate with the PAH HREC on the following:

- Protocol Changes: Substantial changes made to the protocol require HREC approval.
- **Problems and SAEs:** The HREC must be informed of any problems that arise during the course of the study which may have ethical implications. Serious adverse events must be notified to the HREC as soon as possible.
- Lapsed Approval: If the study has not commenced within twelve months approval will lapse requiring resubmission of the study to the HREC.
- Annual Reviews: All studies are required by the NHMRC to be reviewed annually. To assist with
  reporting obligations a short questionnaire will be sent to you 11 months after initial approval this
  form is required to be completed and returned to the HREC within the 12 month reviewing period.

As this research involves the recruitment of patients from the Princess Alexandra Hospital Health Service District (PAHHSD), it is my responsibility to remind you of your ongoing duty of care for all people recruited

| Office                      |
|-----------------------------|
| Princess Alexandra Hospital |
| Health Service District     |

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Postal Ipswich Road Woolloongabba Q 4102 into projects or clinical trials whilst public patients. All conditions and requirements regarding confidentiality of public information and patient privacy apply. You are required to comply at all times with any application requirements of Australian Law including the Health Services Act, the Privacy Act and other relevant legislation, ethics obligations and guidelines which may be applicable to the PAHHSD from time to time including, without limitation, any requirement in respect of the maintenance, preservation or destruction of patient records.

When the study involves patient contact, it is your responsibility as the principal investigator to notify the relevant consultant and request their approval.

Should you have any problems, please liaise directly with the Chair of the HREC early in the program.

A copy of this letter should be presented when required as official confirmation of the approval of the Princess Alexandra Hospital Human Research Ethics Committee.

We wish you every success in undertaking this research.

Yours sincerely

Dr David Theile Snr

CLINICAL CHIEF EXECUTIVE OFFICER PRINCESS ALEXANDRA HOSPITAL HEALTH SERVICE DISTRICT

118107

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Princess Alexandra Hospita Health Service District



Queensland Health

Enquiries to: Telephone: TTY: Facsimile: Email: Our Ref: Date:

PAH Human Research Ethics Committee 3240 7672 07 3240 7737 3240 7667 Pah\_ethics\_Research@ health. qld.gov.au 2007/099

24 October 2007

Mrs Nelly Bruinsma Princess Alexandra Hospital Ipswich Road Woolloongabba 4102

Dear Mrs Bruinsma

#### Re: 2007/099

A phenomenological study of Spanish-speaking patients experiences of pain after surgery in an acute setting. (Spanish-speaking patients experiences of pain after surgery)

On the 23 October 2007 the Chair of the Princess Alexandra Hospital Human Research Ethics Committee reviewed, noted and approved the following:

• Letter dated 10.10.07 regarding amendment to Information letter to Participants version 1, dated 18.5.07.

If you have any queries please do not hesitate to contact the Human Research Ethics Committee on 3240 7672.

Yours sincerely

Ms Sharorf Knight Ethics Manager Human Research Ethics Committee Princess Alexandra Hospital Health Service District

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