

**A MIGRANT FAMILY'S EXPERIENCE OF PALLIATIVE**

**NURSING CARE**

**by**

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## **ABSTRACT**

The focus of this research was to explore the migrant family's experience in palliative care. In writing this thesis it became evident that cultural safety was a connection that warranted further study in relation to end-of-life nursing care as was illustrated by the intergenerational case study of this migrant family in New Zealand.

The use of the case study method of qualitative research enabled the voice of the migrant to be heard and the story of the migrant family's experience to be showcased. The uniqueness of this family's palliative care experience was around the religious and cultural needs and migration as a process of transition from a previous society to a new one. Palliative care was defined by the family approach with strong community support and empowered by culturally safe and appropriate nursing practice.

End-of-life illness is a time when cultural perspectives are challenged for patients and their families and religious and cultural practices take on a new priority, regardless of how they have lived life previously. As a migrant nurse living and working in the New Zealand context I identify as an important factor, the nurse-patient interaction as an encounter between two cultural perspectives, the patient's and the nurse as bearer of her own culture. Acknowledging this factor is an important step in developing a culturally safe approach to practice, an approach that proved to be a major ingredient in planning and caring for this patient and his family in end-of-life illness. This study and thesis explores the underpinnings of culturally safe palliative nursing care and identified 'reflexive bracketing' as a useful practice in the process.

## **ACKNOWLEDGEMENTS**

The journey into academia has been a long and arduous one but completion is sweet and I reflect on the many years with retrospective wisdom.

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I wish to pay tribute to the Jassat family, in particular Bibi, Faizel, Munira and Riyah who never hesitated in sharing their story, always welcomed me into their home and illustrated for me the impressive life of their late father, Salie Jassat. Without their enthusiasm this story would have been incomplete.

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'The road is long with many a winding way', a saying that my family can use to describe mum's years of study. My special thanks to Stephanie and Richard for so much because you never knew how much your inspirational words in birthday and mothers'

day cards boosted me and carried me till the end of this study. I shall always be there to do the same for you.

I thank my husband for his patience through a restricted social life with continued reasons for not accepting another social invitation, living with a mountain of books and a laptop and yet another computer crisis.

The last word belongs to my computer companion, Ben, the true migrant in many senses with an unknown background and who listened always without imposing his opinion.

## **PREFACE**

*Nothing in life is to be feared*

*It is only to be understood.*

Marie Curie (Curie, n.d.)

### **As a Migrant**

As a migrant to England first and then to New Zealand later, the lived experience of working in a health care environment as a student nurse and then a qualified registered nurse, my existence went through a modifying process. This process served primarily to reinforce values and beliefs ingrained in me as a child of ethnic and Eastern origins, but some were latently altered through socialisation into the new societies I lived in. By this I mean that through exposure to western values, processes and learning, I have socialised into western society and lead a lifestyle that reflects my changed perspective. I have contemplated this process since the beginning of my studies for the MA (Applied) in Nursing and the advent of my position in nursing education in Palliative Care Education and believe the change in perspective to be an evolutionary process that spells progression rather than just assimilation. By progression I refer to a process of layering where new learning has built upon the existential rather than replaced it.

My visits back to Malaysia, my birthplace, are family times where I can visit my roots and ‘walk the walk and talk the talk’ of my native country. The initial couple of days of adjustment introduces feelings of discomfort or strangeness, which fades as I slip back into familiar surroundings and lifestyle. Similarly my return to New Zealand starts with a couple of days of change when I re-assume a Western perspective, a subtle change

that is evident to family members close to me, I am told. My perception of living between two worlds is a personal view and one that I choose to use to advantage others.

The result is an understanding of where I have originated from coupled with an awareness of a dominant Western perspective that exists in New Zealand society

### **As a Migrant Resident in Auckland**

Auckland has been my home for some 32 years now and I have matured in life years witnessing the increased cosmopolitan setting that has developed with migration policy which parallels global trends. The multicultural nature of the population in Auckland now reflects the diversity that I grew up with as a child in cosmopolitan Malaysia and a vision of harmonious living amongst all cultural groups is what I hold as important to aspire to in society.

### **As a Migrant Nurse**

My personal journey as a migrant has led me to research the migrant experience to uncover information that will assist in palliative nursing care. In order to apply the research findings particularly to my area of practice in Palliative Care education for nurses, I began to realise that before sharing the migrant family's story the first step is to explore the fundamental process of how nurses achieve cultural safety in their palliative care practice. Positioning the story to illustrate the process of developing culturally safe practice then became a crucial approach in this thesis. This then led to a decision to present a contextual analysis, which reveals the argument for education about culture. The case study of the migrant family's experience of palliative nursing care illuminates this argument. The result was a family centred approach to care

determined by the family who were empowered by the culturally safe practice of the nursing team who supported them.

The co-occurrence of some statements under two different nodes reflects the views from two perspectives in this intergenerational case study or in some cases two different meanings or consequences. These co-occurrences illustrate the richness of the narratives and meanings in the context of family interaction and cultural practice for the nurse to develop an understanding of 'families' from a different cultural perspective. The Jassat family were enthusiastic to share their palliative care experience in order to assist others in education and this case study provided a special means of achieving this objective and honouring their father. I feel privileged to have been entrusted with their story to support my exploration of cultural safety in palliative nursing care.

Throughout the writing of this thesis I have chosen to lead certain chapters with inspirational quotes and verses that have made a significant impression on me. However the words that are indelibly etched in my memory are those by the Honourable David Lange in his speech to graduands at my graduation in 1999 for a Bachelor of Health Science in Nursing:

“Rejoice in the population mix. Savour the cultures, be international, be competitive, be strong and be enterprising and in the end, with the gifts of all these things that have been inculcated in you throughout your education, be very human for there’s nothing that beats that.”

(Lange, 1999, speech to nurse graduands, Manukau Institute of Technology)

## TABLE OF CONTENTS

<b>ABSTRACT</b> .....	<i>i</i>
<b>ACKNOWLEDGEMENTS</b> .....	<i>ii</i>
<b>PREFACE</b> .....	<i>iv</i>
As a Migrant .....	<i>iv</i>
As a Migrant Resident in Auckland.....	<i>v</i>
As a Migrant Nurse .....	<i>v</i>
<b>TABLE OF CONTENTS</b> .....	<i>vii</i>
<b>LIST OF FIGURES...</b> .....	<i>ix</i>
<b>LIST OF TABLES</b> .....	<i>ix</i>
<b>1.0 INTRODUCTION TO THE STUDY</b> .....	<i>1</i>
1.1 Definitions .....	<i>2</i>
1.2 Background.....	<i>3</i>
1.3 Significance of Culturally focussed studies .....	<i>9</i>
1.4 Cultural Safety in Nursing.....	<i>13</i>
1.5 Justification.....	<i>15</i>
<b>2.0 A JOURNEY THROUGH THE LITERATURE</b> .....	<i>21</i>
2.1 Search Strategy.....	<i>21</i>
2.2 What is known? .....	<i>23</i>
2.3 Migrant Experience.....	<i>25</i>
2.4 Cultural Safety in Nursing.....	<i>28</i>
2.5 Cultural Safety in Palliative Nursing Care .....	<i>33</i>
<b>3.0 USING A CASE STUDY APPROACH</b> .....	<i>41</i>
3.1. Qualitative research .....	<i>42</i>
3.2 The case study method.....	<i>43</i>
3.3 Case studies in nursing research .....	<i>49</i>
3.4 Selecting the best sample for the purpose of the study.....	<i>50</i>
3.5 Ethical aspects of case study research .....	<i>51</i>
3.6 Interviewing family members.....	<i>54</i>
3.7 Rigour and congruence.....	<i>55</i>
3.8 Analysis and interpretation .....	<i>58</i>
<b>4.0 WALKING THE RESEARCH PATH</b> .....	<i>60</i>
4.1 Recruitment of study participants .....	<i>60</i>
4.2 Beginning the case study – meeting the family .....	<i>61</i>



4.3	Attending to the formalities of the research process .....	64
4.4	The interview .....	65
4.5	Transcribing the tapes .....	66
4.6	The second interview.....	67
<b>5.0</b>	<b><i>WHAT EMERGED?</i></b> .....	<b>68</b>
5.1	Themes .....	72
5.1.1.	Family.....	72
5.1.2	Support from Community .....	78
5.1.3	Palliative Nursing Care.....	80
5.1.4	Communication .....	83
5.2	Threads.....	87
5.2.1	Religion and Culture.....	87
5.2.2	Migration .....	88
<b>6.0</b>	<b><i>WHAT DO THE FINDINGS MEAN FOR PALLIATIVE NURSING PRACTICE?</i></b> .....	<b>90</b>
6.1	Interpreting the themes.....	91
6.1.1	Family as principle carers .....	91
6.1.2	Support from Community .....	95
6.1.3	Palliative Nursing Care.....	95
6.1.4	Communication .....	97
6.2	Positioning the Outcomes.....	98
6.3	The Threads of Impact and Influence .....	100
6.3.1	Migration – A Stage of Transition .....	100
6.3.2	Religious and Cultural Underpinnings.....	102
6.4	A view from the palliative care provider perspective.....	105
6.4.1	Cultural Safety in Palliative Care .....	106
6.4.2	Assessing the needs of patient and family .....	110
<b>7.0</b>	<b><i>THE IMPACT OF THIS CASE STUDY</i></b> .....	<b>115</b>
7.1	Migrant families as recipients of palliative care .....	115
7.2	Palliative Nursing Care Today .....	116
7.3	Palliative Care Education for Nurses .....	118
7.4	Further Research.....	120
7.5	My Reflections on the Research .....	121

## List of Tables

Table 1	A diagrammatic view of the ‘Themes’ in the four quadrants with the presence of the ‘Thread’s’ through each Quadrant .....	71
Table 2	Assessment of needs and care plan .....	113

## List of Figures

Fig. 1	Percentage change in ethnic groups in New Zealand 1991-2001.....	5
Fig. 2.	Kawa Whakaruruhau – a cultural safety process developed by Irihapeti Ramsden for nurses in nursing and midwifery education. ....	29
Fig. 3.	The Nursing Council of New Zealand’s recommended model for achieving cultural safety in nursing and midwifery practice (2002) adapted to include ‘reflexive bracketing’.....	109
Fig. 4	Ecomap for the Jassat family identifying support networks. ....	114
Appendices .....		123
References .....		124

## CHAPTER 1

### **1.0 INTRODUCTION TO THE STUDY**

*...men are not blank tablets on which the environment inscribes a culture which can readily be erased to make way for a new inscription.*

Oscar Handlin (cited in Sowell, 1994, p. 1)

New Zealand society has experienced growth in the appearance of new cultures in the last twenty years of my residence in this country. Migration policies have had a positive effect on the number of migrants arriving in the country as also have overseas world events of war that have resulted in refugees who have sought safe residence in New Zealand.

In the introduction, I consider it vital to set the scene of my emerging interest in studying the migrant experience. It stems from my personal experience as a migrant in two countries – England and New Zealand – and includes many transcultural transitions and socialisation experiences. I have chosen to describe my background in the preface of this thesis as a way of bracketing my personal experience before approaching the stories of the research participants. The focus of this thesis is cultural safety supported by the stories of the family who participated in this research.

In this chapter I will define key operative words with reference to literature related to cultural studies, explain the justification for the exploration of this topic, and the significance of cultural safety in palliative care nursing practice.

I began my study in cultural awareness by exploring my personal, individual culture to inform a developing culturally sensitive attitude. It was necessary to look at the influences, beliefs, values and changing philosophy that are a part of my lived experience, which inform my individuality today. I used questions and definitions of terms as stepping-stones.

To invite the reader to engage with the significance of my story, there were several key questions that confronted me at the beginning which are present in my mind as follows:-

What is “trans-culture”?

What code of culturally acceptable care would I like used when I am treated?

I began exploring these questions initially by considering definitions of ‘culture’ by prominent nurse scholars, to which I will refer to make clear my direction of inquiry into cultural awareness.

## **1.1 Definitions**

‘Culture’ can be defined as the “lifeways of an individual or group with reference to values, beliefs, norms, patterns and practices that are learned, shared and transmitted intergenerationally” (Leininger, 1997, p. 38).

Eliason (1993) defines ‘culture’ in a broad and general sense to include differences other than ethnic e.g. health beliefs/practices, gender, economic class, sexual identity, age identity.

T. Loliyang says of culture that “it is a way of life lived by people in a particular moment in history in response to social, political and economic changes” (as cited in (Masibli, 1996, p.1). Accordingly, indigenous culture has been subjected to war, modern technology, marriage, new social trends and health reforms, possibly all in a person’s lifetime.

‘Trans’ is defined as across, beyond or into another state or place according to the Oxford Concise Dictionary (Sykes, 1987). Referring to a person’s life experiences, ‘transculture’ is, then, the transition/s made from one culture to another by way of travel, marriage or any other process that dictates a change in lifestyle. Although in a different sense in nursing, ‘transculture’ refers to care given across cultures according to Eliason (1993).

While the definitions opened possible directions, the strongest pull was my story of transcultural experiences.

## **1.2 Background**

I have been engaged in a personal search for cultural meaning since I wrote an exploratory paper about my cultural journey in an earlier study. This became a revelation of discomforts and a task of great enormity that has continued for me since. The discomforts I suggest are personal and emotionally experienced and represent a dissonance that has arisen with each ‘transcultural hop’ along the way in my journey. By the term ‘transcultural hop’ I refer to the many cultural transitions and socialization processes that I have experienced in my lifetime. A question I often pondered has been:

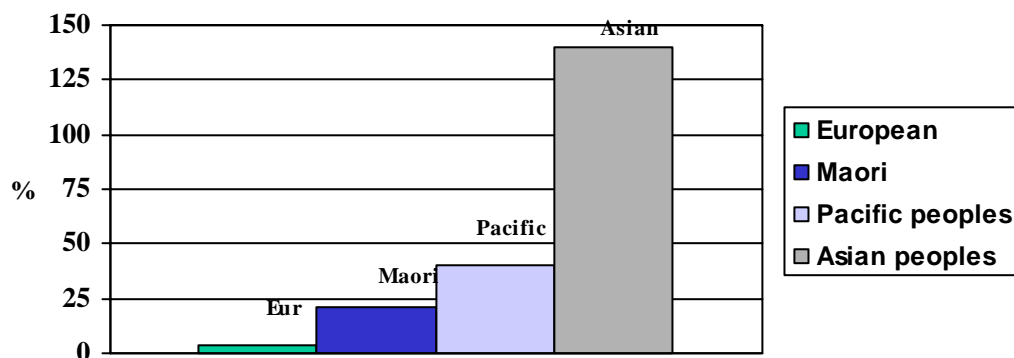
“Where to from here?” This provoked in me a growing passion to name and understand the challenge of ‘discomfort’ and ‘dissonance’ within a cultural context of change? My contemplation has subsequently led me to this study and thesis.

I have wanted to understand and describe the ‘migrant journey in New Zealand’ so that nurses might inform their attitudes, practices and interactions in a culturally appropriate, sensitive and safe manner. This has been a constant aim of mine for sometime. Through focussing on the migrant family experience of palliative care I have informed my role as a nurse educator teaching palliative care. Articulating my experience enables me to involve others in learning about the migrant journey and its impact on end-of-life illness and the experience of palliative nursing care. My life experience as a migrant nurse in New Zealand has been described in the preface to this thesis and has provided me with the motivation to conduct this study, which reveals the story of a migrant family at a special time in their lives.

As a migrant, I have experienced feelings of dissonance that have arisen from my acute awareness of the experience of adjusting to the difference between the host country and my country of origin in a bid to normalise existence in a new culture. Dissonance is the term I use for the feelings of difference or discord between experiences of two situations. Dissonance in my perspective is the discord between the present society I live in and the society of my origin and birthplace which gives rise to feelings of discomfort. My interest lies in trying to understand the social journey that people from other countries experience and the accompanying emotions that prevail when they migrate to New Zealand. Understanding the personal stories of migrants may contribute

to a better encounter of mutual benefit to patient and nurse, migrant family and the health care team. Insight may dissipate some of the ill feeling that sometimes can be experienced by both parties and enable a positive encounter. Hall, Stone and Fiset (1998) refer to a finding that resulted from a hospice survey of patients and staff, revealing that stress and frustration are experienced by nurses when caring for people from an ethnic minority group. The reasons given were poor communication with the patient, a lack of knowledge of cultural differences and a lack of resources, all of which are barriers to holistic palliative care.

In a number of countries particularly throughout Europe, Africa and Asia, war and political strife result in cultural disharmony. Refugees from these situations choose to seek safer and attractive countries conducive to family living, New Zealand being a popular choice possibly because of its ‘clean green’ and ‘outdoor lifestyle’ image that is portrayed in advertising literature but also because it represents a relatively safer environment than the country of origin for their families.



**Fig. 1 Percentage change in ethnic groups in New Zealand 1991-2001**

According to the 'Quick Facts' on-line Directory, permanent and long-term immigrants numbered 92,660 in 2002, an increase of 23,170 from 2001 (Department of Statistics, 2003). Figure 1 shows the percentage increase in population for four groups of people in New Zealand, European, Maori, Pacific people and Asian people between 1991 and 2001. The biggest increases are evident in the Asian and Pacific populations. Although a percentage of these people can be attributed to New Zealand born generations, it still demonstrates the increased ethnic diversity in New Zealand society today.

I have mentioned war and political strife as major contributing factors to New Zealand's increased immigration numbers but natural disasters are also compelling reasons for forced emigration of people from their countries of origin and have a significant effect on how they adapt and live in a new country. Other reasons for emigration from a country are personal motivation for benefit and re-unification of family; again reasons which have a significant effect on how people adapt and live in a new country. Sowell (1994) suggests that reasons for emigration from their original country have a direct effect on how immigrants adapt and live in a new country. Apart from these massive assaults on personal cultural identities, there are other life experiences such as intermarriage, education, children, social contacts, work and career that change our cultural perspectives slowly and sometimes unconsciously. "Key social institutions – government, family, schools and so on – create and reproduce dominant values and beliefs" (Jones, 1994, p.97). These societal effects on various members of one family are varied according to their new lived experiences, which in turn may have an effect on their experience of healthcare systems in New Zealand where healthcare policy and practice tends to focus on the dominant culture in society.



The choice of palliative care as a context for this study is a natural progression for me because I am involved in the organisation of palliative care education for nurses. The focus of care in this specialty area of healthcare is achieving a quality of life; this is possible and achievable inspite of a life-challenging illness for many patients and their families. My involvement with palliative care started when I worked in primary healthcare as a practice nurse and worked with families who were caring for a family member with end-of-life illness. The region I worked in had a multicultural population with a high number of migrants. Cultural issues especially shyness with health practitioners of a Western culture, language difficulties and lack of knowledge about treatment and services proved to be barriers to migrants accessing medical care. Many families had socioeconomic problems that made healthcare inaccessible because of financial considerations. For those patients requiring palliative care, I could provide them with the link to hospice care but they were still reticent to access this care because of the cultural difference of the hospice staff who were on appearance predominantly Western. This reticence has waned slightly in the last six years since I worked as a practice nurse in Primary Healthcare and then as a nurse educator with the Hospices of Auckland. In my role now as a nurse educator with the University of Auckland in palliative care education, I have observed that the multidisciplinary team of health practitioners in some regions are now multicultural and the postgraduate students who attend courses that I facilitate come from many cultures, a factor which may help increase the access to palliative care by migrant families. This view is supported by Randhawa (2003) who states that an exploratory study of South Asians living in Luton, England showed that not enough carers in palliative care are recruited from ethnic

communities. These ethnic carers would do much more than speak the same language but they understand the whole cultural way of life. Nevertheless continuing effort is needed to increase the access to care by providing culturally safe care appropriate for all groups in society.

Neuberger (1998) claims that those who have settled in a new society do retain their cultural practices at times of birth, marriage and death. An observation in palliative care is that patients choose to spend this time in the midst of their loved ones exploring issues of family tradition and religion, reflecting on how they have lived their lives, whilst their families take the opportunity to cherish and care for their loved one in a loving environment. It is at this particular time that individual spirituality and exploration of one's 'roots' and 'beginnings' can become a priority and often presents challenges for people living far away from their country of origin. This has been endorsed by Nyatanga (1997) who suggests that most cultures still return to their rituals in practice at significant life events like births, marriages and in end-of-life illness situations. In order for this priority to be facilitated for migrants in palliative care situations, nursing care and allied health services that are culturally safe are crucial. Culturally safe care can be achieved when nurses develop an awareness of personal and patients' cultures and appreciate the unique differences of people in their care.

Working with nurses in education to develop this awareness has dictated the direction of this thesis, which is informed by my personal experience as a migrant writer.

### **1.3 Aims of the Thesis**

Contemplation of the crucial aspects of the foundation discussion for the thesis has revealed three main points that I wish to focus on:

- Look critically at cultural safety in practice as it applies to migrants in palliative care;
- Examine the socialisation process of migrants in the New Zealand context and its effects on families;
- Capture and present for student learning the experience of palliative care for a migrant family which coincides with socialisation to a new society;

### **1.4 Significance of Culturally focussed studies**

The significance of exploring the migrant family's perspective is the information on their cultural perspective and their preferences for care that are revealed and are of interest and significance in palliative care education that I am presently engaged in. Yates (1997) describes the effectiveness of a professional development programme for palliative care nurses and claims that attitudes, beliefs and skills are amenable to change. This has informed the essence of my motivation. Encouraging cultural awareness stems from personal experience because I know that a route of learning that includes an exploration of self is crucial to cultural awareness. Reflection and the resultant learning informs attitudes towards patients and their families, and will allow the "patients to define themselves rather than impose categories on them" (De Souza, 1996, p. 203). End-of-life rituals and funeral rites are possibly the final connection between the dying and the bereaved according to Nyatanga (1997); this time is viewed by many as a finality that spells a safe journey onwards for the former and strength to

face a loss for the latter. A culturally safe approach to care is therefore a major ingredient in nurse education when planning and caring for patients in end-of-life illness, a concept that is becoming more and more complex in a multicultural context very evident especially in Auckland where I live and work.

In considering the specific outcomes of cultural safety for nurse education in palliative care, the Nursing Council of New Zealand's learning outcomes of priority below are based on four main principles outlined in the document, *Guidelines for Cultural Safety* (2002, p. 12) and are of particular relevance.

That student nurses and midwives will:

- a) Examine their own realities and the attitudes they bring to each new person they encounter in their practice;
- b) Evaluate the impact that historical, political and social processes have on the health of all people;
- c) Demonstrate flexibility in their relationships with people who are different from themselves.

Although it originally arose from issues in the undergraduate education programme for nurses, the learning outcomes represent desirable continued learning practice for nurses in all areas of healthcare and in this case, palliative care. The benefit for patients and families will be the improved standard of culturally safe care. Culturally appropriate and safe nursing care could lead to improved access to health care and palliative care for marginal groups in the community, thereby fulfilling one of the provisions outlined in

the New Zealand Health Strategy document (Ministry of Health, 2000) and also the New Zealand Palliative Care Strategy document (Ministry of Health, 2001a).

Research in culturally safe practice like this study that is specific to the New Zealand context, will build on the historicity established by the Treaty of Waitangi and its implications for health care for Maori which could be seen as a precedent for marginalized groups in our population. Treaty of Waitangi educators have utilised the method of developing awareness of personal culture to initiate learning about Maori, the indigenous people of New Zealand. By developing an awareness of cultural difference, nurses can facilitate the legitimacy of cultural difference in their practice and care for all people.

In the New Zealand context, Durie (1996) describes the four dimensions of wellbeing as spiritual, emotional and mental, physical and family in Whare Tapa Wha. These dimensions also reflect the holistic cornerstones of hospice palliative care named in the philosophy that underpins palliative care which is presented in the Palliative Care Strategy (Ministry of Health, 2001a). These dimensions depict the interconnection between the recognition and awareness of the cultural determinants, wellbeing and care. Nursing care that addresses the needs of all four dimensions is a critical goal to aim for in quality of life and care of the dying patient.

Richardson (2003) claims that the acknowledgement of the importance of cultural determinants like the nurses' own cultural 'baggage' and power inequalities in the nurse-patient relationship are significant factors for focus in education. Addressing

these factors can have a significant outcome in shifting the power of determining culturally appropriate care from the nurse to the patient in this relationship. The empowerment that results for the patient will enhance wellbeing whilst the culturally safe practice of the nurse will facilitate the spiritual aspect of patient care, one of dimensions mentioned in relation to Durie's (1996) discussion above. This could only be good practice for achieving quality of remaining life for people with end-of-life illness, a time when cultural practices and spirituality become prominent considerations. In examining the link between cultural safety and determinants of wellbeing, I traced a path through cultural discussions in the New Zealand Health Strategy document (Ministry of Health, 2000). The "re-configuring of the health and disability sectors", includes an identification of socio-economic and individual factors as determinants of health and wellbeing. Some key determinants named are age, gender, ethnicity, income, education, employment and housing. It also occurred to me that some of these points are mirrored in the definition of culture that Eliason (1993) identified from an anthropological setting and I mentioned earlier in this chapter under definitions of culture. I deduced from this that the cultural perspective of a person is linked with personal wellbeing and if any part of the former is subjected to abuse it will affect the entire wellbeing of a person and in the case of people in end-of-life illness their achievement of quality of life. This argument appears to be echoed in the New Zealand Health Strategy document (Ministry of Health, 2000), which recognises that these factors interact in many ways and addressing one will impact on others. This could be an important consideration in endeavours to increase the usability of palliative care services and resources by ethnic populations and other minority groups. Making access

more equitable is a significant part of the role of nurses and other health professionals working in palliative care.

One of the New Zealand Health Strategy (2000) principles is an improvement in health status of those currently disadvantaged by the present health system; the significance of studies on cultural safety and delivery of education in this area then is the major impact it can have on the care nurses deliver to our ethnic minorities according to this principle. The New Zealand Health Strategy (2000) and the New Zealand Palliative Care Strategy (2001) specifically address the needs of Maori and Pacific people but do not identify other cultural minorities. This is a significant gap given the diverse face of Auckland society in particular, and the growing migrant population with a need for culturally safe and appropriate care who have formed a major part of the ethnic population. Palliative care is a significant sector in health care that requires the delivery of nursing care for migrants in end-of-life illness. Recognising the importance of this fact has led me to focus on the migrant experience in palliative care in this thesis.

## **1.5 Cultural Safety in Nursing**

The concept of 'Cultural Safety' originated as one of the Nursing Council standards for undergraduate nursing education in 1992. The introduction in 1991 of this standard was the outcome of the explored need for cultural safety (Kawa Whakaruruhau) for Maori student nurses in 1989 and was written into the Guidelines for Cultural Safety by Ramsden in 1991 and further developed by the Nursing Council in 1996. The model recommended in the Guidelines (2002, p. 8) works through a staged developmental process which will be discussed in the next chapter, under the heading 2.4 Cultural Safety in Nursing. It is pertinent to look at what cultural safety means as defined by the

Nursing Council of New Zealand for nursing education and practice within New Zealand. The Nursing Council of New Zealand defines cultural safety in its guidelines (2002, p. 7) as:

The effective nursing or midwifery practice of a person or family from another culture, and is determined by that person or family. Culture includes, but is not restricted to, age or generation; gender; sexual orientation; occupation and socioeconomic status; ethnic origin or migrant experience; religious or spiritual belief; and disability.

The increase in the number of migrants to New Zealand has introduced diversity in cultural perspectives and needs of migrant people in healthcare and palliative care. DeSouza describes migration as a stressful life event that requires of migrants “adaptation to a new language, new way of life and new social values and norms” (in press, p. 4). These stressors may also inhibit access to necessary services should the need for palliative care arise. DeSouza (in press) also states that attitudes to newcomers influence the care that is delivered in health care organisations. Care that is culturally ethnocentric and reflects the values of the dominant culture in society is culturally unsafe for migrants especially in end-of-life illness of a family member. It can be presumed that culturally insensitive and unsafe practice will be a major factor then in services not being accessed by migrants

The need for cultural safety in palliative nursing care is accentuated by the fact that in end-of-life illness cultural and religious traditions take on an importance for patients and their families in their bid to come to terms with the end-of-life position of a family



member and also ensure a death that is peaceful around their religious and cultural beliefs. Facilitation of cultural considerations and religious beliefs by nurses working in palliative care assists the patients and families towards spiritual comfort and relief of suffering that may cause pain that is more than physical. Lack of understanding leading to a lack of facilitation of the spiritual needs of the patient and family in turn lead to ethnocentric practice or an imposition of one's own perception of cultural practice on to those in our care which increases their suffering in end-of-life illness.

## **1.6 Justification**

### Why I want to do this research?

As a migrant nurse I have a background of life experiences from the three countries I have lived in, Malaysia, England and New Zealand. This lived experience gives me a rich understanding of the socialisation process particularly in the two countries I migrated to, New Zealand being the later of the two. As I have lived, nursed and studied through the social changes of New Zealand, I have witnessed the increasing diversity in the population and the change from a predominantly bicultural society of Maori and European to a multiculturally diverse society. The impact of this change on healthcare in particular has necessitated a review of strategic planning, the outcome of which could include a redirection of focus in public policies that will make minority group cultures one of the priorities to be addressed. The discussion on service issues, nursing care being one, that prevent current palliative care services being accessed appropriately and adequately by people who are challenged by end-of-life illness cites cultural barriers as a reason as stated in the New Zealand Palliative Care Strategy (Ministry of Health, 2001a). Wolffers, Verghis and Martin in their review (2003) of a World Health

Organisation (WHO) report on the health of migrants emphasised the human rights of migrants to health care services. The need for cultural sensitivity and safety in palliative nursing care delivered in any healthcare setting is a major factor that can improve access for migrants in end-of-life illness of a family member.

My impression is that there may be a lack of awareness around concepts that people of a host country and well adjusted to their society take for granted in societal life and so are unaware of the plight of migrants who are struggling to adjust to new processes in a new country that are unknown to them. Although I have not experienced this personally, I have witnessed this situation occur with migrant patients I cared for when I was a practice nurse previously. I was unable to organise services to assist them because of their nervousness at being cared for by nurses from a different background and culture. Migrants from an ethnic background particularly are committed to the care of a member of their family in end-of-life illness and have refused assistance from available services in the community in order to care for them at home by themselves regardless of the difficulties and stress that are present. This is partly due to a commitment to the care of personal family members and also because of nervousness that the practice of cultural traditions may be judged as inappropriate by nurses from another culture. This point is of significant importance in the planning and implementation of policy and delivery of care and services that are provided by a different cultural perspective in society.

Processes where care services are set up to assist families in caring for their loved ones in the community e.g. district nursing, hospice facilities and general practice facilities may also be alien practices to migrants who come from countries where services like

these are not available. Their experience of health care in their countries of origin may have consisted of a visit to the nearest hospital facility, regardless of distance and access and then a possible wait in queue for a variable length of time for medical or nursing attention. This practice from the past may continue into their life in their new host country where they are not aware of the appropriate alternatives for medical care or unable to access them because of financial or language problems or simply lack the awareness of what is available, a fact that is endorsed by Dirie (2002) in her account of her return visit to her homeland, Somalia. Public policy and education that focus on the people who work in these services, namely nurses, who provide resources to and spend a significant part of their work time with these patients need to be addressed with an overriding aim of achieving competence in cultural awareness, sensitivity and safety. The possible consequential effects of improving nursing practice and increasing accessibility to nursing services will then also have a positive effect on the numbers of migrants from minority groups that use the services.

The Government has acknowledged and begun to address the challenge of addressing the problem regarding 'access' to services in the New Zealand Health Strategy (Ministry of Health, 2000) and the Palliative Care Strategy (Ministry of Health, 2001a). The previously mentioned 'access' to services has presented the Government with a challenge to overcome. In New Zealand the Treaty of Waitangi has created a precedent for special consideration of cultural minorities with its negotiations for Tangata Whenua or Maori people in health care and other areas; nursing care is included. This is a significant springboard for other minorities who wish to improve social conditions for their people and thereby improve their health outcomes. In addressing the needs of the

indigenous people of New Zealand, recognition of all ethnic groups has been acknowledged and their uniqueness respected and upheld. The Government's Health Strategy paper (Ministry of Health, 2000) and the Palliative Care Strategy paper (Ministry of Health, 2001a) both recognise and plan to target the cultural essence of society and the cultural barriers that prevent people accessing nursing and health care services. As the Government endeavours to come to grips with the multicultural reality in New Zealand society, there is increasing awareness of the need to recognise cultural differences, and improve the innocent lack of knowledge and insensitivity that may exist in the everyday lived experience of nurses working 'at the coalface'. Education that is grounded in research on life experiences of migrants can help nurses to develop and enhance cultural safety in practice. This idea is how I perceive knowledge gained from this research can make a difference to palliative care education for nurses. Hence my interest in exploring the migrant family's experience of palliative nursing care in New Zealand.

### Rationalising the Research Question

To justify the specific research question I chose which is "What is the experience of palliative nursing care for a migrant family in New Zealand?" I asked the question "What would be a way of creating awareness for nurse students of the migrant palliative care experience?" This research project arises from the motivation to address the need for knowledge and understanding of the migrant experience, for example the experience of the plight of the Afghanistan refugees in August 2001 trying to gain entry into Australia, which was a sad and dehumanising experience for the victims of war and disaster. Why did I focus on 'palliative care' specifically? There are two reasons for the

choice of this area of healthcare. Firstly, I work in the area of palliative care education and being a migrant myself I have a natural interest in trying to understand the behaviour and feelings experienced at this time. Secondly, end-of-life is a time when the focus of care “embraces the physical, social, emotional and spiritual elements of well-being” as set down in The New Zealand Palliative Care Strategy (Ministry of Health, 2001). As mentioned before spending time in the midst of family in their own homes, is a foremost wish of the majority of patients in end-of-life illness whilst their families take the opportunity to care finally for their loved one. It is also a time when patient and family may resort to traditional and religious beliefs and values, no matter how they have lived their lives previously, in preparation for the transition to the unknown ahead. Because of the multicultural nature of New Zealand society, this preparation and experience in end-of-life illness presents diverse needs for nurses and challenges around how to assist migrants achieve appropriate and culturally safe care at this time and also negotiate with other patients within the same facility who feel compromised by different cultural practices. In addition I also wanted to explore the case stories of three generations of the migrant family experiencing end-of-life illness and receiving palliative nursing care. This intergenerational approach coincides with a statement by Rhandhawa, Owens, Fitches and Khan (2003) who found that the nature of communication with migrant families varies with different generations. This was also found in a study commissioned by Luton Health Action Zone in England (2003) of South Asians with terminal cancer, which explored the role of communication in delivering effective services. Exploring the palliative care experience with an intergenerational approach across three generations produces a rich picture of the multidimensionality of the experience.

By exploring the stories from a migrant family about palliative nursing care my intention is to challenge the expectation that migrants will change in order to fit the health care system be replaced by a system that recognises and values differences of cultural perspectives and treasures the diversity and difference in society.

I have reflected on my personal journey as a migrant and have observed that personal feelings of 'being different' were accentuated when I perceived an expectation by others that I should fit in seamlessly with the status quo and this caused feelings of discomfort for me. If the situation was one where I was seeking health care, these personal feelings of discomfort proved to be a barrier in communication with the nurse or health care practitioner concerned and a lack of trust became yet another barrier in the consultation. Achieving a satisfactory solution to the health problem then became a difficult mission and as a patient I have departed feeling disempowered and diminished. Disempowerment and a feeling of being diminished have had a deleterious effect on my whole 'being' and affected my ability to then seek a satisfactory solution to my health problem. I wish to identify if this experience is mirrored for other migrants who are, in addition, trying to socialise into a new society; an unfavourable incident like this in palliative nursing care then has unhappy consequences for the patient and family at an already vulnerable time. Preventing incidents like these and promoting empowerment of patients and family are objectives that are worth pursuing in palliative nursing care.

## CHAPTER 2

### **2.0 A JOURNEY THROUGH THE LITERATURE**

*Key phrases: Migrant experience, palliative care, cultural safety.*

In this chapter I describe the exploration of literature I undertook around the concepts significant to the research question. The research question is “What is the lived experience of palliative nursing care for different generations of a migrant family in New Zealand?”

The concepts I explored are the migrant experience, cultural safety and palliative nursing care. The information conveyed in this chapter reveals how my thinking evolved with my critique of the literature. There is a generalised lack of information that surrounds the experienced migration process and its subjects; invaluable information that could assist us in all areas of life. My longer term intention is to develop a conceptual framework for practice and education in this thesis with the research as an integral component.

#### **2.1 Search Strategy**

I began my search of the literature with the websites of the Ministry of Health for the strategy papers in health and palliative care and the Nursing Council of New Zealand website for information on the Guidelines for Cultural safety.

The next stage of the literature search included the databases of Medline Ovid, Cinahl and Ebsco, *Qualitative Health Research* on Proquest and the University Sociology database. I sought to identify literature specific to migrants and their cultural experience and related it to healthcare first, before linking it with palliative care. Specific websites were also visited e.g. the *International Journal of Palliative Nursing*; Ira Byock's (American Palliative Care Specialist) website; the *World Health Organisation* website and *Nursing Inquiry*.

The search also revealed several published articles particular to healthcare practice and concerned with racism and discrimination in medical care but none specific to the migrants' experience in particular or the New Zealand scene. Editor (The Lancet, 1999), Epstein and Ayanian (2001), Monteith and Voils (1998) and Romano (2001) all discuss the reality of institutionalised racism in general and in health care.

Literature on migrant experiences was difficult to locate outside of the domains of Hispanic and Asian populations. The New Zealand published literature on the migrant experience was limited and apart from a journalist's look at short stories written by migrants and reviewed by Schwass (1985), important and relevant literature yet to be published by DeSouza (in press) was very revealing of migrants and health services in New Zealand.

A subsequent literature search more recently of the *International Journal of Palliative Nursing* to update the material obtained initially, revealed articles on specific religions and the related practices for Sikhs and Muslims in end-of-life and immediately after



(Gatrad, Panesar, Brown, Notta and Sheikh, 2003; Gatrad and Sheikh, 2002; Neuberger, 1998; Nyatanga 1997). Informative literature from the staff perspectives of working with ethnic patients in palliative care and communication as a major barrier for working with ethnic patients in palliative care was located (Diver, Molassiotis, & Weeks, 2003) and (Hall et al., 1998).

## **2.2 What is known?**

Socialisation as a natural process that migrants experience on arrival in a new host country is written about in the literature around reasons for migration and how these affect the process of settling into a new environment (Sowell, 1994). The personal experience of facing the challenges of relocation and resultant feelings that are the migrant's story, are not easy to locate in the literature.

I was invited to a meeting of ethnic women organised by the Migrant Centre in Auckland where I became aware from discussion of some of the dilemmas that face ethnic elderly people in everyday life in a new host country. A particular instance was cited of an elderly relative living in a private hospital who found the daily diet of western prepared food not appropriate for her after a lifetime of a rice based diet. There appeared to be no organisation solution to this issue and so the family were supplying all dietary needs, which was proving to be a stressful measure for them.

Communication is identified as a significant area of misunderstanding in cross-cultural issues because of language difference and also a misunderstanding of cultural perspectives (Diver, Molassiotis and Weeks, 2003; Hall, Stone and Fiset, 1998;

Kagawa-Singer and Blackhall, 2001; Randhawa, Owens, Fitches and Khan, 2003). Yet communication represents a major strategy for improving cultural safety in care for migrants and will be discussed further in the subsection on cultural safety.

Discussion on access to health care services in New Zealand and cultural safety has centred on Maori people and the effects of the Treaty of Waitangi (Ministry of Health, 2000 & 2001). Richardson (2003) states that because of the recognition that the health status of Maori was poorer overall than non-Maori in the postcolonial era, a strong emphasis on biculturalism within Governmental agencies was the result. This confirms the lack of mention of cultural groups other than Maori and to a lesser degree, Pacific people in the New Zealand Palliative Care Strategy (2001). The discussion of cultural safety in healthcare practice as it affects marginalised migrant groups is still rare and represents an area that needs more exploration

Literature on ethnic cultural needs for nurses working in palliative care consists of specific religious and cultural traditions and practices especially in the dying context (Gatrad, Panesar, Brown, Notta and Sheikh, 2003; Gatrad and Sheikh, 2002, Nyatanga, 1997; Neuberger, 1998). Families of ethnic origin seldom avail themselves of respite care in in-patient units and consider it inappropriate for reasons that need to be identified and addressed. Kagawa-Singer and Blackhall confirm this notion in their discussion on cross-cultural issues in palliative care in America (2001). The deeper issues of nurse-patient relationships and the dominant cultural bias represented by nursing and healthcare practice in care for migrants is a path I wish to explore in the literature in relation to healthcare and palliative care access.

### **2.3 Migrant Experience**

When exploring the 'migrant experience', it is helpful to understand the process of migration. Sowell (1994) provided considerable resource material in this area. For instance he expanded on the notion that the degree of adaptation to a new country by migrants is influenced largely by the reasons why they left their country of origin.

According to Sowell's (1994) premise of migrant groups, theoretically migrants can be categorised according to reasons why they left their country of origin or sought new countries in which to 'try their luck'. He suggests that there are different categories of migrants determined by the implications of reasons like war, natural disaster, motivations for personal gain and family reasons which are all common reasons for migration and could all be important factors that play a part in how migrants socialise to a new country. Migrants in the various categories based on these reasons for migration have varying needs and motivation to adapt in a new society.

Taking a closer look at the first two as mentioned in the Introductory Chapter on background, I deduced that war and natural disaster are compelling reasons for forced migration to another country as 'refugees' where a new life promises safety and a sense of harmony in family life. However this often presents challenges in the socialisation process for refugees in a new country as differences may necessitate a degree of change in lifestyle. It is difficult to give up one's lifestyle easily or willingly when the motivation to leave the home country was an imposed one. The result is that a person may arrive in a new host country in a traumatised state physically and psychologically.

The next group of reasons around personal gain whether for education, material needs, a more attractive lifestyle or financial accumulation of enough money to then return to country of origin, applies to a group Sowell (1994) calls 'sojourners'. They have a choice to return to country of origin if conditions are not suitable for them. This group also possesses a personal motivation to join the new host society and the individual initiates the process of socialisation into a new life. Marital status does play a part in that unmarried individuals may form liaisons with individuals of another culture and intermarry so introducing change to their cultural perspective. This group experiences fewer difficulties as the motivation to adapt to a new country and society is strong. However, Sowell (1994) also identifies another group who migrate for personal gain which he calls 'middleman minorities' who form the hardworking class of small businesses, working long hours and living on the business premises for financial reasons to establish a new life. The result of these long hours and hardworking schedules can be an isolating existence from society and cultures other than one's own family and kinsmen, and effect slow or little adaptation to the processes in the host society.

Another group I have identified as a common category seen in New Zealand is based on family reunification reasons and appears to be a mixture of a need to be reunited with family in a different country and a difficulty of letting go of life in a loved country of origin and satisfactory lifestyle. This ambivalence is often associated with elderly relatives who make the major decision of joining family overseas and then lead an isolated dependant existence within the family and away from outside social contact because of language and transport barriers. Here the degree of adaptation is slow in parallel with the motivation to be in a new country.

The range of categories described above is synonymous with the continuum of full choice and no choice described by DeSouza (in press) in her chapter in a book in print at present about migrant populations in New Zealand.

I also explored material from a sociological source, namely Jones (1994) who described societal effects as having a profound effect on the new lived experiences of migrants. Societal effects may be in the form of processes and policies from key institutions like government, schools, community and family. Sowell's (1994) and Jones' (1994) texts opened up a vista of literature for me on cultural diversity globally and also in New Zealand. Contemplation of these massive influences on personal cultural identities and the struggle to adapt that may face individuals, led me to explore the literature on transcultural experiences, which I see as journeys with significant cultural transitions.

'Transculture' has previously been defined in Chapter 1 as the transition/s made from one culture to another by way of travel, marriage or any other process that dictates a change in lifestyle.

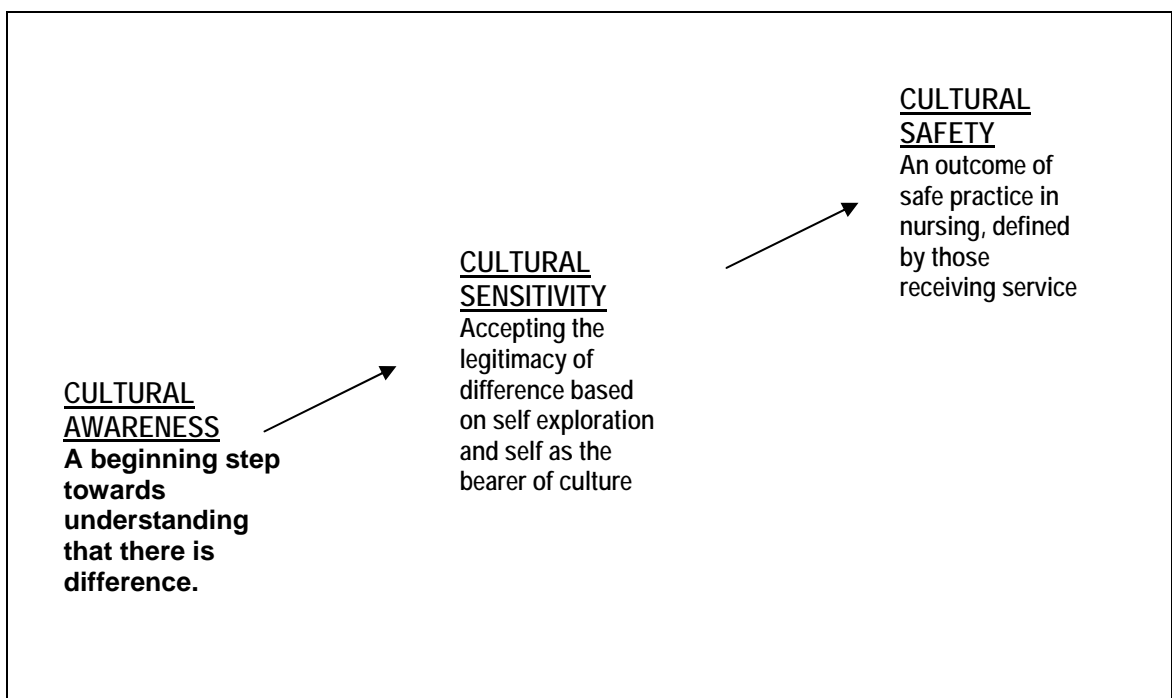
DeSouza (in press) discusses the notion of 'assimilation' as an expectation of migrants to fit in and not change the society they have entered. Although there has been a small shift with multiculturalism, according to DeSouza (in press), remnants of this expectation are still present in society and are responsible for culturally inappropriate attitudes in health care practice.

## 2.4 Cultural Safety in Nursing

A review of the nursing literature on transculture revealed Madeleine Leininger (1997) as the first nurse to recognise the challenges facing nurses caring for culturally diverse patients in the American context in 1991. She articulated the importance of culturally congruent care, the theory that emerged from her perspective as a researcher from a dominant culture viewing multiculturalism as a group of many other cultures. She recommends that the needs of each culture be studied by a specialist nurse practitioner to inform other nurses. This view is consistent with the idea that culture-specific information would address the needs of nurses working within culturally diverse contexts. From personal experience I have found this to be a difficult exercise for nursing practice due to the enormity of the task around the extensive cultural diversity in New Zealand society today. Moreover it does not address latent personal attitudes to culturalism and remains sadly an academic exercise. By latent personal attitude I refer to the stance of nurse as bearer of her culture in an interaction with another person and if her position is not one of personal awareness then her approach may be influenced by her own cultural beliefs and practices.

As I perused the literature within the New Zealand context, Kawa Whakaruruhau (Ramsden, 1992) was the model of cultural safety in nursing practice that came up consistently in the New Zealand literature. It was initially written by Ramsden in the *Standards for Cultural Safety for the Nursing Council of New Zealand of 1992* and arose in response to recruitment and retention issues of Maori nurses (Nursing Council of New Zealand, 1996). It was developed from conversations with a group of Maori nurse/midwife educators and practitioners. As purported by Coup (1996), the model that

was the outcome of Ramsden’s study was created by Maori from an ethnic standpoint and was not a continuation of an ethnocentric process. However Kawa Whakaruruhau describes a bicultural stand and refers to the meeting of two cultures, Maori and others (Richardson, 2003). Ramsden’s recommendations include attitude changes from a point of cultural awareness and progressing through to cultural sensitivity and to cultural safety, a process that can gradually eliminate ethnocentric practices. The Nursing Council of New Zealand, in its review of this document has focussed education on cultural safety identifying the core issues of nurse as “ a cultural bearer; historical, social and political influences on health; and the development of relationships that engender trust and respect”(2002 , p.6).



**Figure 2. Kawa Whakaruruhau – a cultural safety process developed by Irihapeti Ramsden for nurses in nursing and midwifery education.**

Figure 2 shows the process that was developed by Irihapeti Ramsden for the Nursing Council of New Zealand into the *Guidelines for Cultural Safety in Nursing and Midwifery Education* in 1992. It shows the progression from a place of personal cultural awareness, to cultural sensitivity towards difference of others, which enables cultural safety in practice. In a current database search for New Zealand literature I found an article by Richardson (2003) which discusses this cultural safety model in Aotearoa/New Zealand since it was integrated into the nursing curriculum by the Nursing Council of New Zealand in 1992 in which she identifies the lack of an evaluation of its outcomes.

Cooney (1994) and Coup (1996) critiqued the approaches by Leininger (1991) and Ramsden (1992) to reveal the major differences between the two. Cooney (1994) discusses the differences between the two approaches as multiculturalism (Leininger) versus biculturalism (Ramsden), the perspective of Leininger as a member from the dominant culture whilst Ramsden developed her concept from her own cultural reality as a Maori. Cooney also refers to the idea that nurses need to understand their own cultural values as a starting point as being described in both Leininger's and Ramsden's approaches. Coup (1996) identified an important focus in Ramsden's approach is an 'attitude shift' in nurses to enable safe nursing which does not demean another's cultural values whilst Leininger's approach focuses on delivery of care that is cognisant of culture specific information.

The latest search of the databases namely Ebsco and Proquest for up-to-date literature found an article by Randhawa et al (2003), which claims that communication is the



most significant problem that is identified in ethnic groups' evaluation of their experiences of care. Communication as a dilemma in cross cultural issues is identified also by Kagawa-Singer and Blackhall (2001) who highlight this as a difficult issue in medical care for people in end-of-life. Using two case studies, Kagawa-Singer and Blackhall highlight ways of using communication skills and language to illicit information from families and also confirm their understanding of information given. Although the article is written using an American context, valuable insight is offered in the use of the language of the dominant culture that is English, to enhance understanding between doctors and families. Minimising misunderstanding of information is an integral part of improving cultural safety of patients receiving care and their families. The study by Randhawa et al (2003) identifies a variety of responses around perceived, received and accessed information by migrant patients and how it varies between different generations. The perceived and received messages by nurses and other health professionals can also be varied. An intergenerational approach to researching migrant families could reveal valuable insight into communication issues.

Reid (2002), in her article *Multicultural Psychology: Bringing together gender and ethnicity* states that between 1995 and 2000 less than 18% of publications included discussions on cultural diversity.

As mentioned in the previous section on the 'migrant' experience, DeSouza (in press) discusses the effects on the health of migrants, of the migration process and its accompanying stresses. However when healthcare systems reflect society's expectations of migrants to change and fit in with the dominant values and practices of the host

society, these expectations become an added stressor. The expectation 'to fit in' then threatens the cultural safety of the migrant in need of healthcare.

Schwass (1985) highlighted some significant points about migrant writing, such as the question of whether the authors of these works had experienced migration directly or vicariously. The subtle difference is that the evocation of one experience could be so vastly different from others. This fact has highlighted for me the need as the writer of this thesis to be aware of personal experience and stories as different to the subject's stories, and focus on understanding the family's experience without imposing the personal view on them. However according to Diver et al (2003), the cultural background of the researcher may also have a subtle influence on the conversation and interpretation of the data. I interpret this point to mean that if the researcher is from a different or more dominant culture in the country of research, the subjects may be reticent about giving honest answers to questions from a place of shyness, respect or perhaps even fear. Therefore the advantage of migrant researchers carrying out research with migrant participants from similar origins is that they may feel more comfortable about divulging and describing information about their own experiences. From a personal standpoint as a migrant I have sometime found it difficult to describe my opinions and feelings about experiences to people who are unaware that there is a different cultural standpoint. Being comfortable to exchange information with a researcher from a similar experience is a result of trust that is developed between researcher and participant and similarities experienced by both parties assists in developing this trust.

## **2.5 Cultural Safety in Palliative Nursing Care**

The literature on culture and palliative care yielded more results specific to cultural sensitivity in end-of-life care without the use of the specific term ‘safety’.

Since the beginning of my search of the literature on cultural safety all information appeared to fall into one of two categories. These categories were discussed in section 2.4 of this Chapter. Stated simply the first category produces ethnographic information to be used as a tool while the second category refers to an attitude shift from intolerance of cultural difference to valuing of cultural difference. I found the task of reviewing articles from here relatively straightforward following these two categories

It is strategic here to focus on literature related to cultural safety in palliative care, the crux of nursing care in this thesis. I found articles by Nyatanga (1997; 2002) prominent in literature from overseas on cultural care in end-of-life illness. Nyatanga (1997) reviews the need for knowledge and understanding of different cultural needs in palliative care because even though acculturation and enculturation take place, some basic rituals at death and dying remain and are practiced. Nyatanga (1997) defines ‘acculturation’ as the modification to original culture whilst ‘enculturation’ is the process of continued change and influence that culture undergoes in society to adopt new ways. Nyatanga (1997) also includes descriptions of specific rituals and practices in end-of-life for the religions of Judaism, Islam, Hinduism, Sikhism and Buddhism, as a basic guide for nurses delivering palliative care. This information giving does not address the deeper issues of the nurse-patient relationship and the effect of the dominant culture on determining patient care for people in end-of-life illness that is not

appropriate for that person. In another article, Nyatanga (2002) sets out to explore the reasons why palliative care services in Britain are not accessed equally by ethnic minorities. Nyatanga continues to challenge ethnic groups to be more proactive about their care by influencing its provision. Education is also mentioned as an important strategy in establishing culture sensitive care. Nyatanga raises the possibility that the way the patient perceives and defines a problem and need could be quite different from the professionals' view. Nyatanga (2002) refers to the 'extended family' model of care but cautions the adoption of this model because family members may have become acculturated and not adhere to this approach and health professionals may wrongly deduce that their intervention is not needed. This point signalled to me that a case study approach to research of families could reveal essential information about their experience of palliative care.

My review of the nursing literature on culturally safe care revealed an article by Eliason (1993), which contained important facts to substantiate the concept of valuing of cultural difference. However it did not include a strategy that enables an 'attitude shift' as outlined above in category two. Eliason (1993) argues the ethical importance of cultural factors in nursing care and uses five case studies in her article to support this stance. The five cases are stories of patients with different cultural beliefs about health and remedies for healing or recovery. Eliason offers two responses to each situation; one that is ethno-relative and culturally appropriate in care, and the other that is ethnocentric and demonstrates the incompatible cultural stances of the patient and the nurse. Eliason then recommends consultation with the patient at all times as an important strategy in the delivery of care.

Culture specific information appeared frequently in literature during my search. I found an article of Boyle's (1992) that once again addresses culture-specific information and does not address the attitude of the nurse as bearer of culture who may be practising from a position of cultural dominance in the nurse-patient relationship. Boyle (1998) echoes the previously mentioned recommendation of Ramsden (1992) that awareness of personal culture promotes cultural competency in practice while outlining a transcultural assessment model by Giger and Davidhizar. This model outlines six cultural phenomena that can be applied to nursing practice, communication, space, social organisation, time, environmental control, and biological variations (Boyle, 1998). The intention is to use information obtained under these headings as a beginning point for the provision of culturally appropriate care and is an ethnographic tool for the collection of culture specific information.

A writer whose line of thinking struck a cord with my ideas because of its reference to a shift in attitude is DeSouza (1996; in print). I review DeSouza's 1996 article here because of its inference of working with people in their cultural context, a poignant point that bears a close relationship with a culturally sensitive attitude of the nurse in palliative care. In a conference paper DeSouza presented at the Mental Health Conference in Auckland in 1996, she discussed the possible barriers to migrants accessing mental health care. The list of barriers to access could also apply to all health care for migrants and DeSouza (1996) refers to an intrapsychic model used by counsellors in communicating with mental health clients as a more appropriate approach in healthcare services. The intrapsychic model works on the premise that a person's difficulties are a result of personal disorganisation rather than in a wider context of an

oppressive society. With a focus of working with a person's personal difficulties, it avoids the tendency of denying society's 'ills' and blaming the person. Relating it to culturally appropriate care, this model enables the health professional to respond to the person in their cultural setting rather than to their cultural setting, a subtle but important difference in approach to patient care. DeSouza's chapter (in print) has been discussed in section 2.4 of this Chapter.

Institutions too have cultural obligations, the major emphases of which are to review their policies in cultural safety in practice and assist employees to develop safe practice around cultural difference. The relevance of an article by Gunaratnam (2000) to this discussion is the reported result that the Stephen Lawrence Inquiry had on the British Government extension of the 1976 Race Relations Act to cover direct and indirect racism in public bodies including the National Health Service. Gunaratnam (2000) explores the subverted issue of 'institutionalised racism' in relation to palliative care as provided by eurocentric organisations who use a "culture of niceness" to suppress confrontation of issues of racism within their organisations. This article focussed on the highly publicised Stephen Lawrence case to highlight cultural barriers to accessing care from organisations providing palliative care in England. Stephen Lawrence was a young ethnic man living in Britain who was murdered at a bus stop in South East London. The subsequent judicial inquiry into the case revealed that 'institutionalised racism' played a central role in the police mishandling of the case. Gunaratnam also confirms that palliative care services are rarely used by ethnic minority groups and attributes this to eurocentric ways embedded in organisations providing care.

An article that I have referred to often because of good communication strategies was written by a nurse and a doctor working in palliative care. Kagawa-Singer and Blackhall's (2001) present case studies of two families in end-of-life illness which was published in the *Journal of the American Medical Association* and focuses on the physician-patient relationship and communication as a central concept in improving outcomes of care. It states that Asian American families will usually access hospice services (mainly the homecare services) with considerable oversight and control (Kagawa-Singer & Blackhall, 2001). Although focussed on the American setting the study is a valuable resource for all health professionals delivering care to people in end-of-life and facing communication difficulties. Suggested strategies for eliciting information in English from people who are culturally different from the health professional, in this case doctors, are helpful but do not address difficulties of language difference and the use of interpreters that are experienced in palliative care settings. Valuable discussion around filial piety, religious and spiritual considerations, truth telling and decision-making were focussed on communication and the best way doctors can explore these issues to be more informed about the family in their care. However the notion of the health professional as bearer of personal culture in a meeting with another is also a significant issue that can present as a barrier to communication if an ethnocentric stance is presented. This is not mentioned in this study.

I once again identify the gap in the studies focussing on the patient and family as recipients of palliative care and wish to bring the voice of the patient to the fore in particular their cultural experience of end-of-life illness. Wilson-Barnett and Richardson (1998) in their chapter on nursing research in the *Oxford Textbook of Palliative*

*Medicine* allude to research studies that span the 1970s to 1990's and focus on the attitudes and experiences of nurses caring for the dying as disappointing. Wilson-Barnett and Richardson also contend that nursing research that examines hospice care, tends to be service and organisation based in its aims "while practice-based and direct patient care research is sadly lacking" (1998, p. 194).

At this stage of my foray in the literature, what is less clear in these previous examples is how the migrant family in the midst of socialising to a new country and way of life, finds the experience of palliative care. What is also apparent is that what is missing in the literature is the voice of the migrant, that is, the experience of palliative care as described by the migrant. This gap in the literature suggests the need for further study on migrants requiring palliative care. Hence my decision to use the case study method to present the migrant's perspective. All other literature found has been written and described by health professionals from an observation standpoint. Reid (2002) emphasises the importance of cultural research by ethnic researchers to address the questions relevant to ethnic populations. This argument would parallel that of migrant researchers and migrant writing where personal experience assists in a deeper understanding of issues experienced and described by the subjects in the study; an empathy that aids clarity in identifying the issues and a view with which I fully concur.

Another significant point to consider is the links between the concepts of a person's spirituality, cultural roots, place of belonging and end-of-life experience. Oneha discusses these connections from her Hawaiian position in her powerful statement of identity: "a sense of place, of 'rootedness', is directly linked to self identity, self esteem



and spiritual well-being for indigenous people” (2001, p. 299). This implies that disconnection from one’s place of origin and feelings of being unsettled in a new environment can be a cause of spiritual and emotional discomfort and turmoil especially in an end-of-life family experience and also crucial in ‘terminal distress’ in end-of-life illness.

Palliative care as philosophically espoused by hospices internationally, declares a focus on total or holistic care. ‘Cultural pain’ is a term coined by Oliviere, Hargreaves and Monroe (2000) who state that it may colour all other pains. ‘Cultural pain’ is a consequence of care that is incognisant of the patient’s cultural and religious needs and divorced from an appropriate facilitation of these needs.

### Conclusion

Cultural safety as a developed sensitive attitude and respect for the unique difference in others stands out as a priority that will enhance nursing practice in palliative care. I have argued that education and practice on cultural safety in palliative nursing care must involve a more developed appreciation than just identifying a person’s culture and religion specific information and targeting communication skills. It must include developing an attitude and manner in practice that is cognisant of the position of the migrant family and their needs and the difficulties they face in their end-of-life experience in a new country and society. There is obviously a gap in the New Zealand literature on health care in general and particularly in nursing and palliative care that presents the migrant’s voice and the voice of the patient and family in end-of-life illness. It is crucial to record their personal experience of palliative care. In conclusion, I would reiterate that the literature around migrants’ experiences has been written by

health professionals and lay people as observers and from a practice standpoint. Without a descriptive case study to explore the perspective of the migrant patient in end-of-life illness information can only be speculative. It is possible that the very nature of the end-of-life illness phase and trajectory with all its consequences introduces vulnerability as a barrier to research. However hearing the story from others in the experience and from the patient's family circle is the next best authentication of material gathered. The opportunity I have as a migrant and a nurse is the insight I have into the case study method to record a migrant family's experience of palliative nursing care for their relative. The issue of ethics when undertaking case-study research will be discussed at length in the next chapter on methodology.

## CHAPTER 3

### **3.0 USING A CASE STUDY APPROACH**

*Clearly one good case can illuminate the working of a social system in a way that a series of morphological statements cannot achieve.*

Gluckman, (cited in Mitchell, 1983, p. 9)

The nature of the topic that I have chosen which is to describe the migrant family experience of palliative nursing care requires a qualitative research method, a case study approach being the choice. In this chapter I explore my choice of research method, examining and rationalising the use of the case study method, strategies of rigour and the research process. I have chosen the case-study method because of the importance of describing the migrant family in their context. Yin (2003) concurs that the use of the case study method must be a deliberate choice when contextual information is desired.

I have positioned the study using the approach that supports my thinking in connection with studying the migrant experience of palliative care in New Zealand. In qualitative study we deepen our understanding of the subject, in this case the migrant experience, a concept that I will discuss in the choice of method. The subject of ethics is of particular significance in any research that involves human subjects and in this study the significance is heightened because of the involvement of people who might still be in the bereavement stage following the loss of a family member and may still be vulnerable in their grief. Ethical aspects will be discussed in this Chapter in 3.5.

### **3.1. Qualitative research**

Qualitative research deals specifically with the methods of describing, narrating and interpreting to produce or uncover meaning of experiences. Williams suggests that the purpose of qualitative research is “to produce work that says something about the meanings people attach to their experiences” (as cited in Roe & Webb, 1998, p. 60). Further, Williams purports that qualitative research has been used by some disciplines to solve questions and problems around the interpretation of experiences that quantitative methodologies cannot solve (as cited in Roe & Webb, 1998). To illustrate this I cite a study by Hernandez (as cited in Marshall & Rossman, 1999) who explored how newcomer students viewed their educational experiences after participating in community development courses and outreach projects that validate their cross-culturalism. Her research aims were best achieved by the selection of first generation immigrant newcomer students from China, Cambodia, Vietnam, Laos and Korea who commonly undertake community development courses in language skills (as cited in Marshall & Rossman, 1999). This type of selection of sample is called ‘purposive’, that is selecting participants based on their knowledge or experience of the phenomena being studied (Mateo & Kirchhoff, 1999). This is of relevance to this study since ‘purposive’ selection was the choice of case that was the best representation that I could find of the migrant experience of palliative care that I wanted to explore.

Described succinctly, qualitative research “explores the realm of subjective experience, rather than the objective structure and distribution of phenomena” (Roe & Webb, 1998, p. 60). In accordance with Mateo and Kirchhoff (1999), I have summarised the criteria for choosing a case study approach here as: the need to understand or describe a

particular phenomenon about which little is known; the facilitation of an in-depth study of this particular case; and to provide the reader with good raw material for their own application to practice (Stake, 1995).

The case study method is a prominent instrument to address these points and its uses and advantages are discussed at length by Robert Stake as appropriate for “maximising what we can learn” from a case story with the aim of thoroughly understanding first (1995, p. 6). The use of this method will be explored more extensively in the next section as the method of choice for this research.

### **3.2 The case study method**

Historically, according to Mitchell (1983) case studies in sociology date back to the 1930s. There was divided opinion between statistical methods on the one hand and case studies on the other, in research in sociology. Case studies are also widely used in social anthropology and Mitchell states “nearly the whole of the respected body of anthropological theory has been built up over the years from a large number of separate cases” (1983, p. 189).

According to Yin (2003), the case study method has historically been wrongly stereotyped as a weak method and yet, as he purports, it has been extensively used in social science research as well as in fields like urban planning, public administration, public policy, management science and education in addition to the social sciences.

Stake (1995) loosely defines ‘case’ as people or programs. In seeking to understand the subjects in the case, their commonalities and uniqueness are explored with the criterion

of maximising learning of case. 'Case is a specific, complex, functioning thing' (Stake, 1995, p. 2). This definition interests me as an appropriate tool to be utilised in the learning that can be gained by examining the case stories of three generations of a migrant family receiving palliative nursing care for a family member. In this study the 'specific' is the migrant family experience and the 'complex, functioning thing' is palliative care in end-of-life illness.

Stake also states that an important criterion in the selection of a case "should be to maximise what we can learn" (1995, p. 6). Instrumental case study uses a case to understand something about the case (Stake, 1995) and as in the purpose of this study, the purpose is to understand the experience of palliative nursing care of this case which is the migrant family.

In support of my choice of a case study as the appropriate method of gathering the stories of a migrant family's experience of palliative nursing care, I refer to Stake's (1995) description of instrumental case study as the means to explore the case of a person to gain insight into an issue or phenomenon of interest. When considering the aim of maximising understanding and learning in the context of a migrant family's experience of palliative nursing care, the use of case studies stands out as a way of hearing the first hand stories of the migrant family experience. One example of the use of this method is Bar-on and Gilad's (1994) study of intergenerational effects of the holocaust on Jewish families, which portrays the long-range effects of the Holocaust as experienced by parents on subsequent generations of one family. Stake (1995) also claims that the researcher uncovers what is common and what is particular to a case and

applied to this study, as seen through the eyes of different family members with different age perspectives. The inclusion of the third generation is of intrinsic significance because the second generation is not represented just as the child of the first generation but the parent of the third generation with implications on intergeneration attitudes and behaviour, a point emphasised by Bar-on and Gilad (1994).

Mitchell (1983) looks at the five different categories of case studies as set out by Eckstein as contributing to theory. These categories are:

- 1) Configurative-idiographic studies – the material is largely descriptive and provides information and insights into component relationships and not necessarily interpretations.
- 2) Discipline-configurative studies - configuration of patterns that the analyst seeks to interpret in patterns.
- 3) Heuristic case studies – used to stimulate the imagination towards discerning important issues, ‘heuristic’ meaning ‘serving to discover’.
- 4) Plausibility probes – used to test previously established theory.
- 5) Crucial case studies – serve to reject or support theory when circumstances appear to be against it.

The one category as identified by Eckstein (as cited in Mitchell, 1983) that particularly fits with the purpose of this study is ‘Heuristic’ case studies. Heuristic means ‘serving to discover’ and in this context describes a system of education where the student is trained to find out things for himself, given certain known facts like the findings of the study. The findings of the case study are deliberately used to stimulate the imagination

of the readers/students towards their own experiences. The use of this case study as an 'instrument' to maximise what we can learn about this family experience is a heuristic experience for nurses.

Stake (1994) discusses 'naturalistic generalisations' made by the researcher from the case study as vicariously experienced and a 'reliving' or extension of an experience known to the researcher. When narrated and reported this in turn becomes a vicarious experience for the reader who extends personal experience with awareness and understanding. This corresponds with my intentions of using the outcomes of the study to inform nurses in palliative care courses.

Case studies may be used also as a form of narrative inquiry that is described by Diekelmann (2001) when she extols the virtues of Narrative Pedagogy. 'Pedagogy' relates to the science of learning and together with 'Narrative' presents an interesting and holistic approach to education that is conducive to change and modification of views and attitudes. The narratives, in this instance the intergenerational case study, serve as a catalyst for modification of attitudes and practice. My intention was to capture and present a significant portion of the family's stories in order that the realism of the participants' stories is portrayed. The reader is then included in a doubly hermeneutic experience of interpreting what is read through her/his own perception, an interesting outcome of case study research.



I rationalise the use of the case study method here by referring to Fitzgerald's (1999) premise that case studies can be used in exploratory research "where the field of enquiry is novel or under-researched".

#### Rationalising the use of a single-case study method

Yin (2003) discusses the vulnerability of the single case study as a possibility of "putting all your eggs in one basket". He says that analytical conclusions from more than one case are more powerful. However he rationalises the use of a single case study as a means of studying a situation previously inaccessible to research (Yin, 2003). The use of a single case study is justified here, as research of migrant families' experience of end-of-life illness in the New Zealand context is absent in the literature and more specifically that of the migrant perspective or voice. As the experience of palliative care is viewed retrospectively, the subjects of the research may be bereaved and vulnerable in their grief. This vulnerability has been an important factor in the absence of research performed in this area of healthcare, as palliative care was considered inappropriate for research of this kind with patients and families in bereavement. Calman and Hanks maintain that there is a view that "scientifically rigorous research is incompatible with the basic tenets of palliative care" and this view has proved to be a deterrent to some in doing research (1998, p. 159).

The particular choice of a single family to case study is partly because inviting stories of palliative care experience can be emotionally traumatic for the families that are involved and may deter families from participating in the research study. The difficulty then in obtaining more than one family for this research was one reason for the choice of a

single study. However according to Yin (2003) revelatory single case study is the method of choice where a situation has not been accessible to research and the descriptive information will be revelatory. As mentioned earlier, this single study is an instrumental case study as described by Stake (1995) to reveal information particular to the experience of palliative care.

Recruiting and finding a suitable migrant family who had experienced palliative nursing care proved to be a difficult task, due to reticence on the part of families to be involved in research during bereavement. The intergenerational perspectives that were desired further restricted recruitment.

Another reason for the choice of the single case study approach was the size and scope appropriate to the requirements of this two-paper thesis. The time of one year to complete the two-paper thesis was appropriate for a single case study research project.

In defence of single case study research, I cite again Gluckman's statement which heads this chapter "clearly one good case can illuminate the working of a social system in a way that a series of morphological statements cannot achieve" (cited in Mitchell, 1983, p. 187). Having identified the gap in literature in which the voice of the migrant in palliative nursing care is not represented, I believe that the single case study method was an appropriate instrument of research to uncover and showcase the potential information hidden in this area in a sensitive and fulfilling way for the participant family in the study. It is an exemplary way of giving credence to the voice of the migrant family in the study.

### **3.3 Case studies in nursing research**

Application and relevance to nursing practice depends on the research topic and its implications on the culture of nursing. The very nature of this culture encompasses the concept of caring underpinned by a scientific epistemology. The notion of caring which is central to nursing roles requires an interpretive approach in research that describes actions, thoughts and emotions in the search for meaning in nursing experiences.

Nursing researchers have resorted to qualitative research in their attempts to describe and validate nursing practice in an ever-changing political arena. I cite the study by Camiah (1997) of nurse educators whose roles and work underwent major changes with increasing demands as a result of Project 2000 in Britain. Project 2000 (Camiah, 1997) was a British Government initiative to prepare nurses for the challenging needs of society by placing nurse education into a higher schedule of the education framework. Case studies were used to generate the data to demonstrate the whole lived experiences of nurse educators at that time. The resultant data outlined several issues common to the group studied and their apparent needs were identified.

Eliason (1993) used case studies to illustrate some ethico-cultural challenges that nurses face in practice and offered responses that are ethnocentric and ethno-relative to demonstrate the difference between the two.

Kagawa-Singer and Blackhall (2001) used two case studies to illustrate the challenges of negotiating cross-cultural issues in end-of-life illness and was a collaborative nursing

and medical focus by this nurse and doctor. The article outlines the challenges and offers effective ways of negotiating a favourable outcome.

Wilson-Barnett and Richardson (1998) cite case studies as a significant method of procuring great insight in the study of care of dying patients and their families.

### **3.4 Selecting the best participants for the purpose of the study**

The purpose of the study was to explore the experience of palliative nursing care for a migrant family who had cared for a relative living with end-of-life illness in the New Zealand context. I decided an intergenerational approach was appropriate as socialising to a new society as migrants affects generations in a family differently and procuring their stories could offer valuable insights to benefit palliative nursing care. The criteria for selection were created around the ability to obtain the best stories from the different age groups without the risk of influence from other members. The criteria also included the ability of the participants to communicate in English to eliminate the use of interpreters and misrepresentations of statements. With these considerations in mind the following criteria were established and used for selection:

- The family members will have lived in New Zealand within the past ten years;
- The participants will be in a reasonable period of time post bereavement to enable reflection of their experience that is not emotionally traumatising;
- Post bereavement will be less than five years to capture a more accurate account from memory;

- Selection will be based on one representative from each of three generations, if possible in one family or if this is not possible, three individuals representing three perspectives in one family will be considered.
- Participants must be able to communicate in written and verbal English.
- Applicants between 14 years and 75 years of age will be the focus of consideration.

I will discuss the recruitment of the family in section 4.2 of the next chapter on ‘Walking the Research Path’.

### **3.5 Ethical aspects of case study research**

The involvement of human subjects in this study necessitated the application for ethics approval from a regional ethics committee. Ethics approval is mandatory and important to guard the rights of individuals participating in research studies. The fulfilment of this requirement ensures that all ethical obligations are observed by the researcher in relation to the participants of the study, so protecting their rights regarding information they will be providing. The protection of these participants also includes strategies to ensure safety in the event of undesirable consequences arising during and after the study such as emotional responses to memories that are evoked by relating their stories. It also serves to protect the researcher and organisation in the event that unethical challenges arise in the course of the research study.

The information sheet and consent forms ensure informed consent and approval of the proposed questionnaire by the Ethics Committee ensures safe boundaries are maintained

between subject and researcher with regard to information required and the storage and use of this information.

People who have experienced care for a loved one in end-of-life illness and endured subsequent bereavement consciously or unconsciously carry a shadow of vulnerability in the period of grief. Stewart (2000) in her thesis "*When an infant grandchild dies: family matters*" makes a strong case for not avoiding research that involves participants in bereavement because of the potential of distress. She questions the premise that research that explores bereavement is harmful and offers a substantive argument that it is better for bereaved people to have a voice and be able to talk about their experience with the appropriate channels of support available for them. Appropriate strategies for support and addressing emotional events are part of the ethics portfolio in research and their inclusion in the research process is ensured by the ethics committee on application for approval.

The only challenging dilemma I identified that could arise with participants as a consequence of this research was an emotional event as a result of reflection on the loss of a family member. As there are no set time limits for grieving and the period of grief that is experienced by an individual, a more subjective approach was used in assessing the participants' emotional ability to cope with participation in this study. This was carried out with the assistance of the health professional who referred the family and who worked at one of the hospices that assisted in the recruitment stage.

Involving a counsellor was identified as a means of support for the family should they require assistance with grieving due the surfacing of memories. I requested the support of Bereavement Counsellors working in three hospices and the Cancer Society, all of who had offered assistance in recruiting a family for the research study. Hospices also provide a free service that would not financially encumber the participants. I also had the assured support of a counsellor working for a private counselling practice (Assured Directions) for migrants. His letter of support is attached (refer Appendix 1). This range of counselling assistance ensured that wherever the participants resided there would be easy access for them to a counsellor should the need arise. For the purpose of this study the letter of support from the counsellor of the particular hospice who cared for the Jasatt family is included (refer Appendix 2).

Another protective measure for participants is the practice of assigning them pseudonyms in all written work around the research outcomes in reports, presentations and theses as a means of affording them confidentiality. Written consent to participate in the study is a requirement and a verbal explanation is an essential accompaniment to the consent form at the time of signing. In the case of participants under 18 years of age, consent from a parent or guardian is necessary. The consent form and information sheet are included (Refer Appendices 4 and 5)

Consent was obtained from the Auckland Ethics Committee. The letter of approval is attached (refer Appendix 3)

### **3.6 Interviewing family members**

My decision to hold the first interview with all three participants together was endorsed by Stewart's (2000) revelation in her discussion about unanticipated disclosures. Sometimes disclosures are made in individual interviews about other family members or issues that become out-of-bounds for discussion. The comments may be considered 'outside the boundaries of the interview' and not for use. The collective interview of all three participants precluded comments made with the intention of non-disclosure to others in the family.

Trust between researcher and participants and ease of discussion is of considerable importance in gathering data and so I spent the first ten minutes of the interview getting to know the participants by engaging in general conversation about contextual information.

In contemplation of the interview proper and how to draw out the gems of experience in each of the participant's unexplored stories, the questions of 'what', 'when' and 'how' constantly sprang to mind. I realised beforehand that it would be prudent to have an unstructured format to the first interview and begin by inviting the participants to tell the story the way they experienced it. According to Bar-on and Gilad (1994) and Stake (1995) an unstructured format avoids the interviewer's agenda from being dominant and being superimposed on the participant's view of the experience. The use of open questions may be used to clarify points of complexity for understanding because as Stake (1995, p. 9) so aptly states, "The aim is to thoroughly understand".



I had envisaged the second interviews to be individual and serve as a clarification time for the stories already collected and any further descriptions to be added to stories. A second meeting was arranged for a later date when I had analysed the data to clarify or amend any points of uncertainty but the family chose to meet as a group again. The participating members of the family were given the opportunity to view the transcribed stories and spoke with me individually on separate occasions by phone.

### **3.7 Rigour and congruence**

Validity in case study research according to Stake (1995) includes minimising misrepresentation and misunderstanding. The process of checking and re-examining the method of collection and analysis of the data is known as triangulation and discussed by Stake (1995). Triangulation represents the effort to see “if what we are observing and reporting carries the same meaning when found under different circumstances” (Stake, 1995, p. 113).

As I was the sole researcher in this study, I chose to recruit the participants of the study themselves to check that first, the transcribing of the interview situation was correct and second, the interpretations drawn from the transcribed stories were acceptable and in accordance with their personal and cultural beliefs. This measure not only enhanced the triangulation of the findings but also improved and enhanced the cultural information in the study from the ethnic perspective. ‘Member checking’ in the study is an important strategy of ensuring rigour in that the researcher needs to demonstrate that an accurate representation of material from the participants was obtained. Ensuring language comprehension between researcher and participants so that correct implications of what is stated and recorded for the study is accurate is high on the list of priorities. Stake

(1995), in referring to this process of ‘member checking’ as one of the strategies for triangulation, endorses my acknowledgement that it improves the case reports.

The significance in cultural studies of avoiding misunderstanding or imposition of the researcher’s perspective over the participant’s is an important priority as well. Researchers have an obligation to be aware of their positions and views in studies and endeavour to interpret and represent the participant’s accounts free of imposition of these personal views. ‘Bracketing’ is a strategy that was introduced by Parse (as cited in Koch & Harrington, 1998) to describe the conscious setting aside of one’s personal views and values to establish ‘separateness’ and truthful account reporting. ‘Bracketing’ and the recommendation of Koch and Harrington (1998) of an ongoing review, explanations of position and reasons will allow a credible stance of the research study.

In considering the trustworthiness of interpreted material produced in this approach, it is necessary to look at other ways of introducing rigour into the study in addition to strategies to ensure accurate representation discussed above. Achieving the element of trustworthiness and defying all criticism to be assessed as a valid study, is a challenge that faces all researchers. How then can this be strategised into the study from its inception by the researcher? Guba and Lincoln (1989) list three criteria for establishing trustworthiness, that of accurate representation which has been discussed above, transferability and auditability.

Transferability is the fittingness of the study findings to other settings, populations or contexts. Mitchell (1983) makes a good case for single case study research and argues

that there can be extrapolation and inference from single case studies. He takes the whole debate on extrapolation and inference back to the question of the study and the purpose of the research. In this instrumental heuristic single case study, my role will be to explore and discover logic of the findings. As the analyst I will use other known information to derive logical relationships of the facts. The logic will be the significance of these relationships that indeed the readers will extrapolate rather than the raw findings from the interviews. The concept of logicalisation has no relationship to that of 'representativeness', a criterion used in statistical studies and crucial to extrapolation and inference of the findings to a wider or parent population.

Continuity and consistency within the thesis as a whole will reflect congruence within the research process as well. Koch and Harrington (1998) say it is vital that the researcher continually reviews and confirms reasons for selecting the particular phenomena to be examined. The need to clarify beliefs and position before the data gathering stage is a recommendation by Koch and Harrington (1998). The continued process of rationalisation throughout the research process ensures congruence within the study and the thesis. These explanations and rationalisations of the researcher I see as imperative and will create transparency of the process from identification of phenomena through data gathering to interpretation and identification of themes that will enable the reader, participants and interested parties to recognise and/or apply to their situations. This continued rationalisation of decisions and clarification is congruent with the strategy discussed by Yin (2003) under 'construct validity' where he states that it is imperative to establish correct operational measures for the concepts being studied. This strategy, together with the process of 'member checking', also demonstrates that the

operations of the study like data collection can be repeated with the same results thus ensuring reliability of the study.

### **3.8 Analysis and interpretation**

In this study I sought to discover what happens to migrants when their spiritual, emotional and physical well-being is challenged by end-of-life illness in the family whilst trying to socialise into a new life in a new host society. When migrants are expected to socialise into a new country, is no attempt made to accommodate their personal cultural and religious beliefs, values and practices? I have explored my cultural experience of living in a country different to my country of origin and have an awareness of the migrant perspective and how it is adversely affected by healthcare processes that are oblivious of an individual's personal values, beliefs and practices.

The first task of analysis involved the transcribing of the tapes, which served as a way of familiarising myself with the material in the interviews. I had audiotaped the interviews on a micro-cassette and an ordinary tape as a back-up measure. I found transcribing to be a slow process of trying to identify words. However this resulted in immersion in the data as intended. As I envisaged, the familiarisation with the content involved several readings to identify ideas and concepts expressed by the participants.

Nvivo, a computer assisted pre-packaged programme that helps analysts to code and categorise large amounts of text, was made available for my use on my work computer. NVivo enables the researcher to highlight sentences and statements and name them by a theme title like 'family' or 'community support'. Having transcribed the taped stories myself I was familiar with the data and able to easily identify recurrent themes prior to

transferring to the NVivo programme. The identified themes I entered as 'nodes' in NVivo and the number of these nodes increased as the experience of the family advanced into the palliative care period.

The next step was to identify clustering of these nodes, which started to resemble a tree-like formation revealing trends and so interpretations. Yin describes the analytical stage as the most difficult stage of doing case studies. Yin asserts that tools are important and useful "but are usually most helpful if you know what to look for" (2003, p. 110). Having utilised NVivo once before, I was aware that it is helpful to be familiar with the text and aware of emergent themes prior to commencing use of the programme.

To conclude this chapter, my choice of a qualitative single case study method was appropriate to the study of nursing, cultural and experiential issues in palliative care. The use of a family case study here was instrumental and revelatory in showcasing important and salient features of the migrant family's experience of palliative nursing care alongside the intention of presenting the findings for nurses and other health professionals to utilise in their healthcare practice.

## CHAPTER 4

### **4.0 WALKING THE RESEARCH PATH**

The case is a specific, a complex, functioning thing.

(Stake, 1994, p. 2).

Walking the research path was an exciting new experience in education for me and in this chapter I will describe the steps taken during the research journey and justify changes that needed to be made to the original plan. In planning ahead for obtaining ethics approval, careful contemplation of consequences for all involved was a focus and resulted in a good application submission. I will explore the application submission here, describe the process of selection of participants and explain the interview format and transcription.

#### **4.1 Recruitment of study participants**

Recruitment of a participant family involved contacting and sending the information sheet to likely contacts who might know of migrant families, recently bereaved and who had accessed a palliative care service. These contacts were a private firm of counsellors for migrants called Assured Directions who supported this study, general practitioners who were known to me, the Cancer Society Counsellor and the counsellors from the three major hospices in the Auckland area. I was not directly involved in approaching families who were potential participants.

The search resulted in two migrant families who were willing to participate, one a Filipino family of two generations suggested by a General Practitioner and the other an Indian Muslim family from Zimbabwe referred to me by a hospice nurse. The latter family met the required 'three generations' criterion and although bereaved six months previously were enthusiastic to tell their story to honour their father.

The family that became the focus of this case study and met the inclusion criteria came from Zimbabwe originally and, who had been resident in New Zealand for three years. Their family experienced the need for palliative care for their father who became ill with progressive lung cancer and died. Their enthusiasm to make a contribution to health research in their new country of residence was apparent during the months we worked together on the research project. The recruitment of this migrant family of three generations who had experienced palliative care for their father and who were eager to share their story was a milestone in my research journey and represented significant progress that enabled the continuation of the project. In the next section I present the family members and the circumstances that led to the husband/father/grandfather's need for palliative care.

#### **4.2 Beginning the case study – meeting the family**

The late Salie Jassat was a person of prominence in the community of Zimbabwe and had enjoyed a very active and successful life with his family and friends. For political reasons he and various members of the family decided to give up life in that country and emigrate to Australia and New Zealand, the latter being his choice and that of one son and his family. His wife Bibi left three months earlier than he did, leaving him to tidy up property and personal matters in Zimbabwe before coming to join her and the others

who had emigrated to New Zealand. Salie was a game hunter and owned a ranch where family gathered frequently and enjoyed the outdoors lifestyle. He was an Indian Muslim who had lived all of his life in Zimbabwe except for the last few months. In contrast his wife, Bibi who originated from India went to live in Zimbabwe as a child with her parents and came to live in New Zealand a few months before Salie did. Salie arrived in New Zealand in December 2002 to join Bibi and their son, Faizel and his family who had emigrated here to make a life for themselves. It was at his pre-emigration medical examination that Salie's illness was diagnosed and at the time he was asymptomatic and felt well. Salie survived about six months of living in New Zealand, enjoyed some of the features of this country that confirmed it as a good choice and finally succumbed to end-of-life in July 2003, surrounded by his wife and family and the new community who had come to know and respect him.

Bibi, the matriarch of the family divides her time now between her family in New Zealand and Australia. She was the main carer of her husband in end-of-life illness and was well supported by her children. At the time of this study she was in her late sixties.

Faizel is the third of four sons and lived the major part of his life in Zimbabwe till emigration to New Zealand in 2000. He and his wife Munira have three children and were also main carers of Salie in his illness and provided the strong support for Bibi at this time. Riyah, the eldest female child of Faizel and Munira's family, is fourteen years of age and was happy to be included in the research study as a third generation participant.



The hospice nurse informed them of the study and gave them information sheets on the research and obtained their expressions of interest to be involved in the first instance (Refer Appendix 5). I made my initial contact with Faizel by phone and then made an introductory visit to discuss the details of the study and how I envisaged the interview might go.

It was at this introductory visit that I realised that Munira, the daughter-in-law had had a pivotal role in caring for Salie, supporting Bibi. She was the point of contact for the palliative care team at any time, whilst also maintaining normalcy in routine for Faizel and the children who continued work and schooling. Her contribution was a vital part of this experience and so to the research too. As the criteria for selection that I had set out was for a representative from each of three generations, I contemplated this alteration to the plan and decided that two representatives from the middle generation would provide an additional perspective and enhance the specialness of the research knowledge from this family case study, whilst still remaining within the parameters of the criteria set for this study.

The Jassat family are of Indian origin, a prominent family in the community in Zimbabwe and proclaimed Islam as their faith. Islam is a monotheistic (one god) religion and according to Neuberger (1998) the followers can be divided into four categories, Sunni, Shi'a, Ismaili or Ahmediyya. Muhammed is considered the messenger of God and Muslims regard the Qur'an (Koran) as their holy book. There are five ritualistic requirements or duties of Islam and these are:

Faith (Shahada) – declaring allegiance to God;

Prayer five times a day facing Mecca (Namaaz);

Alms-giving (Zakah), giving to charity;

Fasting for 30 days (Ramadan);

Making a pilgrimage to Mecca (Haj);

Neuberger (1998) states that the duties of Islam are even more emphasised in end-of-life, although the pilgrimage if not undertaken before now, would not be an option.

### **4.3 Attending to the formalities of the research process**

The formalities of explaining the reasons for this research, the aims of the study and how I envisaged the format of interview and reporting process, was covered at this visit. It was an informal visit where we exchanged information about ourselves - a 'getting to know you' session. Gaining written informed consent was also part of this visit and I explained the intentions for the material that would come out of the interview and narratives, which were to inform my thesis, journal articles that may reach publication, and a conference presentation at some stage. My intention was also to consult with them at appointed stages such as completion of analysis of case material and report of findings.

All four members of this family who were to participate in this study signalled their enthusiasm to participate and completed the consent forms. Faizel also gave the written consent for Riyah's participation. A change of plan happened unexpectedly as the adults expressed their wish not to use a pseudonym and Riyah was happy to do the same. They explained that this would be a way of paying tribute to their father who would have been happy to know of the contribution to health research. Their memory of him as a family man of standing in their extended family and community and whose love of

people was one of the ingredients that brought them together, remains clear and affectionate.

I took the opportunity later to check again with Riyah that the open identification of her in anything that may result from this research was something that she was comfortable with. She endorsed this intention.

Around this issue of confidentiality and identifiability, I mirror a statement of Stewart's that says, "How could I have been so naïve and unthinking not to appreciate the importance of names in this work?" (2000, pg. 152).

The warmth of this family meeting and the promise of what could turn out to be a research study of some magnitude to my work and academic efforts filled me with excitement as I looked forward to our forthcoming appointment to meet and begin work together.

#### **4.4 The interview**

I had planned to invite each participant to tell their story which I would audiotape for analysis and interpretation later. This still remained the plan but it was evident that I would need a few warm up questions and prompts to keep the interview flowing. As a warm up the participants were invited to tell me about their life in Zimbabwe. The data gained added context to the narratives of their palliative care experience and served to illustrate a sense of their lifestyle. The flow of discussion provided a good introduction to the stories and also relaxed everyone including myself as the interviewer.

As Salie's illness was discovered during immigration health tests, the combined story flowed in a sequence of events from the warm-up questions to the end-of-life stage, with many anecdotes of relevance included on culture, religion, memories of Salie and other important points.

The combined interview had the ideal result of a very complete story from everyone's memory and perspective as they recalled incidents and happy and sad times. For me, the researcher I came away feeling like I had a pot of gold that I was keen to take a look at. I had reached a significant stage of the whole process.

#### **4.5 Transcribing the tapes**

The combined interview was recorded on a micro audiotape so that a transcribing machine with a foot pedal could be used later. As a precaution I had taken an ordinary audiocassette recorder as well and used it as a backup.

I planned to do the transcribing myself in order to immerse myself in the material and had the use of a transcribing machine from my workplace for this task. Transcribing proved to be a challenging task in deciphering the taped conversation and replaying certain parts several times over was required to record it in writing. It was slowed down further by the fact that I was writing rather than typing as my typing skills are rather simple and slow. However this familiarised me with the content even more as I remembered several anecdotes from the interview.

#### **4.6 The second interview**

As all participants stated that they were comfortable with all that was in the transcribed information, the second face-to-face meeting was only attended by Faizel and Munira who clarified technical points about Muslim rites in end-of-life and family names and relationships.

As I had already sent them a copy of the transcribed material, Riyah who could not be present at the second interview read and approved the material in the transcripts as correct by phone.

## CHAPTER 5

### 5.0    WHAT EMERGED?

*Dad would have wanted us to do this. He was always interested in research and furthering knowledge.*

The Jassat Family, 2003

Possibly the most important part of my role as researcher had arrived and I contemplated the honour of being entrusted with the family story of the last few months of their loved and respected father's life. As discussed in the previous chapter, the family were united in their desire to waive the confidentiality clause and honour the memory of their father. I would like to acknowledge here the tapestry of information that was entrusted to me at the interview and have identified a quote from them to head this chapter. In this chapter I wish to look at the themes that emerged in the narratives of this family and present my interpretation of emergent ideas as I immersed myself in the data and listened to the voices of the three generations of the Jassat family.

The aims of the study were discussed in detail in Chapter 1 and in reaching this stage of analysis I realised the need to confirm and reiterate here, as a means of positioning my thinking, the main focus of this study which was to explore the experience of palliative nursing care for a migrant family in New Zealand.

Through the transcribing process I had immersed myself in the rich data that was present. As I read the transcripts several times over, certain recurrent themes became

apparent and these I highlighted as a start to the process of analysis. These themes were family, lifestyle, religion, community, social contacts, difference in society. As the stories progressed new themes were apparent like illness, protecting family, support systems, beliefs/traditions, anxiety, respect for Dad. At this point I decided to transfer the transcripts into the Nudist programme NVivo in order to facilitate the many emerging themes and utilise the programmes convenient way of grouping and clustering themes.

These themes were entered into NVivo as nodes. A node is a recurrent prominent theme or idea in the transcript. Nodes identified were communication, protecting family, palliative care providers, prognosis, managing illness, end-of-life care, illness (trajectory), difference in lifestyle, socialisation, beliefs, religion, cultural, traditions, contacts, community, first generation, second generation, third generation, honouring Dad, bonds, decisions, personal attributes, normalcy. When I contemplated these nodes it appeared that several could be clustered together. NVivo allows a cluster formation that enables 'child' nodes to be categorised under a 'parent' node. This formation is called a tree formation, which can be expanded on screen to see all 'child' nodes. Each 'child' node when opened reveals the text that has been named under this node and where in the text document it can be found. I then identified 'parent' nodes that are headings that groups of 'child' nodes were categorised under due to a similarity in theme. These 'parent' nodes were 1) family, 2) community, 3) culture and religion, 4) communication, 5) palliative care and 6) migration process. The order of listing these 'parent' nodes I deduced from the number of 'child' nodes in each category.

This was the limit of the extent that I used the NVivo process as I began to write and contemplate the pattern and relationship of the 6 ‘parent’ nodes. The rest of the chapter discusses the outcomes of the pattern and relationship between the ‘parent’ nodes as I viewed them.

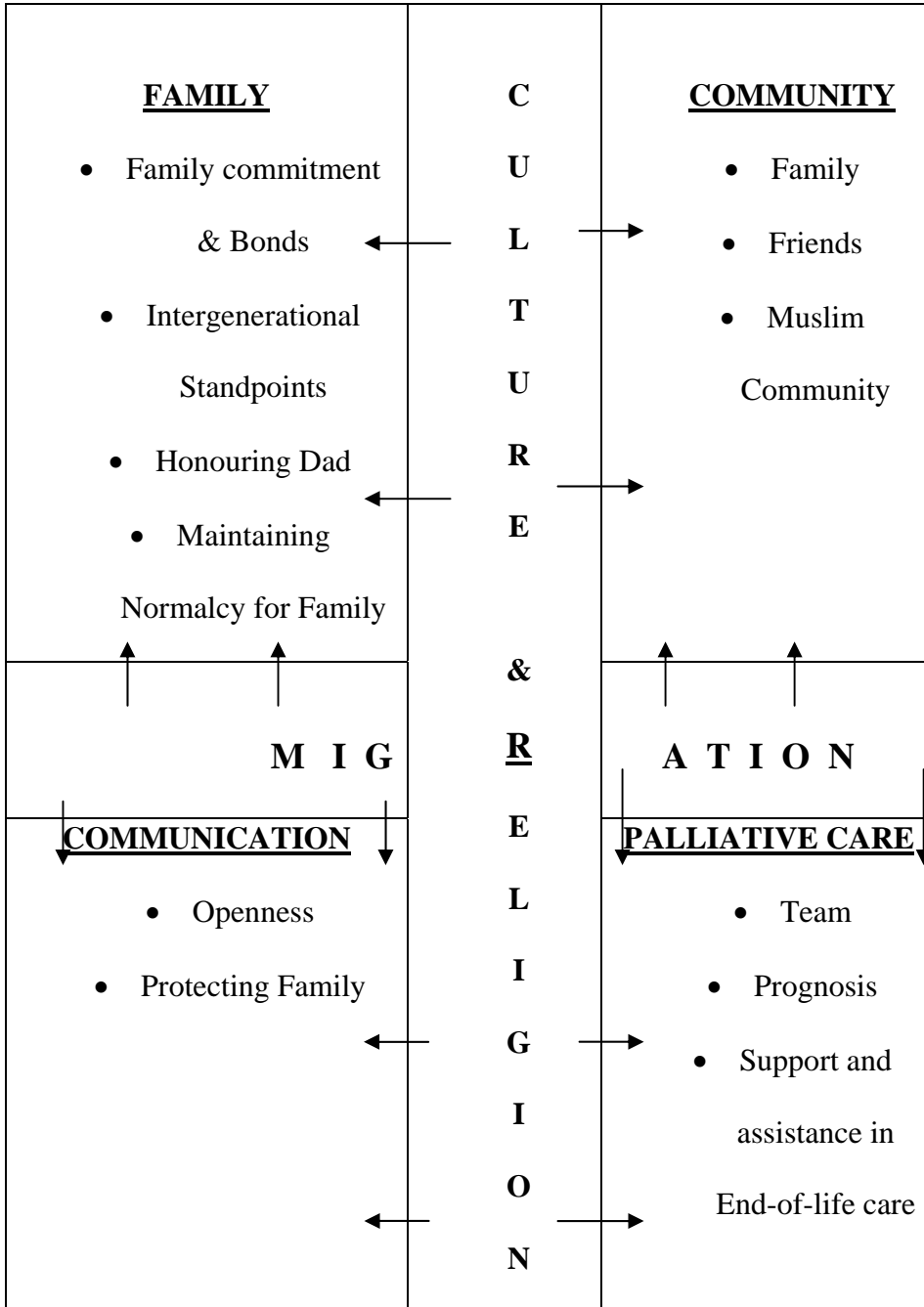
Four of the prominent ‘parent’ nodes represented important themes that were linked to one another because together they made up ‘care’ as Salie and his family experienced it. These were family, community, communication and palliative care. The other two ‘parent’ nodes which although were prominent were overlying ‘influences’ on the direction of care and provided a strong backdrop to the themes in the transcript. These appeared like threads that were present throughout the interview from life in country of origin to the end-of-life experience in the new host country of New Zealand. A few statements were categorised under 2 themes as they demonstrated meanings appropriate under two themes. For instance ‘family decision-making’ was categorised under ‘Intergenerational Standpoints as it illustrates the close bonds between the first and second generations in this case study whilst also being appropriately categorised again under ‘Communication’. Nvivo enables statements to be categorised under more than one node because of the possibility of plural meanings that arise from statements in the narratives.

It is necessary to portray each of these themes and threads as they are presented in the narratives separately. Table 1 is a diagrammatic representation of the relationship of the four themes and the two threads. It also shows the ‘child nodes’ under each theme.



**Table 1 Table of Themes and Threads**

*A diagrammatic view of the ‘Themes’ in the four quadrants with the presence of the ‘Threads’ through each quadrant.*



## 5.1 Themes

### 5.1.1. Family

The theme of family has a few facets, which are all a manifestation of the meaning of ‘family’ and demonstrate the importance of this unit in the end-of-life care of Salie. Byock says of families in end-of-life illness, “Each person in the patient’s family, as well as the family as a whole, is inevitably, inescapably affected” (2003, p. 10)

#### Family commitment and bonds

The three adults described their family as ‘closely-bonded’, a quality that was a vital part of their existence in Zimbabwe in earlier days and remains as a supportive structure when migration has dispersed family members over South Africa, Australia and New Zealand. Munira and Faizel emphasised this closeness by the statement:

*We have always been sort of independent, away from our folks but very, very close as well.....We were a very close family there.*

Their caring concern for their mother (Bibi) was evident in the statement by Faizel,

*...because she has four sons, one of us or all of us she knows are always there for her, no matter what.*

This statement spells a commitment of support that requires no qualifying discussion and I have identified as a feature of most families of ethnic orientation that I have encountered. It is a strong feature of filial commitment and duty and is also a prominent reason that underpins the care that their sick father was afforded right to the end of his

life, a care that encompassed his need to stay with his family and be cared for by them right to the end,

*He wanted to be with his family, he wanted to be at home (Faizel).*

Close family bonds and commitment are also evidenced by their affirmation that the course of Salie's end-of-life illness and being cared for at home and by his family were exactly how they had wanted it no matter how tiring, stressful and emotional a time it had been,

*....we wouldn't want it any other way. (Munira).*

#### Intergenerational standpoints

The case study design included differentiating between the perspectives of three generations of a family. In viewing the narratives of the three generations of this family, a sense of fidelity is identified in statements of family relationships, culture and religion, communication and the migration process even though at a time of considerable emotional upheaval due to end-of-life illness. This sense of fidelity is neither restricting nor rigid but has 'trust' as its framework.

Decision-making is a statement that co-occurs under two nodes and reflects the different view and perspectives of two generations. Bibi, as the first generation member and matriarch was happy to let decisions be made and course of actions to be devised by her children. Although this standpoint may display an acceptance of traditional role boundaries, it represents the trust that underpins the family relationships and acceptance of their concern and protection at such a vulnerable time. This wing of protection

enabled her to devote her time to caring for her husband and spending precious time with him,

*I used to be all the time downstairs with him and*

*I used to spend all the time with him.*

‘Protection’ as a concept in filial commitment will be presented under the theme of Communication in section 5.1.4.

Riyah, as the third generation member and grandchild aged fourteen years, fulfilled an important role of looking after the younger children of the extended family who arrived at the house. She participated in the reading of the Qur’an with the older children of similar age and assisted with carrying messages, a seemingly unspoken role of responsibility in a time of upheaval. Her parents who applauded her attributes affirmed this sense of responsibility displayed by their daughter. She was not perturbed by the expectations made of her at this time and her reflection on that time was that due to the many visitors, the house did not seem like theirs but

*...it was safety with all the family around (Riyah).*

Intergenerational support between the first and second generation is demonstrated by the many duties that various members of the second generation undertook to support their parents. The wider family group included Faizel’s brothers and sister who were in constant contact by phone and they made the journey from overseas several times to be with their ill father and to support their mother, leaving their family units behind in

some cases. Faizel's sister had nursing experience and proved to be an invaluable family resource person during her visit here.

*Of course she came here at a critical time, when Dad really started to go down and it was brilliant having her over here as well (Faizel).*

Faizel's younger brother Moosa who lived with the family in Auckland was also one of the main carers who assisted Salie with showering and daily physical cares. The tenet of 'morality' in Islam prohibits contact between male and female except for couples within marriage. Hence caring for his father's physical needs was an important role as a son and it relieved his mother of the physical strain of these tasks. Moosa also spent nights sitting up with his father particularly later in the illness when sleep became a problem for Salie.

#### 'Honouring Dad'

The idea of 'honouring Dad' was constantly portrayed throughout as Salie's position of patriarch and his prominent standing in the community was voiced often and became linked in my mind to the great family and community support that spontaneously appeared when the demise of this respected gentleman became apparent.

Several statements about his family leadership are in the narratives and are influential factors in their philosophy around culture and religion, lifestyle and openness of communication about his illness. Faizel speaks of his Dad,

*There was a lot of focus on him when he was downstairs. He spent quality time with his friends and family who visited during*

*his illness. He was often spoiled with cakes and fruit gifts. It was incredible the love that he had from people from all aspects of life. He was so well loved.*

Faizel also demonstrated his father's public profile in Zimbabwe with the words:

*And I said 'Dad the best thing for you to do is to compile a letter to everybody....and in that letter try and write as much as you want in that letter and we will e-mail it to everybody and we requested them to – everybody that received it to pass it on to everybody that they knew that knew him. And thereafter it could just pass onto every mosque back in Zimbabwe, back home in South Africa. And that's what everybody did. Everybody that got hold of it, somebody printed it off and clipped it to the notice board at the mosque in Zimbabwe and we just knew that this letter reached everyone. What he's compiled, Yvonne, is from his heart. The way he's written is the way he speaks.*

(Salie's letter - refer Appendix 6)

Munira, who entered the family through marriage, had a high esteem for her parents-in-law whose inclusive family philosophy of their daughters-in-law contributed to the strong bonds of filial commitment at this time of end-of-life illness.

*I never came into this family as a daughter-in-law. The daughters-in-law he always treated as daughters too. He never treated us differently.*

Her continuing statement then illustrated the commitment well,

*...there was a time when he only wanted one of us (herself or Bibi) to administer his medication.*

#### Maintaining normalcy of routine for family

As described earlier Munira played a pivotal role in maintaining the normalcy of the household whilst also playing the part of one of the main carers. As a daughter-in-law she assumed a natural role of co-ordinating the care of Salie within the family to support Faizel and enable him to carry on with his work and maintain a stable home for their children who continued with schooling. This task did create stress for her but her father-in-law's need to stay within the family unit became a strong goal to strive for. Munira's statement illustrates the pressure of maintaining the normalcy of family routine in addition to being a carer for her father-in-law:

*...he wanted to be around his family, he wanted to be home. That made things a little more pressurised for us because once all the family went back to Australia and Zimbabwe, the couple of families that were left here, had work to go to so the taxing periods were the nights, because Faizel couldn't sit up because he had to go to work in the morning. I couldn't sit up that much because of the kids going to school in the morning.*

Ferrell (1998) identified physical demands, altered roles and lifestyles, financial and non-convergent needs among household members as some of the social issues that impact on family carers as a result of advanced cancer in a member of the family. Ferrell claims that "studies of family members caring for persons with advanced cancer have shown that most experience stress in the caregiver role" (Ferrell, 1998, p. 912).

### **5.1.2 Support from Community**

The community around this family unit built up gradually and strongly during the end-of-life illness time, a period of some seven months. Some of the people who were community resources were already known to them from Zimbabwe but the majority responded through their religious and cultural links. Their choice of Auckland as a place of residence was the result of guidance from contacts originating from Zimbabwe and who were aware of their needs and preferences as a family with young children.

*A lot of that community also came out of South Africa, because the background was pretty much the same (Munira).*

#### Extended Family and friends

‘Community’ included the families of Salie’s other children, who travelled to New Zealand frequently in the last few months of his life to spend time with their father and support their mother and brother and family at this time of family crisis. As mentioned previously, decisions were made as a family as close contact was maintained with family members abroad. Her son and daughter from Australia made trips to New Zealand and then her son from Zimbabwe came and stayed for two months to spend time with his parents too. The role of extended family who came from overseas at various times to assist in care has been discussed under 5.1.1 Intergenerational Standpoints.

Community also included friends they had made here in New Zealand.

*We were well travelled because of our business. We were able to communicate with people at all levels, different people, different cultures. (Faizel).*



A prominent person at this time was their General Practitioner (GP), who was also a part of their community and a source of medical support, advice and assistance throughout Salie's illness. Her acquaintance with the family stemmed back to earlier days in Zimbabwe and her knowledge of their background and needs, as migrants, was invaluable at this time of illness as was her offer of availability whenever needed.

### The Muslim Community

The first contacts were related to family but as the need arose, religious links at the communal mosque where Salie and Faizel worshipped regularly, offered their support and commenced a ritual of visiting Salie when it became difficult for him to travel to the mosque. This ritual began with an observation of him being unwell and led to regular group visits that offered spiritual comfort to a man strong in his faith and ended by coincidence on the morning of the day he died when final prayers were offered together.

*The elderly men of his age came over, to pray with him and spend some time with him and just leave, you know and we found that fantastic, really. People that we never even knew took their time, once a week to come over and pray for him (Faizel).*

For the family this contact with the Muslim community was a source of relief and support, as evidenced in the comment by Munira:

*....we were worried because of coming and we didn't know how big the community is and we'd lose Islam.*

However their contacts through a relative with the Muslim community here formed the foundation of a support system in their time of need in end-of-life illness. As Faizel said:

*They came over and visited him and spent time with him and brought fruits and cakes and spent time sitting with him.*

### **5.1.3 Palliative Nursing Care**

Palliative Care as a service was initiated when Salie arrived in New Zealand, feeling well at the time but with a diagnosis of lung cancer. His sons were aware of the diagnosis but thought it wise to wait till he was in the country, a matter of a few weeks, to tell their mother and the rest of the family.

Munira contacted the Cancer Society in Auckland who referred her to the hospice in her area. At this stage of overwhelming questions, the need was for information and guidance. This need was very gently and sensitively addressed by the hospice nurse and an open offer of support was made to the family. The family felt well supported as is illustrated by Munira's statement,

*...we were so well guided, from GP to the Oncologist to the hospital, to the Oncology Department to the Hospice to the district nurses; the whole thing was completely guided.*

Palliative Care was needed only as a presence and support at this stage and the hospice nurse and the district nurse provided this as a shared service. Nyatanga (2002) asserts that when family are the main carers and supported by extended family, professionals may wrongly deduce that their services are not required at all. However this was not the case with this family because palliative care support was available as required.

Palliative nursing care offered to the family included

- Support
- Practical skills
- Symptom management

### Support

The palliative care support given to Salie and his family was a multifaceted care that mushroomed as the demand escalated with the progress of the illness. It included all the skills of guidance, advice, information provision, receptive listening, continuity of presence, direction and access to services as needed and much more besides.

*They put me onto hospice and hospice took me through the whole list. They just calmed me down and said to me “just relax. Write out each one of these points and then when you get to each point throughout each item that you go through, people will guide you as you go along.”(Munira)*

Initially the visits were weekly and as the family needed but increased gradually in the last three months to include assistance with practical and symptom management.

Accessing hospice care as an in-patient was not an option for two main reasons - religious and cultural. An event that is significant in two areas of discussion and occurs here as well as under 5.1.4 Communication is a reassurance given by a health professional about the end-of-life moments. Salie learnt at an earlier stage of his illness that the end-of-life moments would not be laboured and that ‘he would just slip away’. This perception became a source of some anxiety to him because being a religious Muslim person, it was imperative that he have his family around to offer prayers at the

time of death. The perception of being away from the family home and the possibility that they may not be present when he ‘slipped away’ was not something he could contemplate, even when he was tempted to give his family some respite. The offer was made by the hospice nurse for him to try a spell as an in-patient in hospice when tiredness overcame the family members who took it in turns to sit with their father. Culturally, as discussed previously, the family were committed to his care and knowing of his anxiety especially, they were determined to ensure that he passed away in the manner that was appropriate for him. It happened exactly as they wished,

*...we were four around him and every single one of us made that prayer around him. And I think it was important for us and it was important for him and he went the correct way (Faizel).*

#### Practical Skills

The hospice nurse and the district nurse assisted with the practicalities of daily living jointly in the form of checking in with family and offering advice on options or solutions to problems. A service that was introduced by the GP and proved to be of significant value was the homecare service, which was efficiently organised by the Home Healthcare Service of the public health system and in a culturally sensitive and safe manner. This was organised first in an interview with the family, by the coordinator of the service who then appointed a Muslim health care assistant to assist Moosa with care as necessary. The similarity of religious and cultural values of the home care assistant and the family was an insightful move to afford this family culturally safe care.

*She was absolutely outstanding because she understood us, she understood how we lived and she understood everything*  
(Munira).

Whilst the daily care of Salie was firmly in the hands of the family, palliative care as needed was from then on a shared supportive responsibility of the hospice and district nurses with practical assistance in physical care from the home care assistant and provision of medical expertise and support as necessary from the GP.

#### Symptom Management

The expertise of symptom management that includes assessment of symptoms and needs, prescription of medications by the most appropriate method, and continuous observation of courses of action was a responsibility of the hospice and district nurses who cared for Salie and his family. It was probably the most important skill that was required of them as palliative care nurses. As the disease progressed and Salie's journey was nearing end-of-life, the demands on the expertise of the nurses with medical consultation increased and became more complex. Faizel compared the care here to what would have been afforded them in Zimbabwe in the statement,

*How efficient and how easy for us and accessible to get what we required and we know that should he have had that situation in Zimbabwe we would have had a lot of difficulty.*

#### **5.1.4 Communication**

Communication is an important theme that came up in different contexts of this interview, between family members and patient and health professional. The family were always positive about the communication and care delivered to them and expressed the belief that they received outstanding care with many advantages over

what would have been received in Zimbabwe. However it is necessary to look at communication between -

- Family members
- Patient, family and the health professional

### Family Members

When Salie received news of his diagnosis in Zimbabwe, he was geographically isolated from most of his family and most importantly his wife who had already left for Australia first and then New Zealand. Communicating his unfortunate news appeared to be difficult by long distance. He chose to do so to members of the family who were in close proximity at the time,

*Immediately he said he did not want to alarm the family because he was leaving within two or three weeks of that news and he didn't want to break the news to the family before leaving (Faizel).*

Faizel's brothers in Zimbabwe then decided to let him know the news the week his father was arriving in New Zealand. However they all felt protective towards their mother and decided it was best to wait till their father arrived in New Zealand to communicate this bad news and spare her the worry while he was far away. The revelation to her was finally achieved when he arrived in New Zealand and from then openness was always maintained about his progressing illness.

Decision-making, which was previously discussed under 'Intergenerational Standpoints', is an important point of discussion here too and demonstrates family communication. Members of the family who lived in Australia and Zimbabwe were in

constant telephone contact to be informed of his state of health. Decisions were always made

*...as a family (Bibi).*

*...it wasn't just us making the decisions (Faizel).*

This was another example of 'protectiveness' that the family displayed for their elderly parents and for one another too so that the responsibility of the decisions and choices of treatment was shared. Kagawa-Singer and Blackhall explain, "decision-making may be seen primarily as a duty of the family, whose responsibility it is to protect the dying patient from the burden of making difficult choices about medical care" (2001, p. 2998).

However, Salie attempted to mask his discomfort from the family around him for a long time in his attempt not to cause anxiety and it was difficult for any of them to gauge his pain levels, as he would not talk about it.

*He wouldn't alarm us. He'd say I'm just a bit tired and have a lie down. He wouldn't show the strain or anything.(Faizel)*

On consultation with the hospice nurse about him 'rubbing his tummy' and sleeping for longer periods, it was decided to try Morphine for pain relief.

#### Family, patient and health professionals

Salie and his family were always insistent that as a family who were open about his illness, they wanted all information from any health professional they were in communication with. This was a factor that was checked and confirmed at appointments. In answer to the question from the Oncologist who asked Salie and the family how open they were about the illness and how much they knew about his illness, the reply was

*Salie had said no, we're open about it, everybody knows what its about. We want it on the table. (Munira)*

It was at one of these sessions that, in answer to a question, he was told that his end-of-life would probably be quiet and he 'would slip away'. This particular statement recurs in this category and demonstrates the different consequences that resulted from one statement. This event was discussed under 'Palliative Nursing Care – Support' where in-patient care was offered as an option to Salie and his family and arises here again under 'Family, Patient and Health Professional Communication'. Unpredictably this well-intentioned comment did cause some anxiety about cultural and religious influences later in the illness. In Muslim religiosity, it is of prime importance that prayers are said around the dying person in the end of their life. Culturally, the family would be committed to being present at this end-of-life moment to perform religious prayers. Hence the comment about 'quietly slipping away' was a source of some alarm and anxiety, especially when he was admitted to a hospital during a crisis. His anxiety led to his desire to stay at home with family to the end. The family were supportive of this desire as honouring his wishes is part of 'filial obligation' or 'filial piety', a strong practice in Asian families towards their elderly parents.

It appears that the third generation were also part of the openness of communication as Riyah was well aware of the state of health of her grandfather. Riyah said

*We had been told and then we didn't believe it, you know. He just looked so well.*



## **5.2.0 Threads**

As discussed earlier the threads were a backdrop to the whole interview and were important influences that shaped the ‘care’ experience for Salie and his family. The threads are an essential illustration of the particularization of this family. They tell us about the underlying characteristics that make this family unique and the ‘journey’ of massive proportions that brought them to New Zealand. The two main threads were woven into the narratives and could be identified as:

- Religion and culture
- Migration as a process.

### **5.2.1 Religion and Culture**

The family professed a strong faith in Islam, which was an important part of their lives and played a significant role in the settling in period in this country. Religion as they practice it has not been restrictive in their social and cultural lifestyle as their personal attributes played a huge part in the socialisation to this country. Faizel said,

*People could not believe we settled so quickly because we went out and made friends.*

A letter that Salie wrote as a farewell to all his family and friends is testimony of his strong faith in Islam and which gave him strength to face the ensuing months of illness and end-of-life. (Refer Appendix 6).

Religion and culture is also an important part of Riyah’s heritage and life, which has not served to restrict her lifestyle with school friends. Sport and a social life form a major

part of her schedule and there is a trust in her responsibility to uphold the customs and practices of her religion when out with friends.

*I think basically she does know her limits, by that I mean when it comes to type of foods she eats, to stay away from pork because she is a Muslim and she knows. We are very broadminded because of the way we were brought up. We are similar to our children, if we hold them back too much they are going to break away and try their own thing. (Faizel)*

Religion was cited as a reason for Salie's desire to remain in the family home. The family's devotion to his wishes enabled him to be cared for by family at home with assistance as negotiated from outside. This devotion I have identified as 'filial obligation' and it represents a duty of love to one's parents for all their lives. The basis of this will be discussed in the next chapter.

### **5.2.2 Migration**

The process of a permanent shift of family from one country to another had divided the family of Salie and Bibi over three countries. New Zealand however was the country that they chose to migrate to and were resident with their son, Faizel and his family who had been resident here for some three years.

Faizel and Munira navigated their way around the health system here with some ease for their parents and were able to access palliative care as was appropriate to their needs. As was mentioned before, their advanced socialisation into this country after only three years of residence was a result of persona, personal attributes and similarity of lifestyles

in both countries and this saw them through this end-of-life time with help from the new community they were connected to.

*I think once we arrived in New Zealand, because Munira and I are very friendly people and we get along with people we found it very easy to settle in. We just made friends so quickly, settled into the community and society in no time. (Faizel)*

Migration had been a planned process after much deliberation on choice of country for their young family. As it happens they discovered much later, palliative care in New Zealand offered them aspects that were more than were available in Zimbabwe like the use of Graseby pumps that are used to administer a continuous measured dose of medication subcutaneously for the treatment of symptoms and Morphine, an opioid derivative used to treat severe pain, and also the pharmacy service that included delivery.

In the next chapter I will discuss the impact of the themes identified here and also use the threads of religious, cultural and migration factors voiced in the interviews and literature to support and lend some credibility to my observations.

## CHAPTER 6

### **6.0 WHAT DO THE FINDINGS MEAN FOR PALLIATIVE NURSING PRACTICE?**

*Our patients and families are our best teachers.*

Liese Groot Alberts (2003).

This single case study research of a migrant family in palliative care has revealed several important considerations which hold striking similarities related to the care of Maori (Durie, 1996) and Pacific (Ministry of Health, 2001) people in New Zealand who emphasise the involvement of extended family. I will include these similarities in the following discussion.

The findings that are a result of my interpretation of the narratives of the family displayed an emphasis on ‘family’ as the prime carers in the palliative care of their father in his end-of-life illness and supported by extended family. As a result I intend to look at the collective ‘family’ as a major role-player in palliative care and discuss this aspect in this chapter as well as the other themes of support from community, palliative nursing care and communication described in the previous chapter. The theoretical framework outlined in chapter two which addresses culturally safe practice in palliative care informs my discussion. Cultural safety as a practice that is a result of a developed sensitive attitude and respect for the unique difference in others stands out as a priority that will enhance nursing practice in palliative care. I reconsidered the title of this research study to centre myself in the direction of the path of discussion, which is “A migrant family’s experience of palliative nursing care”.

## 6.1.0 Interpreting the themes

### 6.1.1 Family as principle carers

Viewing the narratives elucidates once again the foremost role this family unit played in the care of their father. A statement of Munira's focuses attention on this particular desire of Salie and his family,

*I think that turned out to be the most miserable day of his life because they put him in hospital for a start, as a patient. So we got him home and then he was comfortable ....*

Jones confirms the notion of 'family' as prime role player in her discussion on family and health, "The family is still, despite major change and challenge, a fundamental social institution with a major role in informal health work" (1994, p.85). It is interesting to look at the structure of families here in relation to size, social influences, culture and intergenerational relationships, which is a feature of this study.

Closeness of this family did not just happen as a reaction to the life-threatening event they were experiencing – that is the end-of-life illness of their patriarch. All three generations in this study described life in their country of origin as family oriented with frequent association with extended family. Riyah, the third generation participant in this study talks of her life in Zimbabwe before emigration:

*Oh well I'd mostly go out with my cousins and I was the youngest for quite awhile...*

The general story was that they would spend most weekends on the grandparent's farm in the country enjoying the outdoor lifestyle Salie and Bibi had established there. As Bibi, the matriarch of the extended family concurs,

*Yeah, we all celebrate together.*

It is important to note from the narratives that family associations did not just stop at celebrations and home events but were a feature of the business and occupational lives of the males in the extended family who were all part of an established company that included the middle generation and similar to the practice of the generation before that is Salie and his brothers.

It is apparent that the extended family structure is a fundamental feature of this family that was part of their life in their country of origin and continues in the present country of residence, New Zealand, and Australia for Faizel's brothers. Similarly, Munira who entered the family through marriage has close association with her mother and sisters in New Zealand and America. According to Jones (1994), extended family is where more than two generations live under the same roof, but conversely even she states that this meaning is not sustainable as there are many families whose relatives live separately but are involved in the family tasks of looking after children and dependants and assisting in many family duties and chores on a regular basis. However, "nuclear families predominate in Western societies, and extended families predominate in most other parts of the world" (Jones, 1994, p. 88). She confirms that in a multi-racial society like Britain, minority ethnic groups do adhere to traditional family structures in varying degrees.

It is significant to mention here that in New Zealand the role of extended family in the care of Maori patients is acknowledged as a foregone right as declared in Whare Tapa

Wha (Durie, 1996) and affirmed in the New Zealand Palliative Care Strategy (Ministry of Health, 2001). Durie (1996) says the four cornerstones of Maori health describes four dimensions that contribute to wellbeing, te taha whanau (family and community aspects) being one of them, and the others are te taha wairua (spiritual), te taha hinengaro (mental and emotional), and te taha tinana (physical). The four dimensions represent holistic care as a goal in healthcare for Maori.

One of the manifestations of strong family bonds was the concept of 'protection' initiated by Salie towards his wife when he was given the diagnosis of lung cancer and she was already in New Zealand with her son's family. He was hesitant because of the anxiety and worry around his state of health that it would cause her before they were together again, and enlisted the co-operation of his sons in not breaking this silence till he arrived in New Zealand, after which openness was the preferred option in all medical matters.

When it became known to her, the mother of this family accepted this protective measure in the manner of its intention in the same way that decision-making by her sons around her husband's illness was usual practice. This is another common practice in certain cultures of ethnic origin and represents the lead role that sons play in the family when their parents are medically unable to contemplate matters for decision. As in this case, Bibi devoted all her time to looking after her husband; her son in consultation with the rest of the family, to free her of that responsibility, looked after all decisions. Similarly a point that has been made previously, she was the respected first generation

and matriarch who would always be taken care of by her children and have a home with one of them as a widow.

Cultural factors have a significant influence on this idea of protection of parents in end-of-life illness. The concept of 'filial obligation/piety' has its origin in the teachings of Confucius and is often encountered in care of Asian people especially in end-of-life illness where decisions for active treatment and life prolonging measures are brought into direct conflict with the principles of palliative care. It basically spells the expectation that children will care for their parents without question in gratitude, according to Kagawa-Singer and Blackhall (2001). 'Gratitude' implies a forced expectation on the children that may be devoid of closeness of family and in my involvement with this family I am certain that this is not the reason for their 'filial obligation' but more through strong family bonds. Another example of their strong family bonds is when Salie was anxious about 'slipping away' quietly without the Muslim rite of prayers being said at the time of death if admitted to an institution. His particular wish of having this religious rite observed was honoured by the family who kept him in their midst till the end and went to great lengths to ensure he always had someone with him all the time including nights.

The intergenerational method of this case study illustrated 'within family' support and closeness that was a feature of this family, which was present in the narratives of all three generations. Including the third generation gave the study more insight into the whole experience of the middle generation and the dual roles as principle carers of the first generation whilst also maintaining other aspects of family and work life.



### **6.1.2 Support from Community**

The term community has many connotations in health practice and I explored the social literature (Jones, 1994; Ferrell, 1998) once again to define ‘community’ as an integral part of the context of this family. In health care, community often refers to care by professionals working outside a hospital facility. In the context of this study, a definition by Wilmott and Thomas assert that it is “people who share in common something other than physical propinquity” (Jones, 1994, p. 131).

Part of this community was the ‘extended family’ who lived overseas and came to New Zealand to lend their support whenever possible. But the rest of the supporting community were friends of the family and associates from the Muslim community who were known to the family from their country of origin or present place of worship. According to Jones (1994), the more original of meanings that is aligned with the term ‘Community care’ is that of support given by lay people for people who need help. This describes very aptly the way the Muslim community responded to the need of one of their associates when it was noted that his health was failing and he appeared to find it difficult to visit the mosque to worship. The friends and relatives who formed part of the extended family and gave of their time to sit with him and give the family relief are part of this definition of community.

### **6.1.3 Palliative Nursing Care**

Palliative nursing care provided was only part of its potential entirety and ran alongside family and community care. The hospice and district nurses were present to offer information, advice and services as the family needed as the professional arm of support.

The World Health Organisation states in its definition (WHO, 2003):

Palliative Care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

In essence, this reflects the care that was given in a professional capacity by the nursing team involved in the care of this family in end-of-life illness however minimal it was. Nyatanga (2002) refers to the issue of palliative care and multiculturalism and whether it reflects the needs, wants and aspirations of ethnic groups in Britain. The recommended model of care that Nyatanga purports is preferred by ethnic minorities and involves extended families (2002) resembles the model of care that empowered this family to be the carers. Care of Salie increased as the needs arose to encompass symptom assessment, pain management and assistance with measures to improve breathlessness when it became necessary, but end-of-life care in essence emerged from his being enveloped by family. Nyatanga goes further to recommend the use of this model in palliative care in Britain, which would achieve a measure of success. The drawbacks that he discusses are: some ethnic people have socialised into their new setting and this may not be an appropriate model; professionals may wrongly deduce that their services are not needed with these families; the shortage of practitioners especially from ethnic backgrounds (Nyatanga, 2002).

These are considerations I may have agreed with before this research study but since interviewing this particular family, they do not resonate with my opinions as assessment

of needs and negotiation with this family ensured the ebb and flow of palliative care. However, these considerations may present as issues in other situations of palliative care for migrant families where negotiation between the palliative care nurse and patient and family does not take place or is inadequate at the time of assessment. Good assessment of their needs and support systems and negotiation with nurses could arrive at a satisfactory compromise of extended family and nurses as partners in care delivery. The increase in the number of nurses from ethnic backgrounds in the workforce is one way of creating awareness of the unique differences of people within a work environment and so facilitates the development of cultural sensitivity that informs cultural safety in practice. However the employment of ethnic nurses for ethnic patients and families can be divisive in teamwork and promotes segregation, which is not helpful in developing culturally safe practice.

#### **6.1.4 Communication**

A policy of 'openness' was the practice of this family after the initial protective measure extended to their mother until Salie was reunited with her and the family in New Zealand. This stance of openness was a declared practice here, although is unusual with some families of ethnic origin because of a belief that the patient would deteriorate when he/she becomes aware of the prognosis of the illness.

Cultural and religious consequences became important considerations that directed the course of palliative care for this family. A well-intentioned piece of information formed the basis of total homecare, as Salie anxiously wanted to avoid being alone or without family members present to perform religious rites in his last moments. This also triggered the family's desire to honour his wishes to the end of his life even when times

became stressful between maintaining the normalcy of routine for the family whilst also caring for their beloved father.

Communication also covers the need for negotiation around preferred care options at the time of assessment which has been discussed in the previous section, 6.1.3. This is a necessary strategy to ascertain the care needed around religious and cultural needs. Byock and Corbeil (2003) confirm that smooth progression of care requires excellent communication.

### **6.2.0 Positioning the Outcomes**

#### Change of tack!

As I worked through the themes and what they meant to this particular experience of palliative care, that is the experience of the family of Salie, I realised I needed to identify the uniqueness of this family experience.

I stepped back from the findings and contemplated the data again. A fresh look at the four themes and two threads that weave in and out of the interview were still clear but I realised that the uniqueness of this experience was yet to be identified. The uniqueness of this family experience was determined by the threads of religion and culture and migration as a process of change planning, new decisions, differences, new experiences, new choices, trust and feelings.

The themes discussed in the first part of this chapter represent good palliative nursing care in that it afforded this family the power to define their own needs and then the

support in presence on this journey until more intervention was called for, an ideal that may not always eventuate. Care that is determined by the patient and family is a crucial factor in the patient-family centred approach and is cognisant of the differing needs of the patient at different stages which should be the indicator for what is required in palliative care (National Institute for Clinical Excellence, 2004). The discussion of these themes affirms the brand of palliative nursing care that ebbed and flowed with the tide of need throughout the last seven months of Salie's life and his family's experience in end-of-life illness.

The difference between this case study and the experience of other families in palliative care was the family and community teamwork that combined to keep Salie at home throughout his illness and to die in the traditional way of his religious dictates. Assisting a Muslim family in end-of-life illness is not a common experience for palliative care nurses and observing rituals and moral codes as dictated by the Muslim religion is not familiar territory for the majority of nurses. By respecting their different cultural needs and empowering the family to define the plan of care, a cultural and Muslim based model of care was created to suit Salie's needs and wishes. This model is in contrast to a generic model of care that fits anyone's needs for patients from any culture and creed and provided by strangers to the family in need of palliative nursing care.

So the threads made the crucial difference and particularised the model of care for this family. The threads of religion and culture and migration impacted on the course of palliative care for Salie. I will focus on these threads as the prime determinants of the need for cultural safety in palliative nursing care for this migrant family.

### **6.3.0 The Threads of Impact and Influence**

#### **6.3.1 Migration – A Stage of Transition**

The process of changing one's country of residence involves changes to every aspect of one's life. A new country represents different location, different people (possibly all strangers), different social practices, different weather patterns, different jobs, and different schools. If the move is one of permanent emigration, it can involve a number of losses to the migrant that matches the list of differences above.

Imagine the complex myriad of feelings and effects that accompany this transition and the tremendous coping power needed to enter and complete this transition to a more settled existence. Getting used to new social systems involves a variable length of time and living experience on the part of the individuals. If this experience of settling in a new society includes negative issues of prejudiced attitudes towards minority groups and expectations of newcomers to fit into society by losing their unique cultural ways, new migrants will be burdened with the feeling of dislocation from their heritage and cultural origins. When faced with the end-of-life illness of a family member at this time, this dislocation from heritage and cultural origins accentuates the feelings of loss.

The family in this study approached the transition from their country of origin to this country with pro-active planning and careful consideration being given to all areas of need and suitability to family. Immense effort was made by all three generations of this family to fit into everyday life here but also to maintain their religious identity and faith in Islam, which formed an important part of their family life. Religious and cultural identity as defined by this family is an important aspect of life in a new society and their

wellbeing. When challenged by end-of-life illness of a member of the family and facing loss, their cultural and religious identity empowered them to define the care needed for Salie. This is an important point to emphasise because migrants who are placed in a position of accepting care in a facility that is culturally inappropriate for their needs feel disempowered and are not in a position to define the care they would find culturally safe (Kagawa-Singer and Blackhall, 2001).

Many similarities were identified in the lifestyle of original and new countries like outdoor life, schools and occupations and business possibilities. Faizel and Munira made a preliminary visit to assess suitability of the lifestyle and also made contact with acquaintances here who eventually became their community of friends and contacts. This degree of 'preparedness' reflects their motivation to embrace the country and its typifications. As new residents they brought the merits of their family and business lifestyle and began life in this country using their friendly persona and outgoing attributes to assist in settling into the new community of choice. Migration and socialisation into a new community among other things, reflects an ability to communicate and mix with people of a new society, negotiate systems of everyday living for self and family and involves an investment of person and time, which can reap rewards of friendship and support accordingly. This is evidenced in this study by the community support that was a feature of their palliative care experience. Without the support of the Muslim community, traditional practices might have been sacrificed with consequent unhappiness and spiritual suffering for the patient and family concerned. As it happens, the supported experience proved to be as the family desired and the

narratives are proof of a bereavement that is devoid of recriminations regarding the experience of end-of-life illness care.

Therefore the positive position of being well integrated into their new life in New Zealand empowered the Jassat family to define the palliative care that they felt was culturally appropriate for Salie and work towards achieving this with the team providing palliative care. This definition of care was influenced by the religious and cultural needs, values, beliefs, traditions and practices that were part of their family make-up.

### **6 3.2 Religious and Cultural Underpinnings**

The experience of palliative nursing care as experienced by this family acknowledged their religious values, beliefs and rites of practice in the home setting and so maintained their religious integrity. Kagawa-Singer and Blackhall assert that “culture fundamentally shapes the way people make meaning out of illness, suffering, and dying and therefore also influences how they make use of medical services at end of life” (2001, p. 294). Religious and cultural integrity for this family could have been compromised should the partnership of care have favoured a more dominant approach from the palliative care nurses.

To understand the beliefs around religious rite of prayers at the time of death I resorted to the literature on Islam. The importance of this religious rite is also demonstrated at the beginning of the interview and I reiterate a statement by Munira that has been quoted previously,

*We were worried about coming (to a new country) and we didn't know how big the community is and we'd lose Islam.*



Neuberger (1998) states that the duties of Islam (as described in Chapter 4) are even more emphasised in end-of-life. In Salie's case Shahada (declaring allegiance to God) and Namaaz (prayer five times a day facing Mecca), while always being important was of particular significance in end-of-life. The regular practice of prayers five times a day particularly in end-of-life illness is of great meaning to a Muslim patient and family and there are special requirements of hygiene around praying that have to be observed such as washing face, feet, arms and hands before praying and positioning one's self facing Mecca. The times of prayer vary according to number of daylight hours and are offered five times a day. These religious rituals can be difficult to accommodate for a person in end-of-life illness and the difficulty is accentuated in a healthcare facility that provides care for several patients of different cultures and religions. In a family environment these will be taken care of routinely, but in a health care facility, details may be overlooked which again may be distressful for the patient and family in their helplessness. A ritual of magnitude is the saying of prayers by family at the particular time of death, in close proximity with the patient. This religious requirement of Muslims firm in their faith, proved to be a deciding factor in this family's choice of caring for Salie in his home environment and keeping a vigil by his bed day and night to ensure his spiritual comfort,

*...the day he passed away, we were all around him every single one of us made that prayer around Dad. That was important for us and it was important for him (Faizel).*

Therefore the belief of praying with their father in end-of-life and the cultural commitment to caring for him themselves surrounded by extended family and religious community with the bare minimum of professional involvement, was still the preferred option of this family who was well socialised into their new setting.

Another important tenet of Islam is that of modesty, a consideration of priority for both genders who prefer to be cared for by professionals of the same gender particularly if it involves uncovering any part of their bodies. Gatrad and Sheikh confirm this by stating that “nursing as a profession is considered by Muslims to compromise Islamic values of modesty, and recruitment is problematic” (2002, p. 597). This statement concurs with Salie’s preference of being cared for in end-of-life illness by his own family who were sensitive to his cultural and religious requirements. Disregarding this rule causes distress to the patient and family. Faizel’s younger brother who lives with them undertook these duties around physical cares for his father as his condition worsened.

The Jassat family demonstrated a strong commitment to caring for Salie throughout his illness at home and supported Bibi in her desire to be the main carer and spend her time with him till end-of-life. The cultural belief of ‘filial obligation’ has been described in the first part of this chapter as the strong obligation of care for parents by children that may manifest as life preserving beyond hope or as in this case, the duty of total care of the parents by the children even in the face of enormous stress. This finding has been discussed earlier as an element of Asian family beliefs and practice (Kagawa-Singer and Blackhall, 2001) and is a practice of the Jassat family too. Regardless of place of residence, elements like this present in varying degrees and I have had personal

experience with this practice from my own Asian origin though to a different degree of adherence due to the location of my mother in a different country to me.

The logicity of the findings then is the impact migration and degree of socialisation into new society had on empowering the family. Empowerment then played a major role in determining a model of care that was dictated by the family and culturally and religiously appropriate for them.

#### **6.4.0 A View from the Palliative Care Provider Perspective**

The case of the Jassat family illustrates certain values and beliefs as integral parts of their existence that the migration process has not diminished. These values and beliefs generate rituals and practices that again are an integral part of their lives as a unique family unit in society. End-of-life is a time when these practices come to the fore and are of significance to the individuals in their experience. These beliefs are prominent in the findings, cultural and religious in essence and have been discussed as pivotal in their choice of care.

The consequence of their cultural and religious beliefs was the favourable choice of looking after their father at home with good support from nursing personnel, extended family and community and resulting in spiritual comfort for Salie in his last days and the family in bereavement.

As mentioned in Chapter 2, families of ethnic origin seldom avail themselves of respite care in in-patient units and consider it inappropriate. So how can we achieve the best option for a patient and family centred approach to care? As a service, palliative care can provide care that is multifaceted, that is physical/physiological, psycho-emotional,

spiritual and social, and multidisciplinary in approach. This model of care focuses on holism (Oliviere et al., 2000) in assessment and care as divorced from earlier models that were disease oriented and treated only the symptoms of the illness, so denying the impact on the emotional and psychosocial being of the person and family. Holism in care acknowledges the physiological, emotional, psycho-social and spiritual needs of a person and includes family as an integral part of this person. Both of these approaches however spell a health professional imposed idea of what should be according to their idealistic visions of palliative care. However it appears that we are on the brink of a paradigm shift once again to a more flexible idea of the patient centred approach in palliative care, that is a patient and family centred approach. The idea of flexibility could mark the advent of real cultural safety that is appropriate to each case of difference and diversity. As asserted by Byock and Corbeil “true person and family centered (sic) care at the end of life strives not only to ensure comfort, but also to improve quality of life for people who are dying and for their families” (2003, p. 4). It is a time when situations of family relationships that have been at odds may reconcile, a case of ‘healing’ spiritually.

#### **6.4.1 Cultural Safety in Palliative Care**

As a nurse in palliative care and standing back from the family’s story it was quite apparent that a culturally safe approach for this family was to maintain a presence while offering them the resources and information to make autonomous decisions around Salie’s needs. This approach empowered the family to define the care that was needed.

So what did it entail on the part of the palliative care nurse who came to this family as bearer of palliative nursing experience and her own context of personal culture and

health care practice in New Zealand, all of which presented differences to the culture of the Jassat family? Trust was part of this nurse-patient-family relationship as evidenced in the statement

*....with hospice back-up and between the two of us and the three of them they were at our beck and call. (Munira).*

The palliative care nurses demonstrated awareness of and sensitivity to the need of this family to care for Salie in their own way and by facilitating this demonstrated culturally safe practice without imposition of their own dictates and opinions around care.

As discussed in Chapters 1 and 2, the favoured model of cultural safety is one that facilitates an attitude of awareness of personal culture and difference and informs a sensitivity to difference in others, followed by safe practice. It occurs to me that when awareness and sensitivity are present, a nurse consciously puts her own values, beliefs and opinions aside to formulate a plan of action that is based on the values, beliefs and opinions of the patient and family. This resembles the idea of ‘bracketing’ that researchers employ in qualitative research so as not to colour the data collected from participants with the researcher’s preconceived ideas. ‘Bracketing’ is discussed in Chapter 3 under ‘Rigour and Congruence’ in relation to the research method. To explore this idea I referred back to this literature and another article by Ahern (1999) on reflexive bracketing. The ability not to allow one’s assumptions to shape data collection in research is termed bracketing. Total objectivity is not possible according to Ahern (1999) who introduces the idea of reflexivity as a means of bracketing. Reflexivity is the ability to look back upon self. Reflexive bracketing includes a process of identifying personal values, assumptions, motives, and negative feelings. Reflexive bracketing

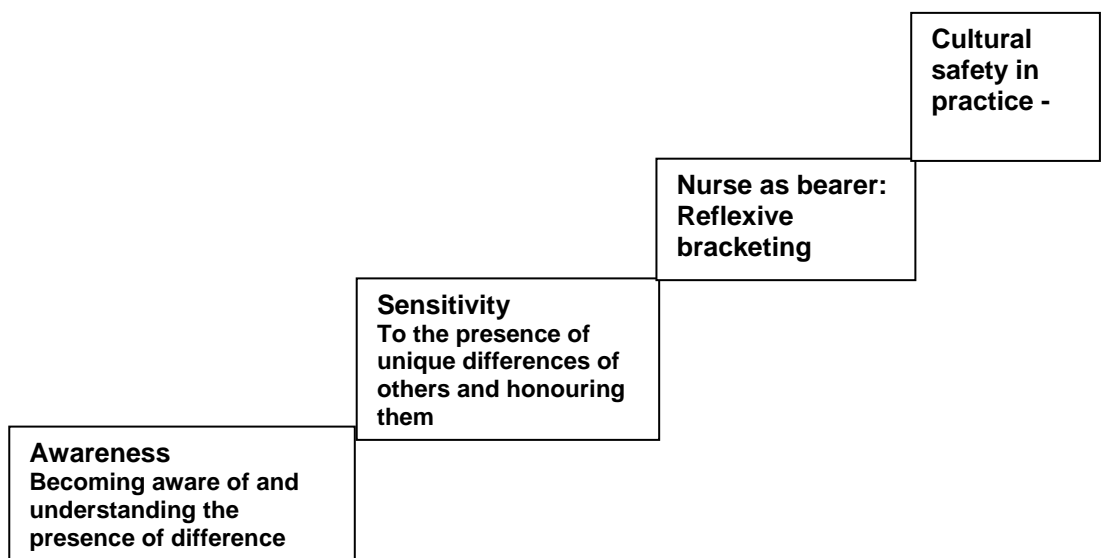
includes the ability to identify preconceptions and assumptions based on personal values and put these aside in order to focus on the other. This process applied to palliative nursing care for migrants is an important step also towards practising cultural safety in palliative care. It also represents a strategy that a nurse as bearer of her own culture can consciously employ to achieve cultural safety in practice.

Practising cultural safety includes being non-judgemental towards the other person in an interaction and the idea of 'bracketing' one's own values and beliefs is a means of achieving this. Crawley, Marshall, Lo and Koenig (2002) write about the need for physicians to develop a non-judgemental attitude toward unfamiliar beliefs and practices by first starting with their personal being. Reflexive bracketing then represents a conscious attempt to lay personal assumptions and preconceptions aside before meeting the patient and family.

For cultural safety in nursing practice of migrants in palliative care an informed approach could resemble a continuum from cultural awareness through the stages of cultural sensitivity, nurse as bearer of culture and nursing experience and reflexive bracketing, and cultural safety in practice. Figure 3 on page 107 demonstrates the placing of reflexive bracketing as a pre-interaction stage before meeting patients as discussed above.

To illustrate the model in practice I describe my journey through the stages and my view of how each step developed. My personal *awareness* of cultural difference began as a child living in a cosmopolitan country, Malaysia. My school friends were all from

different cultures and we celebrated the various cultural festivities by visiting each other's homes. In general cultural festive days were days when people opened their homes to friends and relatives who visited to offer their good wishes and at the same time sample some traditional food and drink in celebration. Having lived with cultural diversity since birth it became the norm for me. Later whilst living in Western countries, England first and then New Zealand, I faced a few challenges as a resident with an ethnic background even though I have integrated myself fully into a very Western lifestyle. The challenges are mainly around cultural divisions in society that promotes segregation socially. Through the experience of these challenges I have developed *sensitivity*, the second stage in the model, to the uniqueness of individuals and their cultural differences. As I have experienced the need to be valued as a culturally different individual, and wanted as a member of a community so have I valued diversity in people I meet.



**Figure 3.** The Nursing Council of New Zealand's recommended model for achieving cultural safety in nursing and midwifery practice (2002) adapted to include 'reflexive bracketing'.

The stage I have named here as *reflexive bracketing* from my experience represents the conscious effort that I make to be aware of my personal values and beliefs and set aside my personal opinions when I interact with someone from a different culture in my role as a nurse and educator. This stops me from imposing my cultural perspective on the other person and requires continuous checking that ‘bracketing’ is practiced. Ahern encapsulates my intention admirably with the statement that “the ability to put aside personal feelings and preconceptions is more a function of how reflexive one is rather than how objective one is ....” (1999, p. 2). The practice of reflexive bracketing also demonstrates a personal awareness of the powerful position of ‘nurse as bearer’ of her own culture in a nurse-patient/family interaction.

The result of continually practicing ‘reflexive bracketing’ is empowerment of the other person in the interaction to voice their needs and preferences of care and be reassured that these have been heard and not judged as trivial and inappropriate, a crucial and significant step towards practicing cultural safety.

#### **6.4.2 Assessing the needs of patient and family**

Having developed cultural safety as a practiced philosophy, palliative care nurses could adopt a strategy of naive assessment of needs and negotiation of a model of care that is tailor-made for patient and family that is uncoloured by personal perception.

The initial assessment of the needs of patient and family is a crucial time of establishing trust and defining a culturally appropriate plan of care for this unique family unit of patient and main carers. This meeting offers the opportunity for a social assessment to



be carried out. 'Palliative care' has been defined in Chapter 2 according to the World Health Organisation (WHO, 2003) and includes the sentence "impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".

Table 2 at the end of this chapter represents a proposed assessment plan with prompts to assist the nurse in the initial assessment of needs of patient and family. The initial assessment is crucial to establishing trust between migrant family and the palliative care nurse. The migrant family may be anxious about the cultural and religious needs in end-of-life that are a priority at this time and that they want to communicate to the nurse and know she understands their position. Language may be a difficulty that adds to their anxiety about meeting the palliative care nurse. This anxiety and language difficulty could inhibit the migrant family from expressing their needs and putting forward their queries regarding resources and management of technical details important to care. The initial meeting to assess the needs then is crucial to establishing a good working relationship with the family and empowering them to continue communication with the nurse whether it is personally or through an official interpreter.

Oliviere et al (2000) discuss the potential value of using eco-maps in assessment that creates a picture of relationships and kinships, supportive groups and social service agencies who are involved with them. Figure 4 is an eco-map created for Salie and his family.

The New Zealand Palliative Care Strategy (Ministry of Health, 2001) outlines the need for care co-ordination that is culturally appropriate and this has seen the creation of the

position of 'co-ordinators' in palliative care facilities and the employment of nursing personnel in this role. The role covers assessment and negotiation around a suitable plan of action and certainly can spell the partnership plan of involvement of nurse practitioners with family, extended family and cultural community in palliative care. Networking with community organisation such as the Migrant Centres can provide valuable resources for migrants new to New Zealand society, in need of liaison with cultural and religious community.

Continued assessment and negotiation creates a culture specific model of care to each unique person and family and negates the practice of stereotyped nursing care, a result of assumptions made from previous experience and practice, the crux of the patient centred approach and cultural safety in practice.

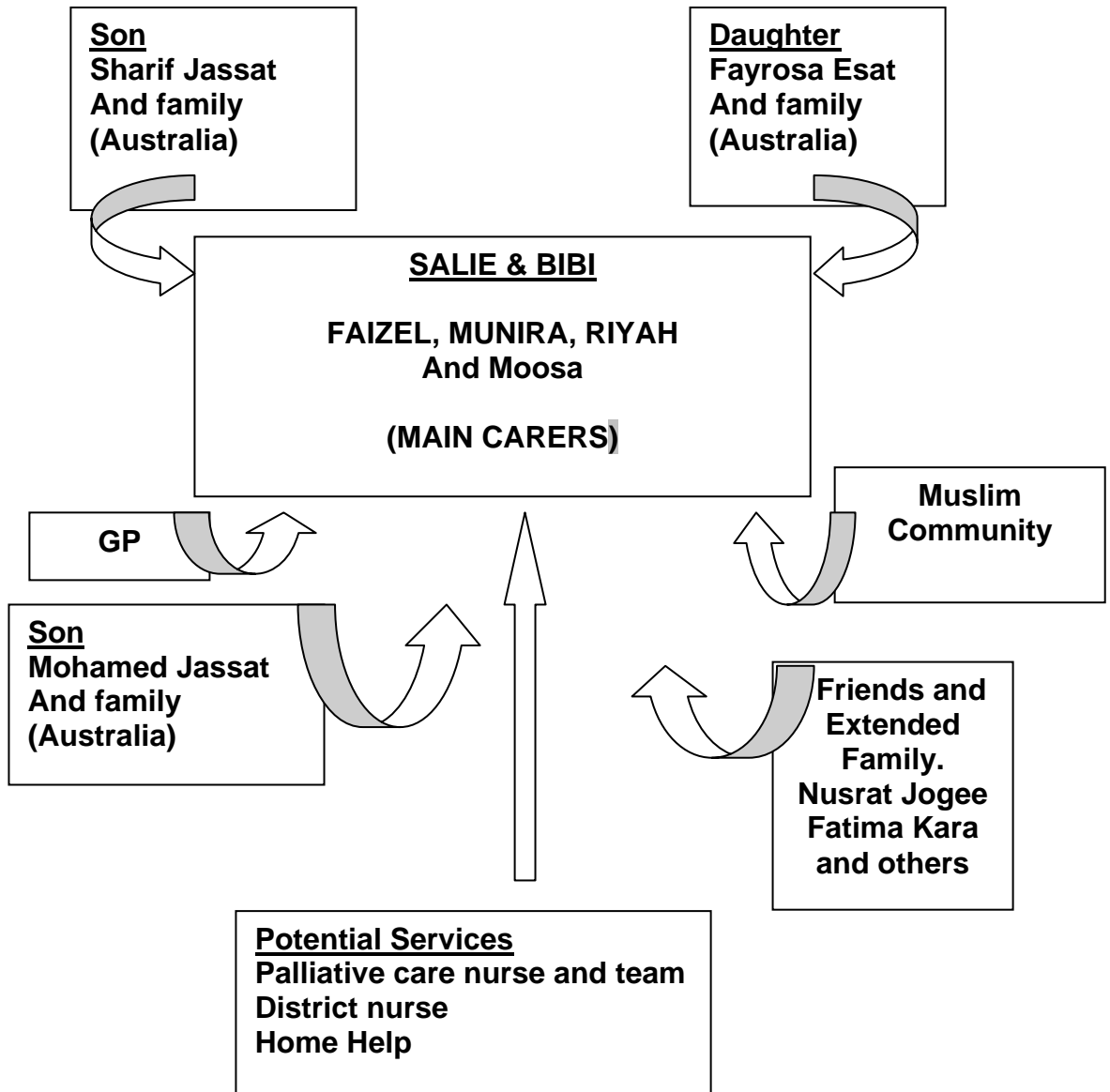
**Table 2 Care and Needs Assessment**

*Proposed plan for assessment of needs and care for migrants.*

<b>Special Needs</b>	<b>Contact Person</b>	<b>Suggested Prompts</b>
<b>Carer Preference</b> Social factors	- Family - Extended Family - Community contacts	Is there a family member who will be the main person responsible for care? Will there be support from extended family? Are there links with a religious, cultural or social community who can support the family?
<b>Communication</b> - Main carer /liaison - Language	Designated Family member Support Family member Other family members	Would you like us to discuss medical information with a particular family member? Are there other family members who we need to consult with regarding care? Is there adequate support for main carer to maintain own role in family? What is the language used in the family? Can the patient speak English? Is the main carer able to speak and understand English?
<b>Community Involvement</b> - Social - Religious	Social contact Religious authority Migrant Centre liaison	If community links are important for support, do you know someone who you would like us to contact? If the person is new to country and community, then ask if contacting the Migrant Centre Liaison person to establish links with support meets with their approval?
<b>Palliative care nurse</b> - Hospice - District Nurse	Advisory Community care Inpatient care for crisis management	If extended family and support structures are adequate, what level of care would be appropriate? This can be increased as required. If there is a crisis, would it be culturally appropriate for admission to a in-patient facility?
<b>End-of-life care</b> - Carer - Place - Support and assistance	Family members Home Healthcare facility	If the level of care by family increases, will the main carer continue in this capacity? Are there other family members who could assist the main carer? Is there a possibility that the family would agree to professional assistance or admission to a care provided facility for this increase level of care?
<b>Religious needs</b> - Prayers - Rites - Spiritual guidance - Religious environment	Who can provide for these?	Are there special religious practices that need to be arranged? Is there a special religious person who needs to come regularly to look after religious needs? Which place of worship would this person come from? Is there a preferred person?
<b>Cultural specific and family needs</b> - Food - Traditions - Practices	Family	Are there special foods that are more appropriate considering the normal diet of the family? Would the family be able to provide this? Are there any traditions that cover eating and diet that need to be observed? Are there other traditional practices that are important to be included in care?

**ECOMAP FOR THE JASSAT FAMILY**

**Identifying Networks**



**Figure 4 Ecomap for the Jassat family identifying support networks.**

## CHAPTER 7

### **7.0 THE IMPACT OF THIS CASE STUDY**

*We shall not cease from exploration*

*And the end of all our exploring*

*Will be to arrive where we started and know the place for the first time.*

T.S. Eliot (n.d.)

#### **7.1.0 Migrant families as recipients of palliative care**

I set out in Chapter one to explore cultural safety in the realms of practice as a crucial concept in care of migrants in palliative care. This intention, as one of the aims, has been fulfilled and showcased by the research and narratives of the family who participated in the study. The family of this case study had a well-developed sense of who was going to care for their father, who was community to them and what their needs were to proceed from point of discussion. Granted that this sense of direction was heavily influenced by cultural and religious considerations, their social adjustment to a new country as migrants enabled them to adhere to their preferences in palliative care without being judged.

Nurses in palliative care are in the unique position of being able to negotiate how much care is needed and how to maintain the delicate ratio of professional to family care in order to allow family autonomy, family satisfaction and cultural and religious rites to be unhampered. This negotiation and balance requires sensitivity that stems from awareness of the pre-eminent position of family and a perspective of sole rights to care

for their loved ones in end-of-life situations with only background support from nursing and other health professionals. As in this case, the community who rose to the occasion of support came from extended family and a strong religious affiliation at their place of worship.

The boundaries of cultural safety in nursing practice need to be acknowledged by all nurses as including all cultural groups in New Zealand society. The model of cultural safety in practice recommended by the Nursing Council of New Zealand has implications for nursing practice and care that involves all cultural perspectives. It underpins the whole gamut of cultural care on empathy and safety care and unequivocally focuses on the inner attitude outweighing the use of ethnographic lists and questionnaires on patients as 'band-aid' strategies. Cultural safety can best be achieved by negotiation, compromise and an agenda that enables the families the opportunity to be the 'Florence Nightingales' and 'knights in shining armour' to their loved ones in end-of-life. The result could be an increase in migrant families accessing palliative care services as specialised to their circumstances.

### **7.2.0 Palliative Nursing Care Today**

As a nurse educator in palliative care I wanted to capture the experience of palliative care as experienced by a migrant family whose socialisation to New Zealand was also in its initial stages. The case study of the Jassat family highlighted challenges that coincided with the key areas that were set out in the aims. Palliative nursing care is provided from many healthcare facilities and the level of care is at variance with resources available at each location or organisation. To recap, palliative care for migrants could benefit greatly from negotiating a greater degree of involvement from

extended family and their cultural/religious community. To achieve a model of nursing care that walks a path with extended family and cultural community support is an important ingredient especially in the care of migrant families. To achieve this model of care, 'impeccable assessment' (WHO, 2003) that includes culture and religion specific information is vital. Eliciting this information can be accommodated by asking the right questions in a culturally sensitive manner. Then implementing the outcomes of assessment can be in a culturally sensitive approach.

Continued negotiation around these points may assist in maintaining a balance of care between family and palliative care service that is appropriate for patient and family. The use of ecomaps at initial assessment could be instrumental in identifying the supportive structures for the family. Continued assessment and negotiation creates a culture specific model of care to each unique person and family and negates the practice of stereotyping, a result of assumptions made from previous experience and practice, the crux of the patient and family centred approach.

It is true that needs and social circumstances of migrants will vary enormously regardless of their cultural preferences for care. Palliative nursing care could follow the tide line, keeping to the edge of negotiated care without assuming a controlling approach to care. In the continuum of involvement, little or just a 'presence' is a reflection of culture specific and safe care where just 'being there' offers support, empowerment and confidence in their care of a loved one. Nurses in palliative care can still practice in a relationship of trust with migrant patients and provide a service of support that encompasses information supply in an unbiased way, choices without

judgement from professionals on right or wrong, a presence that is comforting and a readiness to ‘get their hands wet’ if and when required.

Merits for nurses of adopting cultural safety as an integral part of palliative nursing care practice include enhanced working relationships with all patients and families, achievement of a global awareness of cultural perspectives and a sense of value of personal culture and heritage.

Merits for palliative nursing care are the increased access by migrants of palliative care services, increased ability of palliative care nurses to work effectively with migrant families in end-of-life illness and more cohesive teamwork in a culturally diverse team of nurses.

### **7.3.0 Palliative Care Education for Nurses**

The intended use of the outcomes of this thesis was in education for nurses, which will be the major thrust of disseminating the information gained. It became obvious to me how much the cultural and religious factors shaped the model of palliative nursing care that this migrant family were active partners in. Pluralism is a feature of our New Zealand society today and exists in both our patient population as well as among health professionals. The reality today is that nurses in palliative care facilities are from diverse multicultural backgrounds. If palliative nursing care is to aspire to optimum levels of being accessed by patients and families then efforts to understand each other in the nurse/patient/family relationship is not only desirable but also essential. Education will be an important instrument to assist in this process, utilising the outcomes of the research in this thesis.



If the model of care is to be flexible and assessment of needs around available support from extended family and community is to be a major consideration in this process than palliative care education will have to travel the same path and contain components of cultural safety in care. Kawa Whakaruruhau (Ramsden, 2000), that is outlined in Chapter 2 is about “ protecting people from nurses, from our culture as health professionals, our attitudes, our power and how we manage these things unintentionally or otherwise”. In its naïve meaning it includes powerful but well-intentioned approaches that are insensitive to the subtleties of cultural and religious dictates. The need for nurses to develop a non-judgemental attitude toward unfamiliar beliefs and practices by first starting with their personal being can be initiated in education programmes for undergraduates as well as postgraduates with groups of students, inviting them to contemplate their cultural persona and inviting them to share their stories in class if they so wish. Classes with a multicultural attendance could present a particularly rich learning experience for nurses. As students and teachers extend the parameters of a new knowledge based on personal exploration, cultural awareness grows to include an understanding of differences between people that are unique, rich, natural, complementary, educational, humanising and enhancing to individual esteem. The new knowledge works to inform and foster valuable nurse-patient relationships, assist the nurse to bracket her personal culture around assumptions and preconceptions and practice in a culturally safe manner in all health situations especially end-of-life illness. The essential positive element that connects the nurse to the patient in a helping role is empathy and this is borne out of an understanding of the other’s situation from an unbiased approach

Another strategy that has tremendous value in education is the sharing of stories by migrant families who have experienced an end-of-life situation in the family, in a caring environment created by nurse educators for nurses. Again the personal narratives of families have very poignant messages that remain long after the sessions are over. I have found that there are many families who reach a certain stage in their bereavement when the need to tell their story for the good of nurse education, serves a purpose in their grief process. Care of both speaker and audience needs sensitivity around time and the nature of questions that may eventuate and the ensuing feelings evoked by memories that may necessitate guidance or counselling.

Migrant nurses could also benefit from education on cultural safety, which could assist them in their working relationships with other professionals and patients of different cultures. It could also assist in empowering them in their quest for understanding and acknowledgement in the professional team around role boundaries and advocacy difficulties should they arise.

#### **7.4.0 Further Research**

The migrant experience presented in this case study cannot be extrapolated to the experience of every migrant family. To follow this practice would be a gross act of stereotyping, a practice that is denigrating to the person, and damaging to interpersonal relationships with dire consequences on the experience of palliative care in end-of-life illness. Sowell suggests, “where the implications of a belief can be tested against empirical evidence then it must be done and the belief rejected if it proves inconsistent with the facts” (Sowell, 1994). This statement exposes the potential for more research

on migrant families in palliative care with this study serving as a precursor and in particular the use of multiple case studies as an exemplary method of showcasing the migrant experience and which will be one way of evaluating the effectiveness of the cultural safety model.

I concur with the view that there is an absence of evaluation of the cultural safety approach to care in nursing practice that was identified by Richardson (2003) and a need to define a means of evaluation of this approach as an outcome in nursing practice has yet to occur. Since engaging in case study research, I believe that multiple case studies can be utilised as a means of evaluating culturally safe care.

The use of Nvivo as a tool to categorise and name statements made it easy to begin and record the analysis of the data. However a minor difficulty I encountered was the decontextualising of statements in a category or node, which sometimes necessitated reference back to the original transcripts to understand the meaning especially when statements co-occurred in more than one category.

#### **7.5.0 My Reflections on the Research**

As I reflect on the whole process of carrying out this case study research I recollect the interviews with the Jassat family with warmth and admiration for the love of their father that made this research possible and the courage to tell their story in bereavement in honour of Salie. Their stories have empowered me to complete the research and record the outcomes for nurses in education. Case study research gives families the opportunity to tell their stories in a way that preserves the reality of the situation.

My intention was to record the 'voice' of the migrant family and I believe that in using the case study approach this has been achieved. The Jassat family's experience of palliative care illustrated palliative nursing care in practice that was culturally safe for this family. This thesis reinforces the practice of cultural safety and invites nurses to extend the existing model to include 'reflexive bracketing' as a conscious step in achieving cultural safety in practice.

My experience throughout the journey of this case study research has enriched my perception of migrant families in their culturally focussed care of a family member in end-of-life illness. As a nurse educator and a migrant with an ethnic background I view cultural safety in palliative nursing care as a major component in education and have a personal interest in facilitating the classroom learning around this topic, using the insights gained from personal experience and the case study of the Jassat family.

What is significant for me is that this thesis has realised my personal quest for cultural safety to include migrants and all cultural denominations in New Zealand. As a migrant nurse writer I have satisfied a need to verbalise my experience and feelings in a manner that can be of benefit to others. The case study provided a prolific illumination of the exploration of the concept of cultural safety as it applies to New Zealand society fourteen years after its creation as a model for the Nursing Council of New Zealand *Guidelines for Cultural Safety in Nursing and Midwifery Education* (2002). Whilst following a personal ideal in professional development I believe the aims of the thesis were explored and met with significant outcomes for palliative care and nursing education.

## **Appendices**

Appendix 1

**Head office:** 441 A Mt Eden Road  
**Postal address:** P O Box 67 138,  
Mt Eden – 1030  
**Communications:**  
Phone: (09) 638 3463  
Fax: (09) 638 3462  
Email: anil.t@assuredirections.co.nz

26 March 2003

Yvonne Bray  
Tutor/Co-ordinator  
Palliative Care Education  
Goodfellow Unit  
Department of General Practice and Primary Healthcare  
University of Auckland

Dear Yvonne

**Culture-specific counselling support for  
research participants**

Further to our verbal understanding this letter is to confirm that if required and/or upon your request, I will provide culture-specific counselling support to your research participants, if any issues of grief, bereavement or other emotions come to the surface while you are conducting the proposed research project.

Provision of such counselling would be discussed with Assured Directions on a case by case basis around time availability, location of counselling, actual costs incurred and any other factor unique to the nature of your research e.g: interpreter for the languages other than the one spoken by the counsellor etc.

I look forward to being of some assistance to you through this research project.

Sincerely yours

Anil Thapliyal MNZAC, MFCANZ  
Family Therapist  
Assured Directions Limited

Appendix 2



SOUTH AUCKLAND HOSPICE  
CHARITABLE TRUST

Yvonne Bray  
Goodfellow Unit  
School of Population Health  
University of Auckland  
Private Bag 92019  
Auckland

31 August 2003

Dear Yvonne,

Thank you for your inquiry re counselling support of the subjects of your study.

I would be glad to offer counselling support to any of the subjects of your study who have been connected with South Auckland Hospice if the need should arise.

Please feel free to contact me at any time.

Yours sincerely

A handwritten signature in blue ink that reads "Lynne Condon".

**LYNNE CONDON**  
**COUNSELLOR**

## Appendix 3

*Please include the reference no. and study title in all correspondence/telephone calls.*

### **Auckland Ethics Committees**

Private Bag 92522  
Wellesley Street  
Auckland  
Delivery Address:  
C/O Ministry of Health  
3rd Floor, Unisys Building  
650 Great South Road, Penrose  
Phone (09) 580 9105  
Fax (09) 580 9001  
Committee X Email: pat\_chainey@moh.govt.nz  
Committee Y Email: yvonne\_erixon@moh.govt.nz

15 September 2003

Ms Yvonne Bray  
43B Peary Road  
Mt Eden  
Auckland

Dear Yvonne

**AKY/03/08/196 A migrant family's experience of palliative nursing care in New Zealand: PIS/Cons V#3, 1/07/03**

Thank you for your amendments received 1 September 2003.

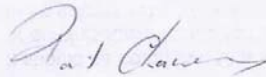
We are pleased to inform you that this study has received ethical approval until 1 September 2004. Please notify us when the study is completed and provide an end of study report for review by the Committee.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider, within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

If the study is not completed by the above date and you wish to extend the date, a progress report is required by 15 September 2003 and a blank form should come off our database for completion and return to the Committee. However, it is your responsibility to ensure that a yearly progress report is submitted to the Ethics Committee.

The Committee wishes you well with your research.

Yours sincerely,



**Pat Chainey**  
Administrator



Appendix 4

VICTORIA UNIVERSITY OF WELLINGTON  
*Te Whare Wananga o te Upoko o te Ika a Maui*



GRADUATE SCHOOL OF NURSING & MIDWIFERY

**CONSENT TO PARTICIPATION IN RESEARCH**

**Title of project: A Migrant Family's Experience of Palliative Care Nursing in New Zealand**

I have read and have understood an explanation of this research project that was given to me. I have had an opportunity to ask questions and have them answered to my satisfaction. I understand that I may withdraw (or any information I have provided) from this project at any time.

I understand that any information I provide will be kept confidential to the researcher, the supervisor and the person who transcribes the tape recordings of our interview, the published results will not use my name, and that no opinions will be attributed to me in any way that will identify me. I understand that the tape recording of interviews will be electronically wiped at the end of the project unless I indicate that I would like them returned to me. The written texts will be used in the report and in subsequent publications as case studies but my name will not be used and any other identifying information will not be used. I also understand that the texts will be kept in locked storage for a period of ten years.

- I understand that I will have an opportunity to check the transcripts of the interviews before publication.
- I understand that the data I provide will not be used for any other purpose or released to others without my written consent.
- I would like to receive a summary of the results of this research when it is completed.
- I agree to take part in this research

OR I agree that \_\_\_\_\_ who is under my guardianship,  
may  
take part in this research.

signed: .....

Name of participant: .....  
(please print clearly)

Date: .....

## Appendix 5

VICTORIA UNIVERSITY OF WELLINGTON  
*Te Whare Wananga o te Upoko o te Ika a Maui*



### GRADUATE SCHOOL OF NURSING & MIDWIFERY

#### **Participant Information Sheet**

**Study:** A Migrant Family's Experience of Palliative Nursing Care in New Zealand

**Researcher:** Yvonne Bray: Student of the Graduate School of Nursing & Midwifery, Victoria University of Wellington

I am a student studying for an MA (Applied) in Nursing at the Graduate School of Nursing and Midwifery, Victoria University of Wellington. As part of this degree I am undertaking a research project, which explores the migrant cultural experience in Palliative Care nursing in the New Zealand context. Palliative care in this project is the care of a person in end-of-life illness and his/her family.

I would like to invite three participants from a migrant family who have experienced palliative nursing care for a family member in end-of-life illness to participate in this study. I wish to recruit one member from each of three generations, i.e. a child over 14 years of age, an adult and an elderly person, with the ability to speak and understand English for the study. Participants will be interviewed twice for a period of 60 – 90 minutes. The interview will be audio-taped for convenience and the tapes will be treated in accordance with privacy requirements.

Participation is voluntary and you may withdraw from the project at any time.

All material collected will be kept confidential. No other person besides my supervisor, Rose McEldowney, and me will see the case studies as personalised to you initially, or hear the tapes before transcription of material or identity and confidentiality has been maintained. The tapes will be securely stored in the office of the researcher. The thesis will be submitted to the Graduate School of Nursing and Midwifery, Victoria University of Wellington, and subsequently lodged in the University Library. It is intended that one or more articles will be submitted for publication in scholarly journals and in these publications all material will be confidential. Transcribed written texts and taped conversations will be destroyed ten years after the end of the project.

Describing the experience of palliative care nursing of a family member may cause feelings of discomfort and distress for you. If this should happen, counselling assistance if needed can

be accessed from the family therapist at Assured Directions on discussion with the researcher.

This study has received ethical approval from the Auckland Ethics Committee.

If you have any questions or would like to receive further information about the project, please contact me at 09 3737599 ext. 86082 or my supervisor, Rose McEldowney, at the Graduate School of Nursing and Midwifery at Victoria University, P O Box 600, Wellington, phone 04 463 5363.

If you have any queries or concerns regarding your rights as a participant, you may wish to contact the Health Advocates Trust, on 0800 555 050 Northland to Franklin.

Yvonne Bray

Signed:

Date:

## Appendix 6

**Sent:** Friday, March 21, 2003 2:34 AM

**Subject:** A message from Salie Jassat

Thursday 20 March 2003

IN THE NAME OF ALLAH, MOST GRACIOUS MOST MERCIFUL!

Assalamu alaikum to all of my dearest beloved family and friends wherever you are in the world today.

It appears My Beloved Allah is calling for my company as I have spent a good 70 years with every single one of you who I love so very much, I know that you all must be feeling very sad and find this hard to take , but I tell you from the bottom of my heart that I am brave (Have you ever known Salie to be scared) and have accepted my fate from my beloved Allah, I have shared the most wonderful life any man could ask for and I have no regrets, how could I ? when I have lived a life with people like you that I know and love , to all of you from all across the globe your duaas and prayers, the e mails, the phone calls they never stop Thank You, I know where ever you are I am in your thoughts as you are in mine!

All of you young and old have heard uncle Salies stories and know now that I am ready to go and share them with all the people up there, know this Your uncle Salie will still be telling his stories in heaven God Willing , and I will be there waiting for you, I need to help the angels to plant fruit trees and chillies (I know the hunting and fishing up there is great) so I can share them with you again one day. To all those that I didnt get a chance to give a little something to, remember one day when we meet insha Allah I will fulfil my dream of sharing a little something with all of you.. To My Beloved Family and friends, all I ask of you today is to say a little prayer that I may one day, peacefully reach THE HAPPY HUNTING GROUNDS and My Beloved Allah!

During my life, and you all know how life can be, I may have offended someone somewhere, I may have told you a story of how I killed a Lion with my bear hands, or maybe I swore or told you your fortune, find it somewhere or somehow in your heart to forgive me as I need to meet my maker with a clean slate. Remember all I ever wanted to do was to make you all smile and appreciate life the way I do! Forgive me please, I am only a man! A man with a wish to go with your love and most of all your blessings!

Which man can boast of wonderful parents a wonderful wife, wonderful kids, grandkids, wonderfull brothers, sisters, cousins, friends, acquaintances and experinces. I know I can!

So my friends and family this is not a goodbye but rather adios! I will be waiting for you all inshaallah and will be canvassing for all you lovely people to be close to me and if I have my way, we will all be together sharing our good times again!

Many of you would have wished that I was close to you in My beloved home town Bulawayo, But I have heard a story from the Hadith (our Beloved Nabi was once delivering a sermon at the funeral of a Sahabah, and the other Sahabah asked , Oh Prophet of Allah, This Sahabah was born in Mecca and lived there all his life, is it not better that he should have died in Mecca in his beloved hometown, and our Prophet answered "Oh my dear people, Allah has promised for those who die away from their hometown Janaat the distance from their hometown to their death place, So it may be that My beloved Allah has taken me 25000 miles away from you all for surely he knows that I needed that space to accomodate you all one day Insha Allah. (God Willing)

Just Remember Uncle Salie will always be RIGHT ON TOP OF THE WORLD

I love you all, Khuda Hafez

**Salie Jassat**

Please print or forward this email to all who know me, so that inshallah it may reach all those people that I have met in my lifetime and if they dont have an email or a fax tell them you have this message for them." I love you all" It is my wish that this message be placed on every Noticeboard of the masjids in my beloved Country in Zimbabwe.

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