#### Science and Mathematics Education Centre

## A PHENOMENOLOGICAL STUDY OF THE HEALTH-CARE RELATED SPIRITUAL NEEDS OF MULTICULTURAL WESTERN AUSTRALIANS

THE REVEREND GEORGINA HAWLEY

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#### **ABSTRACT**

This study was designed to identify the spiritual needs of multicultural Australians with a health problem, in order to understand the educational implications for health care professionals. The rationale for the research was supported by the Australian Council for Health Service (1997) requirement that health care professionals meet the spiritual needs of their patients and clients'. At the commencement of this study, no research had been published on what these spiritual needs might be.

To discover what health care professionals needed to be taught in order to meet the spiritual needs of their patients, I required a suitable group of patients. Then, after identify their spiritual needs, I wanted to explore ways in which these needs could be met. For this to occur, I also needed to identify factors that would fulfill patients' spiritual needs or prevent them from being met. This research proceeded in two stages. The first involved collecting data from all spiritual groups in Western Australia. The second involved the recruitment and interviewing a small number of ex-patients to gain their perspective of health care related spirituality and needs.

To gain data about the various spiritual groups in Western Australia, I wrote to all organisations and associations, asking for information and reference material. This data was analysed using HyperResearch (1995), and themes common to all spiritual groups were developed. The inter-relationship between these themes provided the framework for an emergent model of spirituality.

For the second part of the research which involved a case study of health care patients, a qualitative methodology was used. This approach enabled me to explore the phenomenon of spirituality from the perspective of eight participants, which involved identifying their spiritual needs, the care they desired, and the rite of passage they underwent when receiving health care. The qualitative methodology enabled me to explore the subject from a sensitive holistic perspective, and to protect the integrity of the participants. I wanted to know what patients understood about their spirituality and how spiritual care could be implemented not only in clinical practice but also into health care education programs. The participants' detailed subjective experience was especially important, because I wanted to know how they identified their spiritual needs, how they had requested their needs be met by health care professionals, and the extent to which health care professionals had reacted to those cues.

I formulated an 'interpretive phenomenology research' design based on the philosophical writings of Heidegger and Bakhtin. Heidegger argued that people gain knowledge of a subject from their own subjective experience, and of the person being in their world (simultaneous past, present and future thoughts). Bakhtin stated that to bring about social change, the researcher needed to understand the social context of the people's language including their culture, politics, government-provided amenities (such as education and health care), employment and social interaction, both within and outside their communities in which they live.

The eight participants were interviewed a number of times in order to explore the phenomenon of spirituality beyond the notions already published in the literature (i.e. from multicultural Australian's perspective). They told of hospital or health care experiences that included:

- health care for childbirth, mental and psychiatric illnesses (depression, manic-depression, and anxiety), immunology (lymphoma), stroke, detoxification of alcohol, arthritis, coronary occlusion, hypertension, and peritonitis;
- surgical procedured/s such as repair of hernia, bowel obstruction, eye surgery, orchiopexy (removal of testes from inguinal canal into the scrotal sac), caesarian birth, appendectomy, and oophorectomy (removal of ovaries);
- treatments such as radiotherapy, chemotherapy, and physiotherapy; and hospital experiences in both large and small public and private acute hospitals, private and public mental health/psychiatric hospitals, intensive care and coronary care units.

These situations demonstrate the diversity of contexts which people want their spiritual needs met. The study revealed that it is not only dying patients who have spiritual need; spiritual needs exist in widespread ordinary conditions and across a wide range of health care services.

The eight participants - Ann, Athika, Garry, Red, Rosie, Scarlet, Sophie, and Tom (pseudonyms) - were drawn from many of the multicultural groups resident in Western Australia including Aboriginal, Chinese, English, European, Indian, and Irish peoples. Their spiritualities encompassed Judeo-Christian, Buddhist, Hindu, Pagan Romany, Society of Friends (Quaker), Humanist, Socialist, and Communist values and beliefs.

The results of the research give insight into the eight participants' perspectives on being a person, their understanding of spirituality, perceived spiritual needs, their desired levels of spiritual care, and the rite of passage they experienced when undergoing health care treatment in hospital. The participants' spiritual needs comprised of

four categories: 'mutual trust', 'hope', 'peace' and 'love'. The levels of spiritual care spoke of desiring were: 'acknowledgement', 'empathy', and 'valuing'.

Recommendations are given for health care professionals to provide spiritual care for the eight participants, and implications are considered for the spiritual education of future health care professionals in order to sensitise them to the wide range of health-care related spiritual needs they might encounter in local multicultural communities. It is recognised that the scope of the implications is contingent on further research establishing the incidence of health-care related spiritual needs among the broader population of multi-cultural Western Australians.

The richness and depth of the data and the very sensitive nature of the material that came from the eight people who shared their experiences with me has rendered this thesis an important document. The nature of the various incidents and situations they shared with me, I believe, demonstrated their preparedness to tell their story so that health care can be improved. On many occasions, I felt honoured that they had sufficient trust in me to enable them to report such deep and personal suffering. For example, Rosie told me of her mental torment and of not knowing if she was alive or dead; of how she burnt her legs to try to feel pain in order to see if she was alive. It was stories such as this that gave me the passion to write this thesis well in order to do justice to all people who want spirituality included in health care treatment.

### **ACKNOWLEDGMENTS**

This Ph.D. has been made possible by several factors, namely, obtaining scholarships, finding and having a phenomenologist supervisor who openly encourages creativity, and the participants. This in turn was facilitated by the need for more academic staff to gain their Ph.D. at Curtin University of Technology, which enabled me to reduce my teaching load from full time to 0.2 while undertaking the study. Without any one of these factors, the research would not have been possible to do in the way that it has been done. The initial scholarship enabled me to undertake full-time studies for three years, and the second the (Canon Lawton scholarship for the advancement of science and religion) enabled me to use the St Deiniol's Library in Wales (UK) to obtain literature unavailable in Australia.

The amount of time the participants freely gave me cannot be underestimated, as without the sharing of their experiences and stories with me, this thesis would not have expressed the depths of their lives. I need to offer my thanks and praise to my supervisor Dr Peter C. Taylor of the Science and Mathematics Education Centre at Curtin University of Technology (SMEC). Educationally Peter caused me to "pull up my socks", so to speak, and have confidence in my own ability to plan and carry out the research without asking him what I needed to do every five minutes. He also criticised my "very correct" academic style of science-orientated objectivist writing, and led me to the world of subjective and reflexive interpretative descriptions. It is this new style of writing that was necessary to explore the phenomenon of spirituality from a postmodernist perspective in order to allow the true expression of the participants' stories. Lastly, I could not have undertaken the research and writing without the support of my partner Bill, family and friends. Thanks to you all.

## **PREFACE**

As I descended the steps in the lecture auditorium, I noticed that the first-year students were a laughing, happy group, clearly outgoing with each other, irrespective of their obvious physical, racial and religious differences or beliefs. I had been asked to introduce the concept of spirituality to these students, and to help them understand the importance of spirituality in relation to nursing practice and in their own lives.

Standing in front of the class I introduced myself, and then began the session with them by saying "You have been taught about the physical, mental, and emotional aspects of people, and the relationship between these concepts and the health of people and nursing practice. I have been asked to come and discuss with you the phenomenon of spirituality, so that you can understand the importance of spirituality in relation to nursing practice and in your own life". I then asked them to form into buzz groups to discuss questions about the nature of spirituality, such as:

What is spirituality to you?

What would you mean when you say the word spirit? Do you think a persons' spirit may be individual? Or Do you think it may be something cosmic in nature?"

Where do you think we might get our ideas of spirituality?

#### Then.

Listening to the discussion I know that people have different ideas about spirituality and how that affects their lives...could you suggest some ways spirituality may affect a person's health and the health care treatment that a professional may prescribe for them?

In the ensuing lively exchange of views, the students expressed their ideas of the phenomenon of spirituality. It was my role as a lecturer to facilitate this discussion, and to help them understand how spirituality can affect the health of people and the nursing care that we may wish to give them. I discovered that there was a discrepancy between students' notions of spirituality and the nursing literature, which I had read when writing the basis of the lecture. Although some students realised the ontological significance of spirituality within nursing and the importance of understanding the patient's or client's notion, not all students had questioned their own beliefs or thoughts about ultimacy or their purpose in life, or their meaning of life.

Later, on returning to the nursing literature, I found that previous research had focussed mainly on patients from the Judeo-Christian tradition, and only to a small degree from people with Humanist beliefs. The students sitting in the lecture auditorium were from Indian, Chinese, Malayan, Vietnamese, Irish, English, and Australian parentage and backgrounds. Some of the beliefs they expressed that day derived from Buddhist, Hindu, Agnostic, Humanist, Eastern Orthodox, Jewish, Christian and non-Christian religions, as well as socialist and communist ideologies. Clearly, it was time to explore the phenomenon of spirituality from a contemporary multicultural perspective so that it would be more applicable not only for myself but also for the students I teach and for other health care professionals.

This study arose from my need to understand more about spirituality for my own teaching purposes. Although holistic care is advocated in the health professions, so that the body-mind-spirit of a person are simultaneously cared for as a whole, in my experience this frequently does not happen. I believe this to be a loss because the power of the mind is so strong and can be the factor that causes people to live or die. In Western Australia, among the Aboriginal people, there is a custom in their law of "pointing the bone". That is, an Elder of the community family can perform the spiritual ritual of pointing a bone at a designated person so

that they will die. Over the years, I have seen such deaths occur more than once or twice. The power of such a spiritual belief by the victim causes their mind to believe that they will die, and death does occur for that person. (For other Aboriginal spiritual beliefs, see writings by Tom in Chapter Five and onwards)

My previous research on prayer from the patients' perspective helped me realise the great extent to which prayer as a manifestation of spirituality can help ill people. However, for many seriously ill people the need for prayer must be recognised by another (such as a health care professional) so that appropriate prayer can be sought for the person. However, from my own experience of being ill I had become aware that I found it difficult for health care professionals to facilitate my spiritual needs. This raised the question for me of:

If I were not of the Judeo-Christian tradition (that is, the same as the hospital chaplains) how difficult would it be for me to get help for my spiritual needs?

I believe that in Western Australia among a large majority of health care professionals there is an acceptance that spirituality is the same as religion, when it really isn't. Having been involved in both nursing and chaplaincy, I have noticed that people and health care professionals readily assume that they are the same. For example, some students and myself were visiting a large teaching hospital in the metropolitan area, and I asked a group of nurses on one of the wards how the patients' spiritual needs were met. I was told that the hospital had its own chapel where people could pray and attend Church services and that there were Anglican and Roman Catholic chaplains on staff. The students' realising that spiritual needs were not religious needs and being dismissive of the two chaplains (priests) went off to explore the chapel.

Later that day I asked them about the visit to the chapel. One student replied, "It was real weird, you came in the entrance door in the middle of the body of the church and, at one end, was an altar with pews and the other end was exactly the same". On inquiring from the chaplain, I was told that the east end of the church was the Roman Catholic section with altar and pews, and opposite, facing the

west end, was the Anglican altar and pews. I went to see the chapel and I felt I was in a time warp; it was exactly how the students had described. I was seeing an English Military Chapel of the Second World War era, when the Roman Catholics would worship at one end and the Anglicans at the other, and "never the twain should meet". My difficulty was that I was not in a museum, but a functioning chapel in the late 1990s in a private hospital in a multicultural community. The students had quite a lot to say about the experience, but perhaps a question by one of the students says it all: "The chapel is OK if you are Roman or Anglican, but if I was a Muslim patient where would I go to face Mecca to say my prayers?"

Spirituality is not religion, neither is it multi-faith; rather, it is a complex dynamic concept which is both rapidly developing and essential in the discipline of nursing and other health professions, that is, in the science of health and education (Erickson, 1998). In my experience, difficulties in teaching spirituality arise from the immaturity of some students when they have not questioned their own beliefs or preconceived ideas; the unknown spiritual needs of multicultural and multiracial communities, and rapid developments in transpersonal psychology. Hence, I perceived an urgent need to identify the spiritual needs of multicultural Australians and to understand the implications for health care education.

The writing of this thesis has been developmental in nature. That is, the writing of chapters occurred in relation to my deliberations in exploring the phenomenon of spirituality. My first steps were confused and not clearly defined, as I could not fully understand the existing published literature on spirituality. Although I could understand the advantages of incorporating spiritual care into health care education and practice, I found some of the readings confusing and the phenomenon lacked clear definition for teaching. When I talked to possible research supervisors about the subject of spirituality, they too had difficulty in elaborating the phenomenon.

In order to more clearly understand the phenomenon, I developed a conceptual model of spirituality (in the first year of the study), which clarified the major components of spirituality and the interrelationships between them. This model is described in Chapter Two. Later, when teaching, I found the model to be useful for introducing and teaching spirituality to students in science and nursing, and to teachers of science. The model forms the basis of six questions that both practitioners and educators can ask in order to explore the phenomenon of spirituality.

A qualitative methodology was used for this research in order to explore spirituality from a sensitive holistic perspective, and to protect the integrity of the participants. The style of writing supports this approach by being both personal and narrative. (See Chapter Three) Qualitative research in education is appropriate, according to Erickson (1998), when we want to:

- Identify and understand change,
- Gain information in relation to the implementation of a strategy, and
- Identify the nuances of subjective understanding that motivate people in certain environments.

In this study, I wanted to know what patients and clients understood about their spirituality and how spiritual care could be implemented into education for health care professionals. The participants' detailed subjective experience was especially important, because I needed to know how they identified and requested their spiritual needs to be met by health care professionals.

When I commenced the study in 1998 I employed an epistemological viewpoint representative of what Denzin and Lincoln (2000) describe as the 'blurred genre' of the Fifth and Sixth Moments. As the study developed and data were generated, the emergent research became one with the Seventh Moment. In this way, the epistemology has sought to construct the participants' meanings of spiritual oppression from health care professionals, and to explore ways in which the "vulnerability and truth" can be "liberated" and patients spiritually "empowered" (Lincoln & Denzin, 2000, p. 1058).

In the main, I have used the first person voice when writing the thesis so that the sensitivity of the subject could be more readily expressed through this "softer" approach (Clandinin & Connelly, 1994). At times, the writing of this thesis has been difficult, not just because of the nature of the subject, but because the words that I was familiar with seemed inadequate for what was needed. Frequently, no words seemed to exist for me to realistically describe a behaviour or phenomenon (See Chapter Three). Poetry, sayings and markings that portray various aspects of spirituality have been used throughout the writing of the thesis. Some are drawn from historical documents, others from autobiographies; but all of them I have read at some time, and they came to mind while I was writing. I have used epigraphs at the beginning of some chapters (such as the one at the beginning of this Preface) to illustrate life experience scenarios that helped me stimulate and explore the avenue of a particular thought or theme. These sayings, poetry and epigraphs are written in the font Lucida Handwriting, to denote that I wrote them as part of my musings or reflections when conducting the study.

Although a well-developed literature review was conducted prior to interviewing the participants, the findings of the study caused me to look beyond my previous conceptual frameworks and explore new ideas. Two areas that I explore in the discussion chapter (Chapter 10) are the philosophical basis of spirituality, argued by Don Cupitt, and the cutting edge of both transpersonal psychology and philosophy, by Ken Wilber. Once I started to understand these new subjects, I was able to interpret the findings from a richer perspective. In order to reflect the developmental approach to writing the thesis, the writings from Cupitt and Wilber are not mentioned in the preliminary literature review (Chapter Two). Rather, they are found in the discussion chapter (Chapter Ten).

The thesis is divided into three sections. Section One consists of the chapters that introduce the research, that is, what I found when exploring the literature about multiculturalism in Australia and spirituality, the philosophical framework, and methodology. Section Two consists of the chapters that describe the selection of study participants, their interviews, data analysis and findings. The findings

include the participants' perspectives on being a person, their understanding of spirituality and identified spiritual needs. This is followed by an account of the different levels of spiritual care that the participants received or would have liked to receive. Next, is the journey or rite of passage that the participants underwent when receiving health care treatment and trying to have their spiritual needs met. Section Three consists of the discussion and recommendation chapters. Finally, the references, and appendices conclude the thesis.

## **CONTENTS**

ABSTRACT I

ACKNOWLEDGMENTS II

TABLE OF CONTENTS IV

SECTION ONE	THESIS FRAMEWORK	1
INT	MULTIRACIAL SPIRITUAL CARE IN AUSTRALIA RODUCTION STRALIA DEVELOPS INTO A MULTIRACIAL SO	2
	38-2000)	3
( , ,	Effect of Migration on Spirituality	10
	Implications for the Health Care System	11
NAT	TURE OF SPIRITUALITY	13
	Definitions of Spirituality	17
	Spirituality and Health Care	19
	Measuring Spirituality	21
	Manifestations of Spirituality	22
	Spiritual Needs of Health Care Patients	23
	Known Outcomes of Spirituality on Illness	28
	Multidisciplinary Approach to Spirituality in Hea	alth 29
STA	ATEMENT OF RESEARCH PROBLEM	31
• • • • • • • • • • • • • • • • • • • •	Purpose of My Study	32
	My Research Questions	32
OVE	ERVIEW OF THESIS STRUCTURE	33
CHAPTER TWO	CRISIS OF NOT KNOWING	34
-	RODUCTION	35
	ERSITY OF NATIONALITIES	36
	Location Of Spiritual Groups	37
	The Returned Material or Data	39
	Differences Noted in the Data	40
DAT	TA ANALYSIS	40
	Themes within the Data	42
	Inferences	44
	The Use and Meaning of God within the Data	43
	Stories, Legends, Myths and Truths	45
	Adoption of Truths and Beliefs	46

Rites of Par Inter-relation WOULD A MODE Words That Partice Valuin Adopte Interpre Suppo Challe Model Fit Further Ans	Inship between the Themes L HELP? It Could Portray the Model Process Ipating Ig Ing Ireting Ireting IngIng IngIngIng IngIngIngIng IngIngIngIngIngIngIngIngIngIngIngIngIngI	46 46 47 47 48 51 51 52 52 53 54 56 57 59
	HICAL FRAMEWORK AND RESEA	
DESIGN INTRODUCTION		60 61
PHENOMENOLO	cv	63
-	ology and Spirituality	64
	al Basis of the Research Methodolo	
Типоворию	al basis of the rescaled welloude	67
Peoples' Er	pistemology from Experience	68
Peoples' W	•	68
•	cance of Value in Peoples' Lives	70
	pility to Understand	71
	ve Phenomenology	72
THE STUDY ARG		74
RESEARCH DES	GN	75
Forms of D	ata	77
Data Analys	sis	78
Computer S	Software	79
Documenta	tion	80
Trustworthi	ness of the Design, Data Collection,	,
and Analys	is	82
Credibility		82
	relevance or transferability	82
Dependabil		82
Confirmabil		83
	PHENOMENOLOGY RESEARCH	84
	PR PARTICIPANTS	84
CHAPTER SUMM	AKY	86
SECTION TWO SELECTION O	F PARTICIPANTS, INTERVIEWS A	ND 88

CHAPTER FOUR, TAKING TIME TO SMELL THE ROSES	91
INTRODUCTION	91
SEEKING PARTICIPANTS	92
Purposive Sample	93
DATA COLLECTION	94
Interviews	97
Establishing Initial Rapport	101
Good Person Concept	102
Ethical Outcome	104
PARTICIIPANTS	105
SUPPORT INFORMATION	113
DATA STORAGE AND ANALYSIS	114
Finding of Exemplars	115
Coding of Data	116
Levels of coding and Analysis	116
Level 1	116
The meaning and use of codes	118
Level 2	120
Level 3	121
CHAPTER SUMMARY	123
DON'T THEY TAKE MY SPIRITUAL NEEDS SERIOUSLY INTRODUCTION	125 125
INTRODUCTION	125
PARTICIPANTS' BEING IN THEIR WORLDS OF	
SPIRITUAL AND HEALTH CARE EXPERIENCES	127
Assumption 1. That a person only knows a	bout
something in relation to their own subject	tive
experience	127
The Participants' Knowing of Cultural Worlds	127
The Participants' Familial Knowing	130
Sexual relationships	131
The Participants' Situational Knowing	132
Health care experiences	132
Spiritual experiences	135
THE INTERTWINING OF HEALTH AND SPIRITUAL	
EXPERIENCES	139
The Classification of Health Care Treatment	139
Emergency Treatment	140
Complications Suffered by The Participants	142
Personal Understanding of Situation at the Tim	
A (17)	144
Attitudes and Communication Skills	148
Insufficient Time Coupled with Poor Communic	
	150
Possible Reasons for Poor Nursing Behaviours	
Summary of Assertion 1.	153

	Assumption 2. When participants tell of the	eir
	present experiences, they will remember th	
	as well as be thinking about the future, as	
	this will be included in their subjective	
	experience of knowing.	155
	Having Been-ness	156
	Being Expectant	157
	- ,	
	Assumption 3. The participants will have a	
	underlying need. Or what is their problem	v?
		161
	CHAPTER SUMMARY	162
CHAPTER S	IX, THE MEANING OF SPIRITUALITY: AN	
INTERPRET	•	165
	INTRODUCTION	166
	PARTICIPANTS' DEFINIATIONS OF SPIRITUALITY	167
	DIFFERENCES OF SPIRITUALITY AND RELGION	170
	SPIRITUAL DEVELOPMENT	171
	SPIRITUAL NATURE	179
	Focus or Orientation	179 180
	Beliefs and Values Accessing their Spirituality	181
	Meditation	182
	Prayer writing	183
	CHAPTER SUMMARY	187
CHAPTER S	SEVEN, SPIRITUAL NEEDS OF TRUST, HOPE, LOVE	AND
PEACE		188
	INTRODUCTION	189
	SPIRITUAL NEEDS	190
	Mutual Trust	191
	Hope	193
	Love Peace	199 201
	Participants' Affirmation of the Spiritual Needs	205
	CHAPTER SUMMARY	206
CHAPTER	IGHT, DESIRED SPIRITUAL CARE	208
OHALIER E	INTRODUCTION	209
	SPIRITUAL CARE	211
	Levels of Spiritual Care	213
	"No Standard" of Spiritual Care	213

	Level of Acknowledgment in Spiritual Care	215
	Level of Empathy in Spiritual Care	217
	Level of Valuing in Spiritual Care	220
	PROVIDING SPIRITUAL CARE	224
	CHAPTER SUMMARY	228
		220
CHADTED	NIME THE DITE OF DACCAGE	000
CHAPTER	NINE, THE RITE OF PASSAGE	230
	INTROUCTION PLANTS	231
	RITE OF PASSAGE	232
	Realising Health Problem	233
	Recognisation Of Dissonance Between Usual	
	Feelings	235
	Asking for Spiritual Care	236
	Receiving Or Not Receiving Spiritual Care	238
	Reflection Of Whether Spiritual Needs Been M	
		239
	CHAPTER SUMMARY	243
	HREE DISCUSSION AND RECOMMENDATIONS FOI	₹
HEALTH CA	RE PROFESSIONALS	248
CHAPTER T	EN, POSTMODERNIST PERSPECTIVES OF SPIRIT	UALITY
		252
	INTRODUCTION	252
	CATCHING APPLES	255
	POSTMODERN CARE	257
	POSTMODERNISM PERSPECTIVES OF SPIRITUAL	LITY
		258
	Emergent Model of Spirituality	260
	Spiritual needs	261
	Desired Levels of Spiritual Care	263
	The Down Side to Postmodern Health Care	264
	CODA	265
		200
CHAPTER E	LEVEN, EDUCATING IN THE UNTAUGHT SUBJECT	OF
SPIRITUALI <sup>*</sup>	TY	267
	INTRODUCTION	267
	NEW PERSPECTIVE OF SPIRITUALITY	269
	PROVIDING SPIRITUAL CARE FOR THE PARTICIPA	
	THE TIERRO OF THE PARTICIPA	270
	Health Care Professionals Needing to Understand the	-
	Phenomenon of Spirituality	
	Meeting Spiritual Needs	270
	Desired Levels of Spiritual Care	273
	Desired reveis of oblition cate	275

Incompat	ibility of Health Treatment and Spiritual Belief	s 279
Professio	• • •	281
Spiritualit		282
	n to Improve Interpersonal Relationships Betware Professionals and Patients/clients	veen 284
Те	aching Communication And Relationship Skil	ls 284
		287 288
•		289
	<b>.</b> .	289
CODA		290
REFERENCES	:	294
APPENDICES		301
	1. Census List of Spiritual Groups	
• •	2. Norman Aisbett	
Appendix	<ol> <li>Letter To Spiritual Groups For Information</li> <li>Diagrams Of Relationships Between Them</li> <li>Journal</li> </ol>	
Appendix	6. Information And Consent Form	
	7. Coroners Case	
	8. Letter From Hospital	
	9. Letter Requesting Participants	
	10. Telephone Information	
	<ul><li>11. Questions</li><li>12. Letter To Participants With Transcript Of</li></ul>	
	Appendix 13. Field Notes	
	14. Example Of Coding By "HyperResearch"	
Appendix	15. Peer Review Of Coding Themes And Cas	ses
	16. Letter To Participants With Overall Finding	
Appendix	17. Essay on the Participants' Social Constru	ıct

## **SECTION ONE**

Section One comprises three chapters that provide an overview of the concepts of spirituality and multiculturalism, and the philosophical framework of a research design intended to identify the spiritual needs of culturally diverse Western Australians. This section introduces (1) the thesis as an interpretative study of multicultural participants who had a health problem, and (2) myself, as nurse, university lecturer and hospital chaplain. The identified problem, purpose of this study, and research questions are explained in the first chapter. The second chapter describes my crisis of not knowing about the spiritual groups in Western Australia, and also the extent of the different racial groups and cultures within the State. The chapter explains how I overcame the crisis by collecting and analysing material from the various groups. I also discuss how the information from the different spiritual groups caused me to question my own faith, and how I sought to resolve this state of spiritual distress. Chapter Three discusses the philosophical framework for the research design and the methodology. Although Guba and Lincoln's (2000) genre of Fifth and Sixth Moment are described in Chapter Three, this subtly changes through subsequent chapters, until in Section Three, I recognise that the epistemology has the hallmarks of the Seventh Moment.

## **CHAPTER ONE**

## MULTICULTURAL SPIRITUAL CARE IN WESTERN AUSTRALIA

#### INTRODUCTION

This thesis reports a research study that was designed to investigate the spiritual needs of racially diverse Western Australians, in order for health care professionals to facilitate spiritual care. This chapter traces spiritual roots and how, for a very long period of time, there were only two major types of spirituality in Western Australia. The first being the Aboriginal Dreamtime, and the second the Judeo-Christian tradition of the Anglo-Celtic settlers. The latter group of people became the ruling class of Western Australia and regarded the Aboriginal Dreamtime as heathen, and sought to convert them to Christianity (Kelly, 1990). I believe this created a precedence of spiritual domination that lasted for the next 150-200 years. For in that period of time Australia had a policy of allowing only those people who were similar to the Anglo-Celtic Judeo-Christians into the country. However, since the mid 1970s, Australia has been a multicultural nation, allowing people to enter the country who have been different from the ruling class. Although multicultural policies exist, very little has occurred to enlighten health care professionals of the spiritual needs of those patients and clients both within and outside of the Judeo-Christian tradition. This problem needs immediate attention as the present health care standards state that patients will have their individual spiritual needs met when receiving health care (Australian Council of Health Services, 1997).

It is anticipated that by discussing the two main facets of multicultural spirituality in Australia (i.e., multicultural and spirituality) a deeper appreciation will be gained. The first section of this chapter explains how Australia became a multicultural country, including migration policies and patterns and the effect of migration on spirituality. The second section discusses the nature of spirituality, definitions of spirituality, spirituality and health care, measuring spirituality, the known spiritual needs of patients and clients, and the responsibilities of health care professionals in relation to providing spiritual care to patients and clients. The final section includes the statement of the research problem, the research questions, and an overview of the thesis.

## AUSTRALIA DEVELOPS INTO A MULTICULTURAL SOCIETY (1788-2000)

Australia has been described in literature (in particular immigration brochures) as a "land of opportunity". Immigrants from around the world come here seeking a better life for themselves and their children. Religious freedom, economic opportunity, political refuge and better quality of life are the dreams of many new migrants (Australian Department of Immigration and Multicultural Affairs, 1997). With these dreams comes the expectation that employment will open the door to opportunity, and that hard-earned tax money will be used to provide children with quality education and health care, preparing them for the future (Bates & Lapsley, 1985; Grbich, 1999). However, the health status of all Australians is not equal (Bates & Linder-Pelz, 1988; Australian Bureau of Statistics, 1996; Peterson, 1994). Those who live in poverty and/or low socio-economic status experience substandard health care treatment, and subsequently suffer from poor health status (Bates & Lapsley, 1985; Australian Bureau of Statisitics, 1996; Mackay, 1993; Peterson, 1994). This is especially noticeable amongst Aboriginal and some coloured immigrant people (Bates & Lapsley, 1985; Mackay, 1993). Although ethnic and cultural diversity is not new to us, Australia has entered a state of

accelerated diversity, due to changes in the government immigration and refugee policies (Australian Department of Immigration and Multicultural Affairs, 1997).

Historically, health care in Australia was designed to serve a narrow set of interests: the middle and upper class white Anglo-Celtic immigrants and settlers (Grbich, 1999; Mackay, 1993; Peterson, 1994). According to Peterson (1994), health and power relations in Australia are in a critical condition. Therefore, politicians and health care executives and managers need to recognise the needs of our diverse multicultural population. For this to occur approaches to health care must become more inclusive. To achieve this, we (as a society and health care professionals in particular) must open our mind and spirit to a culturally diverse approach to health care, building on the strengths of the many cultures amongst our people. We need to come to know the various cultures and their embedded spiritual beliefs so that we, as health care professionals, can relate to the patient and client, including their spirituality.

Australia has not always been multicultural. The indigenous Aboriginal peoples of Australia occupied the land for centuries (at least 35,000 years ago) prior to the British invasion in 1788 (Mackay, 1993). At that time, the British government needed to settle in New South Wales (NSW) to provide prison facilities for convicts (Greenwood, 1955). The first so-called 'white' population comprised British soldiers, sailors, and convicts. In 1792, the British government opened NSW to free settlers, however only a very few came the following year. In 1806, "wealthy British gentleman farmers" were offered inducements by their government to come to Australia and settle and farm (Greenwood, 1955). These enticements included land and convicts being allocated to them for use as labour. This approach supplied the migration needs until 1830 when more skills were needed. In 1832, the British government offered trade and labour people of England, Wales and Ireland the opportunity to come to Australia as assisted British migrants (Greenwood, 1955). It was during this time that the Irish potato famine occurred, and some 55,000 Irish people immigrated to Australia (Larkins, 1983). During this period the Aboriginal population decreased to the extent that it

was assumed that they would die out. The European pastoral expansion of the 1820s-40s caused a rapid decline in numbers of Aboriginal people, violence may have taken hundreds or thousands, but the greatest killer was that of disease, in particular syphilis and tuberculosis (Greenwood, 1955).

During the gold rush years, large numbers of people entered Australia in the hope of finding gold (and fortune) for themselves (Greenwood, 1955). This unassisted migration overshadowed any official schemes regulating the types of people entering Australia, and accurate figures of the numbers and nationalities are not available (Larkins, 1983). This resulted in the Intercolonial Trade Union Congress demanding the cessation of all legal assisted immigration in order to protect Australian jobs (Greenwood, 1955). By the end of the 1880s, assisted immigration had all but been abandoned. In addition, the presence of large numbers of Chinese since the early 1850s (the goldrush years) and the South Sea Islanders of the 1860s introduced a new element of racial exclusion into future immigration policies (Greenwood, 1955; Larkins, 1983; Mackay, 1993).

The "White Australia Policy" was formally adopted under the Immigration Act of 1901, which aimed at excluding from Australia, coloured immigrants, particularly Asians (Larkins, 1983). The "White Australia Policy" had it origins in the anti-Chinese riots during the gold rushes. Prejudices were re-ignited when the Queensland (Qld) cotton and sugar growers began to use South Sea Islanders as labourers from the 1860s onwards (Greenwood, 1955). The policy became an objective of the early trade union movement that feared competition for jobs from Asians working for lower wages. In 1920, Prime Minister William Morris Hughes declared that "White Australia" was the greatest achievement since Federation (Greenwood, 1955; Larkins, 1983; Mackay, 1993).

A pattern of predominately white immigration, from 1901 to 1980, was designed to allow only those migrants who would assimilate readily into the Australian way of life and standards. In particular, those people who looked different from white Australians, such as Asian and "other coloureds", were excluded (Greenwood,

1955; Australian Department of Immigration and Multicultural Affairs, 1997). After Australian Federation, each British Commonwealth country maintained separate immigration departments, but the British Commonwealth set the overriding policy. In Australia, "The White Australia Policy" was the formal rule and power invested under the Immigration Restriction Act of 1901. The "English dictation test" become a means for immigration officers to exclude any person they deemed as undesirable from entering Australia (Mackay, 1993). The British Commonwealth, fearing that Asians would occupy Australia unless it was populated by Europeans, reintroduced assisted migration to Australia, and from 1905-14 nearly 400,000 Britons arrived. After the Second World War, a further 200,000 arrived, but assisted migration fell from favour during the Depression period.

The "White Australia" policy continued to be enforced until after the Second World War. However, a series of deportation dramas brought it into disrepute. Some Australians opposed the policy on humanitarian grounds and others believed Australia could not take stances on human rights in world forums while the policy existed. After the Second World War, the Minister of Immigration, Arthur Caldwell, initiated a huge programme of assisted migration and, from 1947 to 1960, some 1.68 million new settlers from England, Europe, Italy and Greece entered Australia (Australian Department of Immigration and Multicultural Affairs, 1999a). This time of assimilation for migrants, also applied to Aborigines, with many children taken from their parents and placed in orphanages to be educated in the English-Australian way (in some instances this continued until the mid 1970s). This generation of Aboriginal children have become known as the "Stolen Generation", as many have grown up not knowing their parents (Mackay, 1999).

When Britain gave India independence and withdrew military presence from Burma, the Anglo-Burmese and Anglo-Indian peoples of those two countries were offered residency status in either Britain or one of the countries of the British Commonwealth (Mackay, 1993). Some of these people went to Britain, others

went to Canada, and many settled in Australia. The highest proportion of the Anglo-Burmese came to Western Australia, as the Anglican Archbishop of Perth (Geoffrey Sambell) was very sympathetic to their needs. (This explains why WA has the highest percentage of people of Burmese origin of all States in Australia).

In the period 1960 to the 1970s, Australia offered tertiary education to selected English- speaking students from India, Malaysia and Hong Kong. This was known as "The Colombo Plan" (Larkins, 1983). One of the requirements was that upon graduation these students would return and work in their own countries. Although this did happen, their new education also made them eligible to apply for migration to Australia. This meant that, in the ensuing years, many former Colombo Plan students returned with their families to take up residency in Australia. In 1966 the door was opened to "well qualified Asians and their families who could be expected to integrate readily" (Australian Department of Immigration and Multicultural Affairs, 1997; Larkins, 1983; Mackay, 1993). In 1965 Aborigines were given wage equality (that is, the same wage as white Australians instead of their previous lower wage). However, the formal acknowledgment and recognition of the Aborginal people in Australia and granting of full citizenship rights did not come until after a referendum in 1967. To me, this is a long time to live in one's own country without any citizenship rights. By 1973, the last sections of the "White Australia Policy" were finally abandoned. From then on, the government immigration policies have not been concerned with the colour of the immigrant; though people must still fullfil certain criteria before being allowed to settle in Australia as a resident.

By the late 1970s, about 2.1 million immigrants had arrived since the first fleet in 1788, and the percentage of inhabitants born outside Australia rose from 14.3 in 1954 to 20.2 % (with the easing of the White Australia Policy and the entry of well-qualified Asians into Australian society). In the late 1970s, Australia accepted a limited number of Vietnamese refugees (Larkins, 1983), and since then has accepted 1500 refugees per year from Asian, African and European countries. Additional residency places to settle in Australia are available through the various

immigration policies and family reunion schemes (Australian Department of Immigration and Multicultural Affairs, 1999b).

It is really only since the late 1970s that Australians started to become open to the idea of more than one race having residence (Mackay, 1993). This change of thinking resulted in the Australian government formulating multicultural policies and recommendations in 1989 (Australian Department of Immigration and Multicultural Affairs, 1999a).

The political change to multiculturalism commenced in 1973, when the Federal Labour Government of the day encouraged minority groups to form state and national associations to promote the survival of their own language and heritage within mainstream Australian institutions (Australian Department of Immigration and Multicultural Affairs, 1999a). In 1979, the Federal Coalition Government initiated the passing of the Australian Institute of Multicultural Affairs Act, which established the Australian Institute of Multicultural Affairs, whose objectives included raising awareness of cultural diversity and promoting social cohesion, understanding and tolerance. This act was repealed by the Federal Labour Government in 1986, which, in 1987, created the Office of Multicultural Affairs in the Department of the Prime Minister and Cabinet. In 1989, following community consultation and drawing on the advice of the Advisory Council for Multicultural Affairs, the Federal Labour Government produced the "National Agenda for a Multicultural Australia", which had and continues to have bipartisan political support. The National Multicultural Affairs Council, which was established to review and update the agenda, found that much had been achieved and recommended further initiatives. Following the election of the Federal Coalition Government in 1996, the Office of Multicultural Affairs was absorbed into the Department of Immigration and Multicultural Affairs. The Parliamentary Statement on Racial Tolerance was endorsed and, in 1997, the Federal Government announced the new National Multicultural Advisory Council (NMAC). In May 1999 the Prime Minister launched the NMAC's report

"Australian Multiculturalism For A New Century: Towards Inclusiveness" (Australian Department of Immigration and Multicultural Affairs, 1999a).

According to the National Multicultural Advisory Council Report (1999b), Australian multiculturalism is a term which recognises the cultural diversity of the nation:

It accepts and respects the right of all Australians to express and share their individual cultural heritage within an overriding commitment to Australia and the basic structures and values of Australian democracy (p. 1).

The report also refers to the strategies, policies and programs that are designed to:

- make our administrative, social and economic infrastructure more responsive to the rights, obligations and needs of our culturally diverse population;
- promote social harmony among the different cultural groups in our society; and
- optimise the benefits of our cultural diversity for all Australians (p.1).

However, multiculturalism is still a relatively new and uncomfortable concept for many members of the Australian community (Mackay, 1993). As a multiracial society, Australians have been remarkably hospitable towards migrants. Although, there has always been outbreaks of racial prejudice towards the latest wave of immigrants — whether Greeks, Italians, Yugoslavs, Turks or Vietnamese (Mackay, 1993). However, the traditional Australian attitude towards migrants is that they have come here to become part of the Australian way of life and that, accordingly, they should be assimilated as quickly as possible (Mackay, 1993).

However, each new wave of immigration of non-European nationalities or cultures has been seen as being physically so different from Europeans as to make their assimilation difficult; their cultural heritage is assumed to be quite unlike that of traditional Australian racial groups; their spiritual and religious practices are scarcely understood; their attitude towards Australians is felt to be aloof and ungiving (often on the basis of the prejudiced stereotyping of 'inscrutable' Asian countenances) (Greenwood, 1955; Larkins, 1983; Mackay, 1993). It is by no

means only Asian migrants who stimulate such concern; it is extended to whatever race is the latest to arrive in Australia. For example, in 2000, the Australian government has offered temporary residency to males from Iraq who arrived illegally by boat seeking refugee status. Within three months of their placement into the community, it is already alleged by some Australians that these people are sending their government allowance back to their families in Iraq, and then seeking additional money, food and clothes from charities (The West Australian, Monday, 28<sup>th</sup> August, 2000). This so-called "double dipping" from Australia's purse is causing isolation of this group from the rest of the community (Channel 9 Television News, Monday, 28<sup>th</sup> August, 2000). This is of course was compounded by the fact that Iraq was termed "the enemy" in the Gulf War, in which Australian military fought. This pattern of behaviour is likely to continue until Australians feel comfortable and understand more about the Iraqis and/or the next wave of new and culturally different people who arrive in Australia.

## Effect of Migration on Spirituality

Due to the origin of the first white settlers to Australia, the first branch of spirituality that was practised in the new colony was that of the Church of England faith. Later, Roman Catholic, Protestant and Jewish people came with their faiths to Australia. This means that religious and spiritual minorities that are different from the Judeo-Christian traditions have become a continual focus of Australians' doubts and fears (Mackay, 1993). For example, many Australians believe that the growing Muslim community from Asia represents a threat to the harmony of Australian society because its values and customs are thought to be very different from those of the largely Judeo-Christian host community (Larkins, 1983; Mackay, 1993). These and other similar issues have become points for debate and discussion at all levels of Australian society, and have become very apparent prior to each Federal Election. Some people want to halt the immigration of Asians into Australia and, at the same time others say it is Australia's moral duty to further multiracial migration to Australia. Irrespective of which side of the

debate a person may be arguing for, the fact remains that Australia is culturally diverse.

The settlement of white Anglo-Celtic and the restrictive migration laws of non-Europeans into Australia causes this country to be unique, and is reflected in the nations' health care system and spirituality. That is, because the first white settlers in the country came from the United Kingdom (U.K.), the political, legal, health care, and religious systems also derive from the U.K. This 'oneness' with the U.K. exists to the present day, with many of our laws and health care management practices reflecting the traditional English Judeo-Christian way of doing things (Hawley, 1994; 1997a & b; Wallace, 1995).

## Implications for the Health Care System

The Australian Government established "The National Agenda for a Multicultural Australia" in 1989, that consisted of recommendations and policies to be incorporated in government bodies, legislation, and community life. However, my experience in health care has found these largely ignored and placed in the 'too hard basket' by many health care professionals and organisations.

Australia's health care system is in a state of flux; due largely to the downturn in worldwide economy, changes of government policy, and with lobby groups and individuals asserting their rights as health care consumers. This state of flux provides opportunities to resolve the present problems acing the health care system in Australia.

A common finding from demographic studies of minority groups in Australia is that economic stability coupled with racial or ethnic identification is strongly correlated with knowledge of health and access to health services (Australian Department of Health, 1998). People from minority cultures, especially refugees are far worse economically than other segments of society, with incomes considerably below the national average (Australian Bureau of Statistics, 1996). A

substantial percentage of these fast-growing ethnic groups live below the poverty level and consequently suffer from socially related health problems (Australian Bureau of Statistics, 1996; Australian Department of Health, 1998).

# Questions need to be asked as to why this may be. For example, are services to these groups inadequate?

One of the keys to developing a successful health care system would be to approaching health care education and practice from a more embracing multicultural perspective. That is, the awareness of the social inequalities that exist in society and the existence of these amongst people from different cultures. It is important that university lecturers and others who prepare health care professionals also recognise the full range of cultural values and beliefs of society when designing curriculum. The formulation of multicultural health care standards (that designate the type of health care to be delivered) will support our cultural diversity. In particular, both education and formulated health care standards would empower the poor of our society (in particular the Aborigines and non-European migrants), by recognising and respecting their cultural diversity.

Hospitals and health care organisations are microcosms of their surrounding communities, and reflect both their social and economic levels (Australian Department of Health, 1998). Therefore, to provide sufficient funding to the public system would allow an opportunity to address the health care factors that lead to diminished health (Bates & Lapsley, 1985). The public hospital system is an ideal arena for designing innovative and adaptable strategies for health, which reflect the cultural and social needs of minority and low-income populations. To include culturally diverse aspects of spirituality into that level of health care would likely improve the status of those recipients.

Little research has been conducted on cultural habits which may prevent or inhibit the utilisation of health care services by minority groups (Mackay, 1993; Peterson, 1994). In fact, no published research has been located which identifies the spiritual needs of multicultural Australians. Health care professionals would need to know these spiritual needs when recommending and/or planning health care, so as not to offend patients and/or clients by being inappropriate to their beliefs. For example, if a Muslim or Buddhist patient was dying, and health care professionals ordered extraordinary measures to keep the patient alive, it is likely that such care would be: inappropriate to their spiritual beliefs, wasted if prescribed or ordered, unethical in as much as it would infringe on the patient's rights, and an inefficient allocation of resources (Hawley, 1997b).

The nature of patients' and/or clients' contact with health services is probably the strongest factor affecting health attitudes and behaviour (Australian Department of Health, 1998). Therefore, it is essential that health care professionals offer a multicultural approach from the beginning in all parts of the health care system. In order to reach increasingly disadvantaged and disenfranchised people, health care education and practice needs to be culturally sensitive, comprehensive and flexible. A broad spectrum of services is needed that addresses multiple needs, and views people in the context of their familes and the family within the social construct of their community. The fact that a person's culture is dynamic and changes over time with exposure to other groups creates particular challenges for those designing programs for multicultural groups (Nigam, 1997). Competent, culturally sensitive professionals need to be recruited to provide health care for underserved groups and populations. Services, providers and delivery sites must reflect the cultural and social aspects of health that affect the population they serve. Medical, mental health, education and social services providers in health care must effectively coordinate services to provide high quality and continuous [spiritual] care.

#### NATURE OF SPIRITUALITY

Throughout the history of the world, there has been a great variety of spiritual groups with differing beliefs, symbols, and rituals, giving meaning and purpose for the people (of that stage in evolution of the world). All aspects of human behaviour have at some time or other been either a force of power or alternatively a taboo (Neilson, 1988). For example, at times food has been a source of power, offered as sacrifice and as appearement to gods. At times people have eaten or fasted, or abstained from certain foods at specific times and consumed these same foods at other times. Manifestations of spirituality have been observed in the behaviours of sleep, sex, childbirth, illness and death. Spirituality has also influenced the management of farming and fishing and the development of various governments' political and social policies (Neilson, 1988; Smart, 1971).

Literature reports the first spiritual groups as being of "phallic" nature (James, 1964; Neilson, 1988; Smart, 1971): that is, the deities were all polite names for the organs of procreation (both male and female). Later, the theory of sungods became popular, with every male divinity of the pantheon being an impersonation of the sun (if feminine then an impersonation of the moon). In this theory, Apollo, Hercules, Samson, Indra, Krishna, and even Christ were thought to be sun gods (James, 1964; Neilson, 1988; Smart, 1971). This theory was followed by "Euhemerism" – the theory that the gods and goddesses had actually once been men and women, historical characters around whom a halo of romance and remoteness had gathered. Later still, a school arose which believed in earth and nature spirits, including gnomes and demons and vegetation sprites. It was believed that these spirits and sprites had magic, which could be enlisted to help a person, or exorcised if the magic was hostile. Over the years, many writers have put forward various schools of thought and theories, each making the most of its own contention.

According to Smart (1971), pagan and religious beliefs have correlated to the psychophysiological development of human beings. That is, as the human brain has developed so too have people's ideas about religion and spirituality. In correlation with early humans came phallic ideas of religion, then spiritual

concepts concerning magic, and the propitiation of earth-divinities and spirits and, lastly, the belief in definite God-figures residing in a heaven. The main stages of this psychophysiological evolution began with simple consciousness, then the development of self-consciousness, and in recent times universal consciousness (Jaynes, 1976; Smart, 1971).

At the basis of the whole processes by which divinities and demons were created, and rites for their propitiation and placation established, lay the concept of fear. However, fear only became a mental stimulus at the time of, or after the evolution of, self-consciousness (James, 1964; Lewis, 1996). According to Smart (1971), in the period of simple consciousness, when the human mind resembled that of animals, fear indeed existed, but only as a mechanical or reflex protective instinct. Because there was no figure or image of "self" in the animal mind, correspondingly there were no figures or images of a human self that might threaten or destroy. Therefore, the imaginative power of fear began with self-consciousness, and from that imagined power has enrolled the whole panorama of gods, rites and creeds of religions down through the centuries (James, 1964; Nielson, 1988; Smart, 1971).

Historically, spirituality has been a vital and pervasive feature of human life (James, 1964; Jaynes, 1976; Nielson, 1988; Smart, 1971). To understand human history and human life it is necessary to understand spirituality, and in the contemporary world one must understand other nations' ideologies and faiths in order to grasp the meaning of life from perspectives often very different from our own. However, spirituality is not something that we can see. Nevertheless, it is true that we can witness manifestations of spirituality, such as temples, ceremonies, and religious art. Although these can be seen, their significance needs to be approached through the inner life of those people who use these external signs of spirituality

The philosopher and theologian, Paul Tillich (1955), urged people to view religion not as a separate component of human existence, but rather as the

dimension of depth in all human endeavours. His classic definition of religion was that which concerns people ultimately. That is, that which makes something religious is not that it is related to a particular being called "God", but because it makes them ask questions about the meaning of existence. To Tillich, "religion was not a special function of our spiritual life, but rather it was the dimension of depth in all of its function" (p. 42). This ultimate concern sensitises people to the fact that authentic spirituality is not confined to the life of theological institutions or churches. It is, instead, the response to what, at the level of its deepest mystery, is the creative reality and ultimate significance in our personal lives.

Spirituality is thus a mode of human thought and feeling that can be found in any human experience, and which prompts encounter with the ultimate questions about existence. On the other hand, secularisation refers to the historical process whereby institutional religion has become increasingly separated from cultural realism, such as law, science, psychology and medicine. Tillich (1955) alerted people to the fact that, although processes of secularisation may have separated certain areas of cultural life from the institutional church, this does not mean that modern society with a more global culture is devoid of genuine spirituality. According to Anderson and Hopkins (1992), and Cupitt (1982) postmodernist people engage in secular forms of spirituality through a range of cultural activities. These activities enable people to transform themselves in ways that enhance their participation in this source of ultimacy and, therefore, they deserve to be understood as important vehicles of modern spiritual life.

In this way, spirituality is a doubly rich and complex phenomenon. Not only has it the complexity indicated by the need to hold together its outer and inner aspects, but it also has existed and exists in a variety of forms of beliefs, faiths and religions. Each of the great spiritual groups in Western Australia is like a growing organism; each growing or declining in its own individual way. Although a person may belong to one of those spiritual groups, and may have his or her own individual perception of spirituality, this may or may not be the same as the corporate view of the group to which he/she belong. When speaking to some

Western Australians about their spiritual beliefs I have noticed that they sometimes do not have a single belief and/or religion. Rather, they seem to amalgamate two or more spiritual groups together for their personal beliefs. It is not unusual for a person to adopt an aspect of one group's belief with something from another spiritual group. For example, a person may attend the local Anglican Church on Sunday for corporate religious worship, and then use Buddhist meditation principles at home. Likewise, a Roman Catholic person might not tolerate the latest Doctrines from the Vatican and has incorporated the Bahai teachings into his/her personal way of life.

## **Definitions of Spirituality**

Various definitions of spirituality exist in Judeo-Christian theology, Eastern religions, and the disciplines of philosophy and psychology. Aspects of these have been adopted either consciously or unconsciously by other disciplines and incorporated into specific realms of health care practice. For example, the discipline of medicine and nursing originated in the monasteries of Europe in the 10-11<sup>th</sup> centuries, and the Judeo-Christian view of theology has subsequently informed the knowledge of these professionals in countries such as Australia, the USA, and UK (Dolan, Fitzpatrick, & Herman, 1983; Reynoldson, 1997). However, with changing worldviews, some health care professionals have explored concepts of spirituality that are more related to Eastern religion, whereas, others have adopted psychological definitions. All of these sources of knowledge, (i.e.the traditional Judeo-Christian, Eastern religions, philosophical beliefs and psychology), have contributed to the building of spiritual knowledge within nursing and other disciplines of health care.

Spirituality is a dimension within all people and, therefore, all people have potential spiritual needs, whether they are religious or not (Benner Carson, 1989; Sommer, 1989; Stoter, 1995). Spirituality is a broader concept than religion in that it includes "dealing with the unknown and uncertainty in life, finding meaning and purpose in life, and awareness of ability to draw on inner resources and

strength" (Burkhardt, 1993, p. 12). Although the terms "spiritual" and "religious" may be used synonymously, they are not necessarily synonymous (Benner Carson, 1989; Frankl, 1978). Spirituality is a personal, individualised set of beliefs and practices that are not necessarily church related, whereas religion refers to a set of beliefs and practices associated with a particular religious denomination, church or sect (Elwell, 1984; Emblem, 1992).

According to Fowler (1987), all people are endowed at birth with a nascent spiritual capacity. Spirituality develops and becomes part of people, in much the same way as they develop life values and beliefs (Barry, 1983; Capps, 1982; Hawley, 1997a & b). Culture and/or ethnicity, religion, education and life experiences affect peoples' spirituality (Aden, 1976; Anderson & Hopkins, 1992; Carson, 1989; Erickson, 1963; Fowler, 1974). Spirituality takes form from peoples' earliest relationships with care givers and those in close contact, and grows through life experiences (Niebuhr, 1960; Pehler, 1997). In this way, prior to becoming religious, before people start to think of themselves as Catholic or Buddhist, they are already engaged in issues of spirituality (Niebuhr, 1960). As individuals develop through childhood to adulthood and experience life in differing ways, so too does their spirituality and related needs change (Aden, 1976; Anderson & Hopkins, 1992; Carson, 1989; Erickson, 1963; Fowler, 1987).

Science, Marxism and Humanism also rival religion in certain aspects, and are regarded by some people as their personal form of spirituality to (Smart, 1971). Although some Humanists do not believe in the spiritual /divine nature of the world, they do state that they have meaning and purpose in their life, although they may not themselves, acknowledge as spiritual these values, beliefs and manifestations. For this study, I have drawn science, Marxism and Humanism into a portrait of Western Australian spirituality as they provide people with purpose and meaning in their life, in much the same way as does religion. To exclude these patients and/or clients from spiritual care because their type of spirituality does not conform to a traditional religion would be ethically incorrect (Hawley, 1997 a & b). A health care professional does not refrain from physically examining the

body of a patient or client if that person is physically different from themselves. So, too, the health care professional must gain an understanding of the differing spiritual groups in order to care for the whole patient or client.

Thus, I write from the premise that the study of spirituality can be a scientific discipline, based on careful observation and sympathetic intuition for the human feelings that formulate the phenomenon. I have attempted to tell the story of spirituality without entering technicalities of specific religious languages and theology. Whether guided by a god/gods or spirits or the hope of nirvana, people have always tried to see beyond their senses. We can observe and study how this may happen. What we may see we can interpret, but we cannot judge their spiritual beliefs and manifestations, as that would be unethical (Hawley, 1997b).

### Spirituality and Health Care

Within health care literature, definitions of spirituality have differed over the years, depending on whether the author or researcher was examining the phenomena in relation to Judeo-Christianity or was trying to look beyond that tradition to incorporate ideas of rational humanism (Saunders & Retsas, 1998). At present, there is no clear definition of spirituality, although many researchers and writers have tried to develop a precise operational definition (Goddard, 1995).

On reading about the various spiritual groups in Western Australia (see Chapter Two), it appeared to me that Australians have tried to find a meaning for various occurrences/actions in their environments in order to explain and give reason and purpose for these phenomena. Hence, depending on the capability of the human brain at the time, people have reasoned as to why and how these phenomena have occurred. For example, for our ancestors thunder was thought to be the God of Thor, whereas, today it is understood to be electrical activity in the atmosphere/stratosphere. There is another concept or theme involved in spiritual groups and that is fear. Could it be that people were afraid of the world that they did not understand and, therefore, adopted a belief that would give them comfort and hope in what was happening around them? This may have developed into the

idea that to be granted a favour or positive outcome of a situation from the god/s, people did actions (for example, feeding the god, worshipping the god, singing and talking to the god) in order to "please" them.

According to Burkhardt (1993), the spiritual nature of a person is multidimensional in that it refers to an individual's relationship with his/her self, a sense of connection with others, and relationship with a Higher Power or Divine source. Although this definition recognises the importance of the multidimensional nature of spirituality, it is possibly dissonant for patients who do not believe in a Higher Power or Divine source. Goddard (1995) called for a conceptual consensus on spirituality from a scientific perspective and proceeded to formulate the definition of spirituality as "integrative energy" (p.810). Some nurses have had difficulty with this definition, and have argued that such a conceptualization effectively strips spirituality of its meaning in the name of spurious scientism (Dawson, 1997).

Tillich (1956) warned us that, although processes of secularisation may have separated certain arenas of cultural life from the institutional church, this does not mean that modern culture is devoid of genuine spirituality. (Secularisation refers to the historical process whereby institutional religion has become increasingly separated from cultural realisms such as law, science, psychology, and medicine.) Modern and postmodern individuals engage in secular forms of spirituality through a range of cultural activities. Insofar as they enable people to transform themselves in ways that enhance their participation in this source of ultimacy, they deserve to be understood as important vehicles of modern spiritual life.

In 1992, Caroline Jones conducted the Australian radio program series, "Search for Meaning", in which she interviewed Australians about their meaning of life and purpose in life. To me, it was compelling listening to hear diverse Australians talking of their life experiences. In her program and book (1993), Jones' guests tell of how a certain aspect of their life gave them meaning and purpose. For some, it was through God and their religion, for others it was the making of a

contribution to a society in which they lived or worked. However, underpinning them all was the relationship the guests had with their loved ones and the environment or creation of the worth. For example, when Nick Carroll (Australian surf champion) was asked about spirituality, he replied that it is more of "an awareness of the pulse of life on earth". When asked by Jones whether he wanted to put a name to this power, he responded that he could not put a name of Buddha, or God, or Mohammed to it. Nick went on to explain that when he was editor of a surfing magazine, probably 20% of 5,000 letters received described how people found solace and meditation in the sea, an activity that helps them find hope and peace in their life.

### Measuring Spirituality

According to Reed (1992), spirituality per se is not measurable any more than are concepts such as physicality, emotionality or wholeness, and investigators should be reluctant to measure spirituality as a variable in and of itself. Yet the nursing literature consistently reflects a basic assumption and concern about the existence of spirituality as an expression and essential characteristic of humanness (Hawley, 1997a; Highfield, 1992; Keegan, 1993; Morse & Doberneck, 1995; Nelson, 1995).

Moreover, people attending health care organisations state they have various spiritual needs, the most important being the need to understand the meaning of and purpose in their life (Fish & Shelly, 1978; O'Brien, 1992). For some, these needs include the opportunity to observe the religious rituals that form part of their everyday life, which they want to continue while in hospital. Other people may become aware of their spiritual needs only when they are told a diagnosis and become aware of the seriousness of their illness or the possibility of their death (Capps, 1983; Carson, 1989; Hawley, 1996). Still others realise they have spiritual needs as they try to reflect on the meaning of suffering and ask questions as to what their purpose in life may be (Baldree, Murphy, & Powers, 1982; Carson, 1989; Conco, 1995; Saylor, 1991).

To date, there is a dearth of research on spirituality and spiritual needs of health care patients (Saunders & Retsas, 1998). The research has been limited to the Judeo-Christian patients' perspective and, to a much lesser degree, to Humanist patients in the USA. Consequently, new research is needed to explore beyond the definitions and descriptions already published. Although recognising the difficulty in researching the concept of spirituality in nursing, Reed (1992) believed this could be overcome if behavioural components of spirituality were specified for research. That is, researchers can study those observable components that manifest patients' spirituality and those that they wish to discuss (Dudley, Smith, & Millison, 1995; Hamner, 1990; Harrison, 1993; Heriot, 1992).

### Manifestations of Spirituality

According to Fuller and Schuller-Ayers (1990), spirituality can be manifested through peoples' values and beliefs about health, religion, and cultural rituals. These include dietary habits related to spiritual beliefs, significance of cultural heritage and use or non-use of certain animals and foods (Carpenito, 1983). Whether or not proposed treatment is to be undertaken or how it will be done can reflect peoples' spirituality (Knights, 1998). Expression of spirituality can be exhibited in peoples' mode of dress, use of language, and presence and involvement of other family members and/or religious leaders, as well as the use of religious or spiritual artifacts (DeLaune, 1998). Some words and methods of speaking by a health care professional may be highly offensive to patients and clients who have spiritual beliefs different from those of the health care professional. For example, a Muslim woman may have the spiritual belief that her body is to be completely covered at all times, and that a male outside of her family may be allowed to talk with her only if the whole of her body is completely covered except for her eyes.

The practice of a specific spirituality in one country may not necessarily be the same as is practiced in another country or within another cultural group within the same country. According to Cone (1992), in the USA Black Baptist spirituality is practiced differently from the Baptist religion elsewhere, and the term "Black

spirituality" is recognised as denoting a specific style of worship that is not derived primarily from theological and historical church traditions. It is possible that in Australia, traditional Aboriginal and other cultural groups meeting together to worship within a specific religious perspective will worship differently from other groups. For example, Anglican or Baptists of Aboriginal, Chinese or Indonesian origin regularly worship separately from the main body of their congregation or community. Because of this diversity, outcomes of spiritual studies will have limitations in relation to generalisation about how people manifest their spirituality in respect to their culture and context at the time (Ellison, 1995; Hawley, 1994).

Manifestations of spirituality may be demonstrated in any human activity relevant to the receiving of health care. In this study, the manifestations of spirituality in relation to health care are identified as the rituals and practices, beliefs (including cultural), attitudes and responses to illness and treatment of patients (see Chapter Two).

### Spiritual Needs of Health Care Patients

According to Watson (1988), spiritual needs are those that reflect multiple dimensions of connectedness within and beyond the self. These include the need for unconditional love, the ability to transcend one's individual life, and to find harmony within one's life. Other studies identified spiritual needs as the care and support of others to experience forgiveness, love, hope, and the trust of God or a Higher Power (Amenta & Bohnet, 1986; Highfield & Carson, 1983). The difficulty with this type of definition is that if a patient does not have a relationship with a God or a Higher Power, then the concept may not be appropriate.

Although the concept of patients' spiritual needs is not regarded as the specific domain of any one health care discipline or profession, by far the largest amount of available research literature has been published by nurses (Emblem & Halstead, 1993). The importance of meeting patients' spiritual needs has been addressed in

nursing literature since the early 1960s (Amenta, 1988; Jourad, 1964; Taylor, & Amenta, 1994). Texts refer to the importance of patients' spiritual needs in relation to quality of life (Halstead, 1994; Landis, 1996; Lindgren & Coursey, 1995; Poloma & Pendelton, 1991; Post-White et al, 1996). Recent nursing emphasis on the psychological aspects of care reflects the view that the body, mind, and spirit are dynamically woven together, with one component affecting the others (Dossey, 1993; Frankl, 1978; Keegan, 1993, Leetun, 1996). Meeting the spiritual needs of patients in relationship with the physical and mental aspects of their health has been identified by both patients and relatives as an important component of "good nursing care" (Anderson, Anderson, & Felsenthal, 1993; Athlin, Furaker, & Norberg, 1993; Clarke & Heidenrich, 1995).

When patients face uncertainty and possible death in relation to the outcome of their health problem, they may have a desire for their spiritual needs to be met so that they can benefit from the comfort and strength their beliefs and rituals give them (Hawley, 1996). Lack of support through inability to practise spiritual rituals can cause considerable distress for patients who need supportive relationships and familiar rituals at this time (Duff, 1994; Hawley, 1998). The seriousness of illness and the possibility of death also can affect patients' spiritual needs. Reed (1987) found that terminally ill people or those who believed they were in danger of dying had greater spiritual needs than did other hospitalised patients. Likewise, hospitalised patients, the elderly and chronically ill had greater spiritual needs than healthy people in the general community (Baldree et al., 1982; Bearon & Koenig, 1990; Koenig, George & Seigler, 1988). Spiritual distress can arise when patients experience spiritual needs that cannot be met (Heliker, 1992; McFarland & McFarlane, 1993). Furthermore, certain factors related to the patient, nurse, environment, and other professionals may hinder the fulfillment of patients' spiritual needs (Emblem & Halstead, 1993).

Other research in the USA by a number of nurses has identified the following spiritual needs from the Judeo-Christian tradition: meaning of life, purpose in life, prayer, trust in God's presence, transcendence, religious rituals and assistance

from clergy to understand the experience of suffering, and relief from anxiety and fear of death (Fish & Shelly, 1978; Highfield & Carson, 1983; McCraken & Gerdson, 1991; Paloutzian & Ellison, 1983; Stallwood & Stoll, 1975). These studies were undertaken with patients from gerontology and palliative care settings where only elderly people were interviewed. Research has not explored the concept of spirituality with patients less than 55 years old and those who are not facing death (Emblem & Halstead, 1993). Therefore, the spiritual needs identified may only be applicable to the elderly and the dying. It is not known if younger patients (those less than 55 years) have different spiritual perspectives (Emblem & Halstead, 1993). In Western Australia, young people are admitted to adult hospitals when they reach 13 years of age or younger if the expertise is not available in a hospital catering for children. However, chronically ill teenagers are not automatically transferred to an adult hospital at 13 years of age (and may remain in the paediatric setting until their late teens). In this study, in order to reach as wide a population as possible, no minimum age was stipulated, as to do so may have excluded valuable data.

The spiritual need of "transcendence" that is evident both within and outside Judeo-Christianity has not been fully explored. None of the published studies explored the existing types of non-theological visions of the nature of people in which transcendence is the vital element (Dawson, 1997). From the notion of personal liberation as transcendence (Reich, 1970), the Marxist tradition of transcendence as future (Block, 1970), and that of transcendence as self-realisation or self creation (Jung, 1933, 1935; Laing, 1960, 1967), to that of Herbert Marcuse's (1964, 1968) perceptions of alternative transcendent historical realities, there is evidence, even in such secular thinkers, of a deep and abiding desire to move beyond the mundane to a grander eschatological vision (Dawson, 1997). In both the individual and community areas of life, this spiritual impulse to strive for a greater, uplifting vision provides the substance which helps to hold the fabric of their existence together, and even enables some people to rise above the brutality of nature and/or other people.

When reading Bert Facey's autobiography "A Fortunate Life" (1981), I was reminded of how some people have the ability to rise above the brutality of others. Bert's story is one of incredible suffering: a parentless boy, an eight year old starting to work in the outback of Western Australia, he travelled from place to place, experiencing both brutality and tenderness. Almost murdered by a stockwhip-wielding farmer, he grows up to face death (of his brother and friends) and wounding in Gallipolli. He returns from the war only to lose his farm during the depression, and to lose his son in the Second World War. Finally, he is left bereft of his loving wife after sixty years. Yet Bert argues there is no God, he says it is only a myth. His meaning in life came from those he loved. After his wife died Bert would go off and have a talk with his "darling"; that is, he would go and sit on his wife's grave and contemplate. In Bert's book I found a story that any person would admire for his practice of charity and hope. The ultimate, though largely unspoken, was lived.

### Is this not spirituality?

Other research in the USA identified the following spiritual needs from the humanist perspective: belief and faith in self and other relationships, transcendence, and communication and connectedness with others and the environment (Benner Carson, 1989; Emblem & Halstead, 1993; Reed, 1992). However, these studies were not extended to other spiritual beliefs, such as Atheism and Agnosticism. Because they were conducted mainly with Appalachian Indians, Black, and Hispanic Americans, their potential use in Australia is mimimal given the cultural differences (Hawley, 1994). Again, the research was undertaken with elderly gerontology or palliative care patients and so the generalisability to patients who are not dying is doubtful.

The current ways of meeting patients' spiritual needs by nurses and other health care professionals needs to be challenged, as spiritual beliefs are personal attributes that are inextricably intertwined within a person. That is, I believe that there cannot be a single prescribed method of providing spiritual care.

The meeting of spiritual needs provides several recognised benefits for patients. The most important benefit is that patients are more at ease in the hospital environment, as they are able to place what is happening to them within the broader context of their life, beliefs and customs (Hawley & Irurita, 1998; Olimude, 1994). However, in order for the health care professional and the patient to become aware of their own spiritual needs they need to be able to reflect inwardly (Somner, 1991). When spiritual needs are assessed on admission, patients know that the nursing and medical staff recognise their spiritual beliefs (Knights, 1998). When patients are prescribed treatment which does not conflict with their spiritual beliefs there is also more likelihood of a faster recovery, given that distress is not generated by unacceptable treatment (Olimude, 1994). If patients and their families have their cultural and religious responses to illness and hospitalisation respected, then hopefully less time will be spent in hospital (Knights, 1998).

Despite the limitations of these studies, they are the only research findings available that can assist the Australian health care professional in this important identification of spiritual needs, so that care can be improved. In this respect, further research is needed to examine spiritual needs outside of the Judeo-Christian tradition to include other faiths and belief systems held by various groups in the community. It should also incorporate patients who are not elderly or dying.

### Known Outcomes of Spirituality on Illness

Several nursing and psychology researchers in the USA found that spirituality can be a positive internal influence on illness behaviour (Bearon & Koenig, 1990; Carroll, 1991; Fry, 1990; Jalowiez & Powers, 1981; King, 1985; Miller, 1985; Miller & Powers, 1988; Sodestrom & Martinsen, 1987; Sutton & Murphy, 1989). For example, Muslims regard hardships and suffering in life as tests by God of their faith (Morgan & Lawton, 1996). In contrast, some chronic illnesses and the associated treatment may not be accepted in some spiritual communities and

churches and, therefore, the patients' spiritual support network could not be regarded as support or a coping mechanism for patients at that time. For example, an illness, which could be related to sexual activity such as sexually transmitted disease, or AIDS, may result in the patient being punished by their spiritual community. Similarly, with haematology for Jehovah's Witness patients some forms of haemopoietic stem cell transplantation would not be acceptable by their church elders. Consequently, if the patient had the treatment they would be automatically excommunicated from their church. Likewise, homosexuals within the Roman Catholic Church can be refused participation in the receiving of sacraments. Lack of spiritual support and, in some cases, hostility because of the type of illness or treatment that they have; is a potential complication that can do without, as they are additional to the existing illness. It can thus be seen that the type of illness suffered by patients may influence their spiritual needs, as can spiritual needs influence their illness.

### Multidisciplinary Approach to Spirituality in Health Care

Over the past ten to twenty years, several countries have encouraged a multidisciplinary approach to health care, with relevant professionals working together as a team. With this approach, no particular aspect of patient and/or client care is regarded as the sole domain of one particular team member, but rather all are expected to contribute to the healing of the patient. In this way, spiritual care is no longer the sole domain of the hospital chaplain, with other members of the health care team now eager to involve themselves in this aspect of care (Australian Council of Health Services, 1995). Codes of Practice for all health care professions recognise the spiritual nature of patients. In addition, published articles reflect the range of health care professionals interested in contributing to the emerging body of knowledge of spiritual care (chaplaincy, medicine, nursing, occupational therapy, psychology, and social work).

Members of the health care team, such as doctors, nurses, psychologists, occupational therapists, chaplains and social workers, have shown an interest in the

spiritual nature of people, and their published research can be found in journals. Several studies have been conducted on the spiritual needs of patients and clients in the USA, but these have been mainly from the Judeo-Christian religious perspective, and limited to either gerontology or palliative care patients (as argued in the first part of this Chapter). Australian society is multiracial and, therefore, many people will have spiritual needs which differ from the Judeo-Christian religious tradition. Although no research has been found in regard to the spiritual needs of Australian people attending a health care organisation (that is, patients and/or clients), one book has been published on religious needs of patients, including religious faiths other than Judeo-Christianity (Kirkwood, 1993). However, spiritual needs are more encompassing than religious needs (Carson, 1989; Morgan & Lawton, 1996). Therefore, in order to fully understand Australian patients' and/or clients' perspective on their spiritual needs more knowledge and greater awareness is needed (Hawley, 1998; Saunders & Retsas, 1998).

The current quality benchmarks or standards set for health care organisations by the Australian Council Health Services (ACHS) emphasise the need for an integrated approach in providing care which is also individualistic in delivery. These standards emphasize that patients are to be treated in a "holistic" manner in which spiritual care is integrated with physical, emotional, and mental health care. Consequently, patients' spiritual and/or religious needs are not seen as being specific to the chaplaincy department, but rather integrated into patients' care. The standards state that nurses should listen and respond in an appropriate way to patients' spiritual needs (ACHS, 1995). However, many nurses and other health care professionals do not know how to do this because they have not received the education and/or lack the confidence (Harrington, 1995; Leetun, 1996).

The limitations of existing studies make it important that further research be undertaken to explore the phenomenon and concepts of spirituality amongst Australian people. The findings could then assist Australian nurses and other health care professionals to improve the role of spirituality in health care. Such a

study would need to examine all spiritual groups both within and outside the Judeo-Christian tradition.

Researchers in both the USA and UK have commenced research to identify patients' spiritual needs from a multicultural perspective and recommend that they be incorporated into patient care. In the UK the National Health Service has developed draft guidelines in this area for purchasers and providers (1997). In the USA, the Boston Children and Family Hospital is conducting clinical protocols to address patients' spiritual needs (Knights, 1998). To date, no research of this nature has been undertaken in Australia.

The cited literature and background information provides support for examining the spiritual needs of Australian people receiving health care. One of the main issues for nurses and other health care professionals today, when providing spiritual care, is the ability to offer people appropriate choices. Peoples' spiritual needs vary according to different health care problems, the effects, the hospital environment and the faith and beliefs or truths of their spiritual group. Consequently, a sound empirical base needs to be built so that peoples' spiritual beliefs can be fully integrated into health care.

#### STATEMENT OF THE RESEARCH PROBLEM

Australia's population today is multiracial due to changes in immigration policy post World War II, and the acceptance of refugees from non-European war-torn countries and those seeking political asylum. According to the 1996 Australian Census, there are 28 religious groups listed in WA, not including spiritual or cultural associations. In the 1966 census (prior to the government policy of multiculturalism) there were only 13 religious groups, all within the Judeo-Christian tradition. (See Appendix 1 for the list of spiritual groups in Western Australia). This means that Australian health care patients now come from a much wider range of ethnic and religious backgrounds than in the past. Limited

availability to patients of a range of different spiritual rituals and practices outside of the Judeo-Christian tradition may be offensive to those outside this tradition, and may be viewed as discrimination and an infringement of their autonomy (Fuller, 1996; Hawley, 1997b).

The meeting of spiritual needs can assist patients in health care services to better adjust to the health care environment, cope with their illness and suffering, and facilitate nursing and medical care. Although all people have the potential for spiritual needs, little is known about these needs from the patients' or clients' perspective, and whether or not these may vary across differing circumstances. Spiritual needs of patients and clients have not been examined from an Australian perspective or from a viewpoint outside of the Judeo-Christian tradition in order to elicit the culturally diverse nature of the Australian people/population. Many people, including health care professionals, can be embarrassed by discussion of spiritual needs. Studies that articulate the health care recipients' perspective will provide the language and the practical means to assist health care members in the holistic care of patients (Retsas, 1995). The aim of this study is to clarify particular Australian needs with a view to facilitating the assessment of patients' spirituality and related needs and the development of standards and/or guidelines for health care practice.

## Purpose of My Study

The purpose of this study is to (1) explore the phenomenon of spirituality for multicultural Australians who experienced a health care problem, and (2) propose a set of recommendations for education, in order that nurses and other health care professionals can be made aware of these needs.

### My Research Questions

1. Who and what are the various spiritual groups in WA? What are their histories, beliefs and truths in relation to health care? Such data would help me to appreciate the diverse nature of the various groups and assist me in gaining

- more knowledge and understanding of spirituality prior to formulating a philosophical framework and research design.
- 2. What would be an appropriate methodology to identify the spiritual needs of culturally-diverse Australians?
- 3. When a person from a non Judeo-Christian background has a health problem what might be the essence of their spirituality?
- 4. When considering the essence of spirituality from a diverse multicultural perspective, what might be people's 'spiritual needs'?
- 5. What are the implications for the education of health care professionals?
- 6. How does the literature (cited in Chapters One, Three, and Ten), reflect and/or support the findings of the research?
- 7. What recommendations could be made for the education of health care professionals within Western Australia in order to improve their knowledge and understanding of spirituality?

#### **OVERVIEW OF THE THESIS STRUCTURE**

My realisation that I understood very little about the notion of spirituality prompted me to explore the spiritual groups in Western Australia as the first step in the study. I needed to overcome my "crisis of not knowing about spirituality and the extent and diverseness of spiritual groups in Western Australia" (see Chapter Two). This data subsequently enabled me to identify key concepts of spirituality and to realise the interrelationships between these components. At the same time, I gained knowledge of the manifestations of various spiritual groups. This data assisted me in understanding the variety of multicultural groups in Western Australia and their affiliations to various spiritual groups.

The discerning of an appropriate methodology to identify the spiritual needs of culturally diverse Australians is discussed in Chapter Three. The process involved in the exploration of selected patients' and clients' concepts of spirituality is

described in Chapter Four; as is the introduction of the participants: Ann, Athika, Geoff, Red, Rosie, Scarlet, Sophie, and Tom. Identification of the participants' spiritual needs commences in Chapter Five, where the manner in which the participants know subjectively about spirituality and health care is discussed. This is followed in Chapter Six with the participants' definitions and descriptions of their spirituality. Chapter Seven explores the identified spiritual needs of mutual trust, hope, love and peace. In Chapter Eight, the discussion of spiritual needs continues with an exploration of the spiritual care that the participants liked or would have wanted. This is followed in Chapter Nine with the journey or rite of passage that each of the participants underwent when receiving health care treatment and trying to have their spiritual needs met. Chapter Ten explores the discussion of literature from Chapters One and Three and further readings that illuminate the findings. Recommendations for meeting the spiritual needs of the participants by health care professionals are stated in Chapter Eleven. Recommendations for the education of future health care professionals within Western Australia in order to improve their knowledge and understanding of spirituality ends the thesis.

Epitaph for Western Intelligentsia

What we come round to In the end Is that all our thinking Has brought us nowhere

That the trail-blazing journey Has ended where it has begun That thought at best Is a protection against further thought

That the heathens we sought to save The masses to educate Need neither salvation or our education That we therefore No particular purpose Perform no particular function Have no particular place to go

And we roll to the ground And we cry like children And we bark like dogs And we learn to wag our tails.

By Richard Allen

#### CHAPTER TWO

#### CRISIS OF NOT KNOWING

She is made one with nature there is heard Her voice in all her music, from the moan Of thunder, to the song of night's sweet bird; She is a presence to be felt and known In darkness and in light....

(Percy Bysshe Shelley)

#### INTRODUCTION

The importance of spirituality as being integral with a person's life can not be stressed sufficiently. This poem by Shelley describes the very pervasiveness with which spirituality can be found and embraced within that person's life. While I had read about spirituality in books and journals, and realised the historical nature, definitions, manifestations, and benefits of incorporating spiritual care into health practice, I did not know what constituted spirituality. Here was part of my crisis! I was embarking on a study of a phenomenon I did not understand and being a 'visual person' my reading of the published research studies on spirituality was insufficient to visually perceive a mental picture of what the phenomenon looked like. The next part of the crisis was that, although I technically knew of the diverse nature of multicultural groups in Western Australia, I did not know how many existed. The final part of the crisis

Chapter Two Crisis of Not Knowing

35

concerned my own spiritual beliefs. This occurred in trying to maintain my own

essense of integrity, and at the same time embrace this new knowledge and

understanding. Thus the purpose of this chapter is three fold: first, to gain a

greater understanding about various spiritual groups in Western Australia,

second, to understand better the concept of spirituality from the viewpoint of

various spiritual groups in Western Australia, and third to explore theologically

how I could work with the various spiritual groups.

The first section of this chapter describes the diversity of nationalities in Western

Australia, how I discovered the location of the various spiritual groups, and

requested documents and other material from them. The second section explains

what I discovered when analysing the returned material and the finding of how an

emergent model can represent the relationship of the various components or

themes of spirituality. In the final section, I explore the effects of this new

knowledge on my own spirituality and how I can be true to myself as both a

health care professional and ordained minister of the Anglican Church.

**DIVERSITY OF NATIONALITIES** 

The most recent Census (Australian Bureau of Statistics, 1996) in Western

Australia states that 32% of the residents (all age groups) were not born in

Australia. Table 1 illustrates the range of countries from which these Western

Australians originated.

Table 1: Countries of Origin of WA Residents

No. of Residents from that Country	
68%	
32%	
305,296	
57,280	
28,244	
27,456	

Although most overseas immigrants to Western Australia were born in Europe, there is a sizeable presence from other geographical regions of the world. Furthermore, of the 68% of people born in Australia, 53% had one or both parents born overseas (Australian Bureau of Statistics, 1996). (See Table 2).

Table 2: Countries or Origin of Parents of WA Residents Born in Australia

Parent's Country of Birth	Population	Percentage
UK and Ireland	214,547	32.52%
Malaysia	17,328	
India	15,226	
Singapore	10,692	
Vietnam	10,065	8.48%
Indonesian	6,087	
Phillipines	4,773	
China	4,554	
Hong Kong	3,527	
New Zealand	39,613	5.3%
Italy	25,124	
Greece	3,454	3.71%
Netherlands	11,072	,, <u>, , , , , , , , , , , , , , , , , ,</u>
Germany	10,062	2.65%
Poland	6,999	
Croatia	4,151	1.39%
Hungary, Serbia	1,413	
Former Yugoslavia	336	

North America	8,834	1.06%
Middle East	2,358	0.5%
Chile	1,162	1.06%

When the figures of Tables 1 and 2 are considered, only 15% of people born in Western Australia had both parents born in Australia. These figures indicate that a very large proportion (85%) of Western Australians are new arrivals (first or second generation) to this country. Because these figures were collected in 1996, it is likely that the next census will reveal greater diversity in cultures as Australia has, in recent years, accepted more refugees from Vietnam, Burma, Cambodia, Kosova, Iran, Iraq, Afghanastan and Africa. However, the amount per head of population entering Australia as asylum seekers (8,257 in the 12 month period ending June 1999) is low compared with those entering the United Kingdom (51,795) and Germany (98,644) (Aisbett, 2000).

Although the size and scope of multicultural diversity does not indicate the spirituality of overseas migrants to Western Australia, this can be surmised (for those residents in the state prior to the 1996 census) by comparing (1) suburb of residence (2) with country of birth and (3) religious group (Australian Bureau of Statistics, 1996). Also, it is known that people from many overseas countries will originate from a predominant spiritual group. For example, the majority of people who come from Italy are Roman Catholic, and from Greece are Greek Orthodox (Church Life Survey, 1999). In Iraq and Iran Christians, are being persecuted because of their religious faith, and some are seeking refuge in Australia (Aisbett, 2000: Appendix 2).

#### LOCATION OF SPIRITUAL GROUPS

Locating and obtaining information from various spiritual groups in Western Australia was the first step towards developing a philosophical framework, and designing the study.

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# Where will I find out about all the different spiritual groups in WA?

I knew that various religious churches and other spiritual groups would be listed in telephone directories, and so I wrote a letter to each of the groups, including churches, various spiritual sects, philosophical groups and multicultural associations (see Appendix 3) requesting specific information.

The letter sent requested published material on each group's identity and included a set of questions pertaining to the origin of the group, its beliefs and rituals, and how these might affect health care should one of their members need treatment. I especially wanted to know which expressions of spirituality would affect birth control, termination of pregnancy, pregnancy, child birth, modesty, blood, transfusion, bone marrow transplantation, medication, pain and suffering, death, organ transplantation, and care of the body after death (including specific funeral beliefs). This, I felt, was important information that would enable health care professionals to respond to their patients and clients in a sensitive manner. For example, it is a time of great crisis for a family to give their permission for life support to their loved one to be removed. Then to be asked in the same time frame by another doctor (the law states that it be a different doctor) if they would donate organs for the benefit of someone else, can cause a great deal of additional distress. This situation may be preventable if the health care professional knows that a person from "X" spiritual group would very probably not believe in organ donation and transplantation. At present, all deaths (except those people dying of cancer and any other terminal disease) in large hospitals are regarded by health care professionals as possible sources for the harvesting of organs.

A total 110 letters were posted in August 1998 and a 50% response rate resulted (that is, 55 groups sent a letter or literature to the researcher). Of the 50% who did not respond this included twenty letters which were "returned to sender", as the post office had not been able to deliver them to the rightful owner/addressee. These letters had been sent to groups who had meetings in either a shop or local hall and had moved without notifying either the owner of the building or the local

post office of their forwarding address. One such group was the Harvest Fellowship, in Hamilton Hill, which I later found had shifted three times in two years. Of the remaining 30 letters, I received no response, and assumed that the group did not want to have contact with me, and therefore no follow-up letter was sent.

#### The Returned Material Or Data

The material sent to me included letters, pamphlets, books, journals and invitations to visit the organisation or group. When sorting the material into the various spiritual groups I discovered, in some instances that more than one letter had been sent to an affiliated group. This meant that I received similar or duplicated material. For example, Bedford Gospel Chapel and Lynwood Christian Church are both Christian Brethren Churches. Likewise, I did not know that the Dadirri Biospiritual Center was, in fact, part of the Roman Catholic community in Perth. This group simply referred me to the doctrines of the Church. Neither did I realise that there were so many diverse Buddhist groups in Perth with similar teachings: (1) Zen (with no Chinese or Asian members), (2) Chinese Humanistic (people from mainland China, Taiwan, and Hong Kong) and (3) Thervada (members are from south east Asia extending across to India and Europeans). New Buddhist migrants find the appropriate group by usually attending their previous country's temple closest to them (for example, Laotian Buddhist).

The material came from the following named groups (that is, their official name).

Aboriginal Bible Fellowship, Anglican, Anglo-Catholic, Assembly of God, Bahai, Baptist, Brethren, Buddhist, Christian Science, Christian Spiritualism, Church of Christ, Church of Latter Day Saints, Disciples of Christ, Dutch Free Reform, Eckanker, Elder Troth, FoGuangShan Temple, Greek Orthodox, Humanist Society, Jewish, Lutheran, Muslim, Naturism, Ninja Society, Pagan Romany, Presbyterian, Reformed Church of Canning, Roman Catholic, Sikh Association., Spiritualist Christian Church, Supreme Master Ching Hi International Assoc., Taoist, Theosophical Society, The Religious Society of Friends, The Revival Fellowship, Uniting Church, and Zen Buddhist.

The information received included letters, pamphlets, reference books and texts. The underlying message, which was repeated on more than one occasion to me, was:

Thank you for taking an interest in the spiritual aspect of health care... if there is any way in which we (the group) can be of further assistance please do not hesitate to contact us.

Six respondents wanted to know why their local hospital and /or medical centre had not requested such information. To them, such information would be utilised more readily at the local level than me teaching about it.

Some groups also invited me to meetings and festivities to see the rituals and activities firsthand. These included community meetings with The Society of Friends, Eckanker, meditation and vegetarian cooking classes at the Buddhist temple, a Retreat, New Year celebrations, and a Sikh convention.

Subsequently, letters were sent to all respondents thanking them for the material they had sent and for taking the time to answer my queries.

#### Differences Noted in the Data

Many hours were spent reading and re-reading the enormous amount of information. During that period, I raised questions and sought answers from the data.

Pagan or heathen? Some groups called themselves these names, but why? Have people the right to describe another person's religion as pagan? Just because it is different from their own?

I had difficulty using the word 'pagan' or 'heathen' because I felt it was discriminatory. Nevertheless, because such a word was used within the official title of the group I had no choice. However, most dictionaries state that Judeo-Christian and Islamic religions are the "true religions" of the world and all others are pagan! On exploring other literature, I discovered that 'pagan' sometimes refers to polytheistic religion, whereas 'heathen' refers to people who have no

religious beliefs. However, I felt that I had no option but to continue using the name when it was included within the title of a group, for example, Pagan Romany. In fact, this group does have multiple spirits that they believe in and pray to, so their name is accurate. So, the difficulty in using the word was my problem and not theirs.

At times during history, it must have been a disadvantage to be called a pagan or heathen, so is it now fashionable? Or is it just more acceptable to have beliefs outside of the Judeo-Christian tradition?

Perhaps with the changing culture of Australia from being a predominately "white people and church attending" society to becoming a multicultural society it is now more acceptable to be different.

Although spiritual groups/religions can be placed in different groups and one of these named "mythical or legendary"; don't all religions and science contain aspects of myths or legends?

Especially since a lot of science comes out of Puritan/Calvinistic thinking.

When examining the material, I developed the five following classifications.

- Religious groups that had spiritual beliefs that were not of the Judeo-Christian tradition (Bahai, Buddhist, Eckanker, Muslim, Sikh Assoc, Taoist, and Zen Buddhist).
- 2. Judeo-Christian churches, including Eastern Orthodox (Anglican, Anglo-Catholic, Assembly of God, Baptist, Brethren, Christian Science, Church of Christ, Church of Latter Day Saints (some Christian groups do regard this group as a religion and would have allocated to the above non-Judeo-Christian groups) Disciples of Christ, Greek Orthodox, Jewish, Lutheran, The Religious Society of Friends, The Revival Fellowship, Presbyterian, Quakers, Reformed Church of Canning, Roman Catholic, Uniting Church).
- 3. Philosophical groups (Humanist Society, Naturism, and Theosophical Society).

- 4. Groups that had the word 'pagan and/or heathen' within their name (Elder Troth, Pagan Romany). Mythical spiritual groups could also be included with this groups (The Dreamtime or Dreaming).
- 5. A group of organisations that declared they were not a religion or a spiritual group per se, but rather an organisation that taught methods for people to gain closer contact with their own god/s for enlightenment (Supreme Master Ching Hi International Assoc., FoGuangShan Temple, Ninja Society).

While these five groups are listed as distinct entities, some groups are a mixture of two or more. For example, The Aboriginal Bible Fellowship has beliefs combining The Dreaming and fundamental Christianity. Similarly, the Christian Spirituality Church accepts the basic doctrines of the Christian church, but also has a strong spiritual emphasis on communicating with the dead and seeking answers from the same. (Although it may be thought that this might be similar to the Pentecostal and Charismatic churches, this is not so. Pentecostals and charismatic people pray to and with the Holy Spirit). Then there was an organization named "Elder Troth" which appeared to be a group of early pagan religions that had their origins in Europe. Elder Troth publishes a journal representing their various pre-history religions.

#### DATA ANALYSIS

The very large mass of the material that I received posed a difficulty to me. Not because of the labour involved in sorting the material, but because the abundance of material could open the temptation for me to rush, and make hasty judgments with what could appear as plausible ideas. I was very much aware that it would be an error to ignore further possible analytical work at a later date. I was also wary of imposing my own unwarranted personal definitions on the information. According to Van Manen (1990), striking an optimal balance is a difficult and probably endless task.

The computer analysis software package "HyperResearch" saved an enormous amount of time in sorting through the narrative data. Not only did it enable me to identify various categories, and apply coding techniques to entire data sets (not just the parts the analyst has time for) but it also helped avoid certain kinds of inaccuracies (Lindof, 1995). For example, when I wanted to rename a category, the program would automatically recode all the data for that same category.

The first task was to identify repeated categories or themes within the data and the possibility of interrelationships. This raised questions such as:

How and where do I place the components of Humanism,
Or for that matter communism and socialism?
Need to work it out.
Need to be able to have a word or term to use that
incorporates God, Higher Power, etc. but also
philosophical beliefs.

After rereading the data and exploring the dictionary and thesaurus, I chose the word "focus" as this means the point on which attention and activity is concentrated. Focus therefore fitted the attributes of being the centre or the core point of a group's ideology. For example, the focus of Judeo-Christian tradition is God and/or Jesus Christ. In Humanism, the focus is the universal family of the world. The groups that had a focus or orientation which did not include a deity or higher power included the various philosophical groups, Naturism, Humanism, Socialism, and Communism. Nevertheless, these groups had powerful truths, beliefs, and rational arguments to provide meaning and purpose for their members.

#### Themes Within the Data

By using the search mode of HyperResearch, I was able to discern themes that occurred within each of the spiritual groups:

- 1. the focus, or core component, of the group such as God/s or Higher Power;
- 2. the truths or beliefs of the group;
- the manner in which members can access their focus (core component, God or Higher Power); and

4. peoples' or members' manifestations and expressions of their spirituality, that is, the expressions people would use in acting out their beliefs or truths.

#### Inferences

Further analysis was undertaken to make inferences from the data. This was done in order to identify the true meanings of groups from other potential meanings. In particular, the usage and nature of God among the various spiritual groups, and what were regarded as symbols of spirituality.

### What are symbols of spirituality?

Some groups have similar symbols, for example, the cross and crucifixion used by some Christian groups, Rosary beads used by the Orthodox and Roman Catholic Churches, and the partaking of Eucharist by members.

Each organisation appears to have their own ,why?
Why do I use prayer and reflection as spiritual behaviours?
Are rituals expressions of personal religious /spiritual belief.
That is, are they practices that externalise private convictions?
Yes!

On further examination of the various symbols, it appeared that they are used to embody the beliefs of the organisation. For example, some church symbols were about the purpose of human life, whereas, others reward those who fulfil the common goals or hold a specific office. However, they could be used to unite the spirits of the individuals into the spirit of the whole society or membership. All organisations had rituals and/or symbols of some sort that allow the member to access the truths or beliefs of their group.

According to Geertz (1973), symbols are powerful means of cohesiveness, but can also be barriers to exclude others or keep a person out. For example, only the initiated can participate in certain activities in which symbols are used. However, in order to have power, symbols need a type of "ghetto" in which they achieve a sense of unity. This was particularly evident with groups that exclude those who are not initiated into their way. For example, to receive The Eucharist in the

Roman Catholic Church a person needs to have been baptised into the church and to have undertaken a set period of teaching. With the Exclusive Brethren churches, a person needs to be invited by another member and taken to the service. A person cannot walk along the street, read a sign that says "Exclusive Brethren Chapel", and enter the chapel uninvited. If they do so an elder of the church will ask them to leave the premises.

### The Use and Meaning of God within the Data

While the traditional Judeo-Christian religions may have thought they were the only ones to worship God, many other groups believed likewise. My analysis of "god/s" revealed the following:

- 1. Some groups used the name "God" to describe their deity or higher power but the group did not actually state or who their God was.
- 2. Others did state who their God/s is/are (Jews, Christians of mainline churches, Muslims, Jehovah's Witness).
- 3. In addition, some groups gave a description and role of their God as to what "he" would do for the person (Fundamentalist Christians, Christian Spiritualist, Jehovah Witness). The word "he" is emphasised as these groups strictly regarded God as male.

# Stories, Legends, Myths and Truths

### What are the differences between truths and myths?

Various groups have sayings (creeds), stories, or teachings (doctrines) that explain a certain phenomenon and various concepts. For example, Roman Catholics, Greek Orthodox, and Anglicans recite either the Nicene Creed or Apostles Creed each time they worship. These creeds commence with the words "We believe" or "I believe..." However, to a person who has different beliefs they could regard these sayings as untrue, or even mythical, depending on the content.

Are myths what another person may regard as an untruth?

If a person believes in a so-called myth then, to them, it would be the truth, because it appears reasonable and has a plausible explanation.

### Adoption of Truths and Beliefs

On reading the data I noticed that the elders or officers/ministers assumed that members would adopt the group's beliefs and truths.

- That their church's religious belief was truth and that all members would adopt that teaching/doctrine/dogma if they wanted to be a member (Baptist; Brethren, Jehovah's Witness).
- 2. Those members only had to adopt the teaching of their particular religion and they would be "saved". That is, it was not necessary to have a personal viewpoint other than the church's, indeed it was not encouraged. (Pentecostal, Church of the Latter Day Saints, Jehovah Witness, and some Roman Catholic).
- Some religions allowed the person to adopt their own personal thinking on specific life situations – abortion, life after death, health care treatment (Anglican, The Society of Friends, Uniting Church).

### Discernment Processes within the Groups

Some groups had a discerning process by which members moved from one level of understanding of the group's truths or "spirituality" to a higher level (Masonic, Druids, Elder Troth, Brethren, Buddhist, Sikh, and some churches). In addition, some church groups placed emphasis on a discernment process to select and/or elect elders, leaders, officers, ministers and pastors, and to Ordination (ministers/deacons, priests and bishops).

# Rites of Passage

Some groups had rites of passage, which had specific significance for the members.

- 1. At birth or shortly afterwards, the introduction to the group and personal naming baptism/christening, anointing.
- 2. Then at the time of adolescence, an initiation into the group of some sort confirmation, bar mitzvah, full membership,
- 3. At the adult stage of life marriage and/or commitment, entering of sacred orders or religious vows.
- 4. At the time of death confession and absolution, last rites, preparation of the body/anointing for burial or cremation.

It was not only the various religious groups and churches that had rites of passage to emphasize the stage of birth, marriage, and death. The Humanism groups have a ceremony to recognise birth and name the child, they also will conduct marriage and funeral ceremonies. The philosophical and pagan groups celebrate birth, adolescence or maturity, marriage, and death.

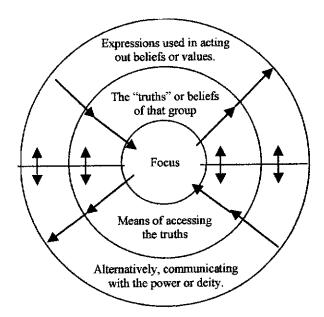
#### Inter-Relationship between the Themes

In trying to clarify the relationship between the four identified themes (focus, group beliefs or truths, means of accessing the truth, and rituals needed to act out the values of truths and belief) I drew diagrams. I did so until I was satisfied that the themes inter-related and I could say that the notion of spirituality consisted of four identified themes which, when joined together, became an emergent model.

#### WOULD A MODEL HELP?

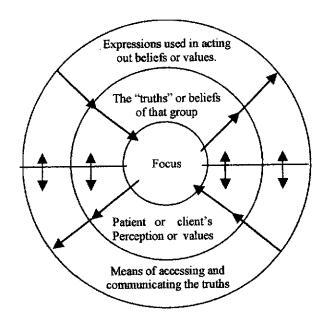
In portraying visually the inter-relationship between these themes I realised that the diagram "provided a way to visualise reality to simplify thinking" (Leddy & Pepper, 1993, p. 145) and could be termed a model, or a representation of the interaction amongst and between concepts showing patterns. My initial diagram is illustrated as follows:

Figure 1



However, this model was incomplete or inaccurate in that it did not include the person's (patient's or client's) personal perspective of their beliefs or truths. An appropriate place needed to be included for the personalisation of beliefs; otherwise, it would be of little use (if I wanted it to be able to be used by nurses and other health care professionals). That is, the model needed to include not only the focus of their spirituality, but also the focus of health care – that is, the person or patient. For example, the person's spiritual group might condemn abortion, but the person might feel that abortion would be the right thing to do in given circumstances. I realised that the inclusion of the person's values into the schema would allow a health care professional to identify possible conflict between proposed treatment and the person/patient's spiritual beliefs. After drawing more diagrams and raising further questions, I decided that the appropriate place for the person's perspective would be next to the focus of the groups, but opposite the group's beliefs. The second emergent model was as follows:

Figure 2



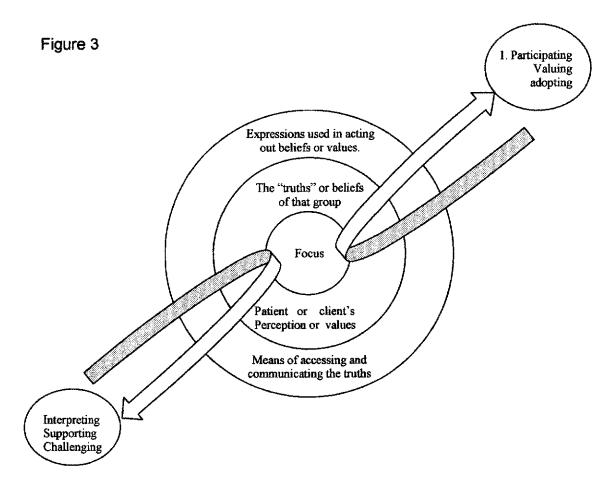
I felt comfortable with this revised model as I believed it could be used to define the potential content of a patient's or client's spirituality. This would enable health care professionals to develop their understanding of the spiritual, ethical and religious dimensions of experiences, including their own. As such, it serves as a map of the knowledge that I believe health care professionals need to have if they are to function in an inclusive manner within diverse and pluralist communities.

I probably need to add words to the model which portray certain behaviours for health care professionals to have greater understanding of the process that is occurring within the model. If I use words that imply the transmission of beliefs, values, and manifestations of those beliefs, then it should make sense.

# Words that Could be Used to Portray the Model Process

Terms that are commonly used by authors when discussing the transmission of moral values and culture are 'interpreting', 'supporting', 'challenging', 'participating', 'valuing', and 'adopting' (Barry, 1983; Hawley, 1997a; Nigam,

1997). Others are sometimes used but these are the ones I have chosen for this model. When discussing traditional beliefs and the person or community, the terms of 'interpreting', 'supporting', or 'challenging' are used to describe the issues and ultimate questions of shared human experiences. Whereas, when exploring the manner in which traditional belief systems affect individual person's patterns of belief, the terms of 'participating', 'valuing', and 'adopting' can be used. When these terms are added to the model of spirituality (Figure 3), we can imagine the process of transmission of the beliefs and whether or not they are personal and could be adopted.



The terms and arrows are intended to indicate something of the complex and dynamic relationship between the different areas of content signified by the circles. They do not indicate some of the learning processes which could be part of an education exploration of spirituality (see Chapter Eleven).

The first of these relationships (marked 1) is that which links individual patterns of belief, which are shared human experience, with traditional belief systems. The arrows indicate a two-way relationship between the individual and the other two areas. This relationship can be characterised by the use of the words 'participating' 'valuing' and 'adopting'. These point to the different levels at which we all relate to the total experience, knowledge and achievements of humanity, including those enshrined in the traditional belief systems.

#### **Participating**

All people obviously participate in the shared experience of humanity in some way and at one level to another. Most of us are aware of the big questions life presents. We have had experiences which highlight life's mystery and challenge, including some that suggest the possibility of transcendent realities. Equally, all individuals participate in particular cultures. We cannot jump out of our historical and cultural skins (Nigam, 1997). We are related in some way to traditional belief systems. They contribute to our shared identity and how we participate in the ongoing life of our culture.

#### Valuing

All individuals emerge in a process of selection in relation to life experience and the traditions to which we belong. Some aspects become increasingly valuable to us and others cease to attract our attention. Our maturity in relation to our own patterns of belief and behaviour is enhanced as we discover those aspects of life which are becoming more important to us and those which have little or no value for us.

#### Adopting

At another level, many individuals consciously go beyond a simple participatory action in the culturally conditioned life about them. They identify with certain groups, lifestyles, and value systems and adopt a particular way of life. Certain human and /or traditional characteristics are seen not only as being important and valuable, they become the focal point of the individual's own sense of identity.

In reality, relationships between individuals and systems are rarely as simple as the above analysis suggests. Yet, it is possible to observe these different levels, for example, by the way in which Christmas is celebrated. Some people carry on the tradition without considering its origins or religious significance. Others will attach value to what it represents in a general kind of way. Others will see it as a highlight of their faith and commitment.

The second relationship with which I was concerned is that which links traditional belief systems with shared human experience (marked 2). Again, the double-headed arrow suggests a two-way relationship, and I have used three terms to describe something of the essential characteristics of this complex relationship.

#### Interpreting

There is a very real sense in which traditional belief systems exist to provide a framework of understanding and a way of responding to the mysteries and challenges of human life. In some cases, this interpreting quality may be seen as providing answers, based on faith, to ultimate questions. In others, it may take the form of providing a framework in which the questions remain open and mysterious.

#### Supporting

There is also a kind of psychological dimension to the relationship between the belief systems and human experience. The experience of being human does not simply pose questions at an intellectual level. It also presents problems at an emotional level. In particular, there are experiences which shatter confidence and undermine the fabric of life, as well as those which stimulate determination and courage. At this point, the various belief systems provide, in their own ways, means for supporting those who need help and encouragement and outlets for courageous and adventurous exploits.

#### Challenging

The traditional belief systems offer important challenges to what might be done by the majority of people at a given time. Because this encapsulates ideals, visions, and ultimate goals, they often have the capacity to call on people to rise above their immediate circumstances and to pursue nobler ends. They can suggest new ways of looking at things, open new horizons and possibilities, and raise new questions about life. Similarly, developments within shared human experience can, and often do, present challenges to the traditions to re-think, or at least, reexpress, some of their basic beliefs and commitments.

The main purpose of the model is to help depict a patient's or client's spirituality so that patients and clients spiritual needs can be facilitated when receiving health care. It also offers an explanation as to how people may come to believe certain values and adopt them as behaviours. However, the model also illustrates a shared experience of humanity, that is, all people have a spiritual quality, and therefore this is something that we all have in common and can share with others. Let me take a concrete example of religious behaviour and illustrate how the model can help move towards an adequate knowledge and understanding of what is going on and at the same time clarify my own values. If I look at photographs of Muslim woman performing ritualised washing (wudu) before prayer, my knowledge of this action is not sufficient if it is limited to the knowledge of prescribed actions of wudu as a knowing that Muslims are required to perform this ritual as part of their prayer five times a day. However, I can also explore some of the ways in which this action (and associated beliefs) is related to the experience of being human in which this woman, myself and all other people participate, that is, the shared human experience. In this way, and from my perspective, I can guess that these actions and the Islamic beliefs that lie behind and are expressed through them, focus on the qualities of purity and cleanliness (as major contributors to human physical, emotional and spiritual health). This awareness of Muslim purity can help me to articulate my own beliefs and values about purity and how these may be expressed or not in my own life style.

To use the model, a health care professional would need to ask the person/patient questions to procure the necessary information. Once the data is obtained then the health care professional would be in a position to facilitate and/or optimise spiritual care. The following six questions can serve as a beginning guide to ascertaining this information:

1. Does the person have a focus or orientation that gives meaning and purpose to his/her life?

- 2. Does this focus or orientation lie within the beliefs of an organization/group/church; and what are these beliefs?
- 3. What is the person's own perception/perspective of these beliefs?
- 4. What ways are used by the person to communicate with the deity, power, focus, or orientation to understand the beliefs and/or truths?
- 5. What expressions (behaviours/actions/rituals) of spirituality would the person need to use and/or maintain while receiving health care treatment?
- 6. What artifacts or rituals would give the person comfort and strength while receiving health care?

Only when the health care professional had data from all six questions would s/he be in a position to facilitate the spiritual health of the person.

This model also allows health care professionals to recognise why some patients or clients accept or refuse treatment. For example, a seriously ill patient who needs a blood transfusion to survive may be Jehovah's Witness, and therefore it would be wrong in the eyes of their church to accept blood transfusion as treatment. In using the model, the health care professional would know of this belief, but would also ask patients of their perception of the beliefs. If the two corresponded, the doctor would then follow the legal guidelines of allowing the patient to refuse the treatment (Wallace, 1995). It also needs to be remembered that spirituality is more personal than are religious beliefs (which express the doctrine of the church and are not necessarily, the patient's spiritual needs). For example, a woman who belongs to a church that condemns abortion, may not regard the status of her embryo or foetus as sacred as does her church and therefore may wish to terminate the pregnancy. Therefore on asking the woman about her individual spiritual beliefs, these can be documented, and information given about the possibility of terminating the pregnancy.

#### Model Fit

This proposed model was checked to see if it fit the information I received from the various spiritual groups. That is, I made templates of the model and then placed the information from the groups (one at a time) on the template to ascertain that the model could work. (See Appendix 4 for examples). This was done and I was satisfied with the compatibility. The model was presented at the nursing research conference for health care professionals "Optimising Health Care Outcomes: A focus on education, research and practice" (Hawley, 1999). The comments at the conference included: some nurses seeking permission to use the model (which was given), and others not wanting Socialism and Humanism included in a model of spirituality, as they felt it was 'unchristian' (even though I had explained that spirituality was more than religious beliefs. Overall, most of the comments made suggested that it would help nurses and doctors to understand the components of spirituality and their inter-relationship. If this model were used in assessment of patients and clients prior to planning and discussing proposed treatment plans the health care professional might more readily realise the extent of patients' spiritual beliefs and, therefore, not be surprised when they accepted or rejected various aspects of treatment. In this way, the model could help the health care professional to support patients or clients in their decision instead of arguing and trying to get to them to agree with treatment they do not want.

Since first presenting the model at that nursing conference, I have also presented it at an international spirituality meeting (Hawley, 2000). The participants at this meeting were health care professionals, lecturers of religious education and theology, priests and chaplains. The responses at this meeting were primarily concerned with the use of the model in clinical practice and also in teaching, with no disagreement in relation to its potential. For example, a lecturer in religious education thought he would be able to use the model when discussing comparative religions. My greatest use of the model has been with teaching, at both undergraduate and postgraduate levels and in continuing education programs about spirituality. I have found the model to be powerful framework for explaining the nature of spirituality and for enabling health care professionals to ask the questions to ascertain how to meet their patients' and clients' spiritual needs. For example, when lecturing a group of continence consultants, they realised the importance of the model for helping them not to offend their patient

or client by prescribing inappropriate treatment, especially to a person with aspects of spirituality concerning modesty, sexuality, and elimination.

Although I presented the model to peers in the Doctoral Colloquium, my belief that it needed to be further critique prompted me to seek publication in a refereed journal. This would assist in facilitating the trustworthiness (by triangulation). In July 2001 I submitted the model as an article to Nursing Education in Practice (Blackwell Science Ltd).

## **Further Analysis**

No further analysis of the data obtained from the spiritual groups was undertaken, as I felt that I had achieved my aim of developing a rich understanding about the nature of spirituality, albeit from the combined perspective of spiritual groups in Western Australia. Although I had obtained much information from various spiritual groups, I still did not know what patients' or clients' felt their spiritual needs to be. Therefore, I decided to use the model when discussing spirituality with research participants and/or in applying data from the participants to the model.

The more I thought about not attempting any further analysis, the more convinced I became it was the right decision. One of the reasons for this, was that I remembered the nascent quality of spirituality and realised the many Australians who had spiritual needs but who did not belong to an organised spiritual group. Furthermore, on reading all the data from the various groups I had begun questioning some of my own spiritual beliefs, and realised it was important to explore this experience of dissonance.

If other people believe certain truths why don't I? Where am I in all of this? I have developed this super model, which makes sense to me, but it is causing me to rethink my own spirituality? There is nothing wrong with this in it self. BUT, from my own perspective I need to explore the Christian theological implications and perspective of teaching in this manner.

## MY NEED TO EXPLORE OWN SPIRITUALITY

In Chapter One, I argued that I and other health care professionals work in a pluralist or multifaith context, and that acceptance, promotion and celebration of diversity are an essential ingredient for the establishment and maintenance of a harmonious and peaceful community. On examining my cognitive dissonance it appeared that one significant source of doubt came from the concept that Christianity is one of the major missionary religions in the world. Being an ordained member of one of these religions, I needed to work through and reflect on this topic, that is, to address the question of what is the theology behind the concept of 'mission' in relation to teaching and clinical practice as a nurse?

This idea of mission has, for a significant number of Christians, been interpreted in evangelistic terms; that is, to actively seek to convert all people to Christianity. This understanding of mission is linked with particular understandings of beliefs in Jesus Christ as the only Son of God and the Saviour of the world. This doctrine implies that the gift of salvation is only available through faith in and obedience to Jesus Christ. This faith and obedience is expressed, primarily, through becoming a Christian (baptism) and participating in the life, worship (confirmation) and service of the Christian church (teaching others about the Christian faith).

# But there must be other ways of thinking of mission, but what are they?

At the risk of oversimplification, if not distortion, let me offer a brief summary of one of these ways. The Mission of God (Missio-Dei) reflects a Christian belief that God is a missionary God. The penetration of God's will into the world,

natural and human, and the accomplishment of God's purpose for creation is, therefore, essentially God's responsibility and task. Placing this notion of the mission of God at the heart of Christian missionary theology, it also reflects the belief that God's mission is directed at the totality of creation, and not just at some 'hereafter' or even 'religious' aspect of life. That is, God's missionary activity takes place throughout all time and within all human activity, religious and secular. Another implication of this belief is that those who hold it interpret their missionary obligation in terms of detecting what God is doing in the world now and, through faith and obedience, participating in it.

To me, this is significantly different from the perspective of Christian missionary obligations, which emphasise taking God and Christ's gospel into the places where they do not appear to be, then, by one means or another, eliciting a response from those who will listen to the Christian message, that is, evangelising.

But how do I, who owns this particular theology to mission, believe that I could detect the missionary activity of God and then join in it?

The Biblical concept of peace or *shalom* is seen by many Christians as the goal of God's mission and therefore as the prime indicator of God's contemporary missionary activity. According to The World Council of Churches, in its publication "The Church for Others", this single term summarises all of the gifts of the Messianic age, even the name of the Messiah can simply be shalom (Micah 5:5; Ephesians 2:14); the Gospel of shalom (Ephesians 6:15) and the God proclaimed in this gospel can often be called God of Shalom (World Council of Churches, 1967, 14). In other words, 'shalom' refers to a set of criteria by which every task and every achievement within the process of God's mission is controlled, recognised and evaluated. It points to all aspects of the restored and cured human condition. It points to a situation in which, among other things, the relationship between people, with all their individual, cultural and religious differences, are such as to promote personal and social harmony, growth, well-being and peace. It would appear that Christian health care professionals, who have this theological perspective to mission, will be able to judge their work on

the levels of shalom that they see emerging among those with whom they work (that is, their colleagues, students, patients and clients). In addition, they will be able to promote and participate in any activity which contributes to the search for a harmonious and peaceful community through, among other things, the acceptance and celebration of diversity.

Now that I have reflected on this notion of Christian mission, as being peace or *shalom*, I no longer feel the cognitive dissonance that I did before. I feel prepared to engage in further teaching and practice, including active participation in the promotion of spiritual diversity for a peaceful community.

#### CHAPTER SUMMARY

A survey of various spiritual groups (churches, spiritual and philosophical groups) in Western Australia was undertaken to gain greater knowledge of the phenomenon of spirituality within the multicultural population in WA. Once the information was obtained it was analysed to identify common or universal themes. It was discovered that the various spiritual groups that replied had a focus and significant truths or beliefs, which were important components of their community member's lives. The manner in which these beliefs could impact on health care treatment was realised, and the ways in which patients and clients may want to use to access their Higher power, deity, or the orientation of spirituality while receiving health care. Questions were developed that would allow health care professionals to understand their patient's or client's spirituality. These same questions were trialled with all the information received from the various religious and spiritual groups in WA, and it was found to be compatible with all of them. I discovered that the basis of these questions were common themes from the data. What I had not realised was the ease in which the model and questions made sense of the information so that it could be readily understood.

The great difficulty today in dealing with the subject of spirituality lies in the very mass of the material to hand, not only on account of the labour involved in sorting the data material, but because of the abundance of facts that could lead to the temptation to rush in too hastily with what may seem to be a plausible theory. That is, the more facts, statistics, and so forth, there are available in any investigation, the easier it would be to pick out a considerable number that could fit a given theory.

By exploring my own personal crisis, I have not only realised that I can remain true to my own beliefs, but at the same time I have also suggested to other health care professionals with similar Christian beliefs a way of working with people of dissimilar spiritual beliefs. That is, perhaps they too can see their active participation in multifaith activities as legitimate and positive expressions of both their professional and missionary obligations. This is because I believe that at least one essential purpose of the spiritual life of the health care organisation, to which health care professionals contribute, is to build up community, not to lead to its disintegration.

Into an unknown land
The pass grows steeper,
The air colder and sharper,
A wind from my unknown goal
Stirs the strings
Of expectation
Still the question:
Shall I ever get there?
There where life resounds,
A clear pure note
In the silence.

(Dag Hammarskjold, 1963)

#### RESPONSE TO EXAMINERS' REPORTS

## A phenomenological study of the health care related spiritual needs of multicultural Western Australians.

When supplying a list of potential examiners' names to the Thesis committee I was seeking criticism from the three different aspects contained within the dissertation. That is, the educational aspects (Professor Nancy Davis), multiculturalism (Dr Seon Uk Lee) and nursing (Dr Mary Kunes-Connell). This response discusses each of the examiners reports separately, that is, the first by Professor Nancy Davis, the second from Dr Seon Uk Lee, and the third by Dr Mary Kunes-Connell.

#### Professor Nancy Davis grade awarded A

Professor Davis expertise in phenomenology, postmodernism, and the works of Ken Wilber, and her interest in spirituality in education (which are all components of the thesis) made her criticism of the thesis very important to me. Professor Davis stated that the thesis had three weaknesses; these were, the one of the model of spirituality, the lack of a summary of the participants' characteristics, and incorrect grammar. In relation to the model of spirituality, I realise that further explanatory power needs to be given to explain the interrelationships and flow between the components. At the time that I was developing the model I lacked the knowledge and understanding of the phenomenon of spirituality, the ability to critically analyse, and also the research skills. In fact I do state in the thesis that I developed the model to try to understand the phenomenon of spirituality. At present, I do not want to make changes to the thesis to give the model greater explanation. Instead, I intend to collect a new set of data in this country (UK) to test the validity of the model. By performing this new project I believe I will be able to give the model the greater explanatory power that Professor Davis says is missing.

Professor Davis states that an example that illustrates the use of the model would make it clearer. Appendix 4 of the thesis included the use of the model with Humanism, and the religions of Buddhism and Judaism.

The lack of a summary of the participants' characteristics had been rectified and this has been included as a matrix on page 125. The grammar mistakes of the pronouns and the antecedents not being compatible have been corrected. Likewise, the typographical errors and author's works from the reference list have been corrected.

What wasn't included in the official thesis report was a suggestion that Professor Davis made to me (via email) for further research in the area of spirituality. This new research will possibly further extend the knowledge and understanding of spirituality. I am at present reading the literature that Professor Davis recommended and looking for research funding to enable me to do this.

## Dr Seon Uk Lee grade awarded A

Dr Seon Uk Lee's knowledge of science education and her personal knowledge, understanding, and experience of living in Australia as a multicultural person made her comments very important. She is person, who, in Heidegger's words, knows what it is like to live in Western Australian's culturally elitist 'Anglo-Celtic Judeo-Christian traditional' world (as described in the thesis). Therefore, I was extremely flattered by Dr Seon Uk Lee's responses to the thesis.

No changes were requested.

## Dr Mary Kunes-Connell grade awarded B

Dr Mary Kunes – Connell expertise is in the field of nursing education and hence I value her comments which she made 'in text' in relation to the nursing care of patients/clients. These she did not describe in her report, instead they were for me to find when reading the dissertation. Basically she was agreeing with the interpretations I had made from the data and the suggestions I included as to how health care could be given in those situations.

I should mention that I met Mary at an international nursing education conference shortly after I had received the results (but at that stage had not received her written comments). Mary congratulated me on the thesis, and we discussed the findings on a couple of occasions (over a glass of red wine in the pub). Mary's research expertise does not extend to phenomenology (as it does for Professor Davis and Dr Seon Uk Lee) and hence her queries and criticisms in the report do not surprise me. In fact she told me at the conference 'there was just so much writing' compared with other research methods (quantitative). In retrospect, the discussions that we had perhaps helped her to clarify the meanings she gained from reading and examining the thesis (i.e. the nursing component). In response to the negative criticism (including weaknesses) written in the report I list each one below *in italics* followed by my response.

#### 1. Overall content.

The writing of the chapters as discrete entities. I explain in the thesis that my purpose for writing the findings as discrete entities was so that the reader would not become confused between the spirituality as experienced by the participants, the identified spiritual needs, the patients'/clients' rite of passage, and the desired levels of spiritual care wanted. Therefore, I bring all these chapters together in Chapters Ten and Eleven (postmodernist spirituality and the discussion). To do so earlier, I believe, would have not only made it confusing for the reader but also for the researcher who was writing the analysis of the data into the findings.

Mary mentions that Moustakas and Cresswell suggest that a single unifying meaning of the phenomenological experience under investigation can be captured and described. To some extent this has been done by the new definition of spirituality that I formulated and wrote in Chapter Eleven. To try to capture a more unifying meaning

of the participants' experience would not be consistent with the interpretative phenomenology methodology of both Benner and van Manen that I was following. Neither of these authors suggests trying to find such a meaning. Thus, Mary's suggestion of a separate chapter describing this common unifying experience among the participants has not been done.

#### 2. Chapter 1

The suggestion that a better connection needs to be made about the economy and the need for a multicultural perspective on page 12 has been done.

#### 3. Chapter 2

The weaknesses highlighted are those similarly made by Professor Davis, and so these will be attended to when the model is validated. In reference to the 50% return rate and why no follow up was undertaken it is stated in the thesis on page 38 why this was not done.

#### 4. Chapter 3

Approach to the chapter is almost so phenomenological that it could lose the reader. This criticism stems from the fact that I did not write two separate methodology chapters. The first, describing the proposed research design and how the data analysis would be done, and then the second chapter describing the actual analysis. Instead I described and emphasised the epistemological process as it occurred. This is a common way of writing phenomenological research and many students adopt this method (see previous Doctoral Thesis in SMEC).

#### 5. Chapter 4

The comment that 'one has to hunt around to find out the actual sample size' is not accurate as it is mentioned in several places throughout the chapter that eight participants were interviewed 3 or more times. The suggestion for a table listing all the possible (30) participants and why they were or were not chosen in the final sample will not be undertaken because it is stated in the thesis that it is a 'purposive' sample, and that I could only use those volunteers who could reflect on their experience. That is, I interviewed those who did have the ability to reflect and contribute to the study, and those who were representative of the various multicultural groups, had different spiritual beliefs, and experienced various health problems. I do not believe that formulating a table and including it in the dissertation would improve the thesis.

The comment in relation to my attendance at spiritual events and the suggestion that data could have been retrieved from these events and be included in the dissertation has not been acted upon. I attended these events as a guest of the various organisations. To include my perceptions in the research, I believe, would be unethical because the invitations were issued with the premise of hospitality.

#### 6. Chapter 5

The comments for this chapter were written on the actual dissertation text. No weaknesses mentioned or changes requested.

#### 7. Chapters 6-9

The comments for this chapter were written on the actual dissertation text. No weaknesses mentioned or changes requested.

#### 8. Section 3

The comment by the Dr Mary Kunes-Connell that case study and phenomenology are two different research methodologies. I stated in the dissertation that the methodology was that of the 'blurred genre', that is, where the theory of phenomenology is blurred with the subtleties of the data collection and reporting (in this instance, case study). (Denzin & Lincoln, 2000, p. 15). Therefore, I do not see the need to make this change to the dissertation.

The purpose of the study as stated on page 31 is not written the same as that in Section 3. This has now been rectified with the words being exactly the same.

Dr Mary Kunes-Connell's response to the dissertation are valued not only because of her expertise in nursing education but also because of her thoroughness in writing her comments and thereby seeking clarification of points outside her area of expertise.

#### Conclusion

The three examiners have supplied me with the criticism I was seeking for the dissertation 'A phenomenological study of the health care related spiritual needs of multicultural Western Australians'. The three different aspects contained within the dissertation, the educational aspects (Professor Nancy Davis), multiculturalism (Dr Seon Uk Lee) and nursing (Dr Mary Kunes-Connell) have now been evaluated. If it is appropriate I will write to the examiners thanking them for the time and expertise that they contributed to the process.

The Rev'd Georgina Hawley, October 2002.

#### CHAPTER THREE

## PHILOSOPHICAL FRAMEWORK AND RESEARCH DESIGN

The morning air was crisp, as most spring mornings appear to be, except in this case I was walking at about 1,000 metres above sea level. The road was unsealed and there was evidence of recent landslides in the area. The fields on either side of the road were planted with pyrethrum flowers, with their dainty yellow heads waiting to be harvested by hand with a bush knife. As I walked along, I wondered if the crop would be brought in and sold for a good price, or whether it would go to seed before the people were well enough. You see there was an influenza epidemic racing through the highlands of New Guinea, with many villages seriously affected to the extent that harvesting was not done, people were extremely ill and some dying.

Government figures showed many indigenous people dying from the influenza. These numbers had been obtained anecdotally, and could not be said to be a true account. However, that did not stop journalists in the territory and overseas from publishing them as true facts. Being out in the countryside on patrol at the time of the epidemic, I realised that some people were dying from the influenza, but that also some deaths could be attributed to local custom for that community of villages.

These highland people had a custom of bringing about their own death when they were old and tired and didn't want to live anymore. For them, it was quite simple. The person who wanted to die took themselves off to a hut on

the edge of the village or outside and instructed their kinfolk not to bring them any water or food. Due to the steep terrain of the countryside if they were old or sick they would not be able to get their own water or food, and consequently died through will power and starvation.

For others who did have the influenza, Tetracycline was given by health care workers on patrol with us and those at local aid posts. Hence, the scenes that I witnessed out on patrol among the people, and those reported by the press of the day were widely inconsistent. Such an experience taught me to question reported statistics, as it made me realise how a very wrong picture could be presented as truth, a picture that has stayed in my mind all these years and resurfaces each time I plan a piece of research or review statistics in a published study.

#### INTRODUCTION

The diverse nature of the population of Western Australia, built from successive stages of immigration over 150 years, and the recent acceptance of refugees from other countries, has resulted in a range of cultures (as can be seen in Tables 1 and 2 in Chapter Two). All the people, including indigenes, migrants and refugees, require health care from the one government system (in the largest and most geographically rambling State in Australia). In order to design a research study that would identify the spiritual needs of this diverse population, I have been guided by three interconnected, generic activities that define the qualitative research process. According to Denzin and Lincoln (2000), these are the "gendered multicultural researcher, with a set of ideas, a framework (theory ontology) that specifies a set of questions (epistemology) that are then examined (methodology, analysis) in specific ways" (p. 11).

This style of methodology in the history of qualitative research is known as the 'Fifth Moment' (Denzin & Lincoln, 2000). Such an approach came about as the result of the crisis of representation (the Fourth Moment) which occurred in the

mid 1980s. It is since that time that new models of truth and method have been sought to rectify the faults with the previous ways of qualitative research. The problem areas that were targetted were (a) the assumption that qualitative researchers could directly capture the lived experience of their participants, and (b) the traditional criteria for evaluation, such as validity, generalisability, and reliability, which are not suited to poststructuralism. What developed was the Fifth Moment, which acknowledged that the researcher can only interpret the behaviour or situation, and that there is no difference between writing and field work - they occur simultaneously (Denzin & Lincoln, 1994a). In this study, I have used the genre of the Fifth Moment, in that the researcher is no longer aloof and occupied with grand theory, but is more in favour of "local, small scale theory to specific problems and specific situations" (p. 11). The specific problem being that the spiritual needs of multicultural patients and clients was not known, and the specific situation being that of health care in Western Australia.

In order for me to undertake a Fifth Moment approach in qualitative research I needed a philosophical framework that would enable me to validate the uniqueness of each person's mother culture and, at the same time, to explore commonalities amongst their spiritual needs (Denzin & Lincoln, 1994a). This chapter describes the philosophical framework I used to guide the phenomenological approach of my research design. The procedure, methods, sample, trustworthiness, evaluation, and the means for protection of the participants (human subjects) are described. The selection of participants and the methodology of their interviews are described in the following chapter (Chapter Four, "Taking Time to Smell the Roses").

The philosophical framework was translated into a research methodology for understanding the relationship between the phenomena of spirituality and health care and the nature of the culturally diverse population. For this reason, I employed a postmodernist interpretative approach based on participant narrative research (Benner, 1994; Denzin & Lincoln, 1994b; Erickson, 1998; van Manen, 1990). I have named my methodology as "interpretative phenomenology" in order

to describe the epistemology taking place; that is, although utilising interpretative methods, I have remained faithful to hallmarks of Heideggerian (1978) and Bakhtin phenomenology (1986).

The first section of this chapter gives an overall description of phenomenology, and that of phenomenological spirituality and self. The second section outlines the philosophical basis of the research framework, incorporating the elements of Heidegger and Bakhtin. The final section contains the philosophical elements that were adopted as assumptions for the study (Denzin & Lincoln, 1994a). The descriptions of phenomenology and the philosophies of Heidegger and Bakhtin are discussed so that the findings in Chapters Five to Nine can be explored, interpreted, and discussed in relation to these writings.

#### PHENOMENOLOGY

Phenomenological research aims to question basic assumptions, and to go back to the original situation prior to theoretical explanations in order to reveal phenomena in a new light (Madjar & Walton, 1999). Phenomenology is derived fundamentally from an emphasis of concern with ontology, that is, a concern with what it means to be a person and how the world is intelligible to them (Benner, 1994). Phenomenology was first described by philosophers Husserl, Heidegger, Merleau-Ponty, Marcel and Sartre in the early part of the twentieth century. Phenomenology strives to gain insight into specific phenomena in order to gain understanding and description of human experience (van Manen, 1990). has been used in various disciplines produce Phenomenology phenomenological sociology, phenomenological psychology and psychiatry, and phenomenological education (van Manen, 1990).

Phenomenology differs from various human science approaches, such as ethnography, symbolic interactionism and ethnomethodology, in that phenomenology makes a distinction between the appearance of something occurring or happening and the essence of that occurrence (Madjar & Walton, 1999). Phenomenology is primarily concerned with the nature or meaning of

something, that is, with the essence (van Manen, 1990). Moreover, phenomenology does not produce empirical or theoretical observational accounts. Instead, it offers accounts of experienced space, time, body and human relationships as they are lived (Benner, 1994).

According to Madjar and Walton (1999), a person's experience is their "basic mode of being in the world; consciousness is embodied consciousness, and a person is an embodied being, not just the possessor of a body" (p. 4). That is, the meaning of being a person exists only as personal subjective knowing by the person concerned. Such a view recognises the whole person (including the person's embodied spirit), capable of remembering past experiences of illness, injuries and life experiences of coping or not coping with such situations (Madjar & Walton, 1999).

I believe that phenomenology is the ideal research methodology to use in this study because of the compatibility, or fit, between the principles of phenomenology and the research questions posed in Chapter One.

## Phenomenology and Spirituality

According to Csordas (1994), spirituality falls within the cultural phenomenology of the self-body and, as such, phenomenologists have defined their understanding of spirituality as a kind of modulation or reorientation in or engagement with the world. According to Eliade (1958), spirituality is a way of attending to the world, and observed that the object of spirituality was towards another. It could be said that spirituality is an existential encounter with otherness, that is, spirituality is the touchstone of our humanity (Tillich, 1955). According to Geertz (1973), such encounters are said to include systems of symbols that are articulated in a system of social relationships, and spirituality can act to establish long standing moods and motivations found in the phenomenologists' notion of otherness (Geertz, 1973).

For each person the idea of their body is unique and unlike another persons (Csordas, 1994). Furthermore, the perception of our body is not without value-laden descriptors (be they spiritual or religious assumptions). For example, when giving spiritual counselling (to facilitate her spiritual needs) to a woman having difficulty in conceiving, I might ask her if she has expressed her emotions to her god about the situation. The range of responses I receive reflect the woman's values about her body, and the job description she has allocated to her god. For example, such responses have included: "we were taught at school that you don't talk about sex to other people, and my prayers certainly wouldn't include something like that!" and "I tell God to make me pregnant, I certainly don't tell him that I cry each month when I realise I am not pregnant". In such cases, the women are limiting the potential development of their own spirituality, which could perhaps help them with their image of sexuality and difficulty in becoming pregnant.

Spiritual beliefs are also embodied through practices which may be said to precede the beliefs. In other words, devotional practice (as a manifestation) to a spiritual belief is not an optional frill of a metaphysical theory acquired elsewhere. Rather, practices are the very mode of spiritual beliefs, ultimately transcending the thought/action divide (Csordas, 1994). Conversely, the inability of people to access their spirituality by, for example, entering communion with God through prayer or meditation may occur because they have not had any spiritual education or teaching.

People generally regard their "self" as neither substance nor entity, but as an indeterminate capacity to engage or become orientated in the world. According to Csordas (1994), this also involves effort and reflexivity. In this sense, self occurs as a conjecture of prereflective bodily experience, culturally constituted world or milieu, and situational specificity or habitués (Landrum, Beck, Rawlins & Williams, 1993). That is, a person's self is processed by orientation in which aspects of the world are thematised, resulting in the self being objectified and becoming a "person" with a cultural identity or a set of identities (Geertz, 1973).

Each person's perception is the essential concept in the definition of self as self-awareness, that is, the persons' recognition of themselves as an "object in a world of objects" (Csordas, 1994). This self-awareness is both necessary to the functioning of society and as a generic aspect of human personality structure in self-understanding. The displays of self are very wide in Western Australia due to the diverse range of cultures and the various countries people come from (see Chapter 2). For example, it is usual to see the covered Muslim woman or the Sikh man with his head turban, just as it is to see the teenager wearing the latest in basket ball apparel complete with Nike trainers.

However, no matter how much conceptual sense our definition of the self makes, it remains empty theorising unless it is capable of dialogue with lived experiences of phenomena. In this study I needed to identify participants' spiritual needs from my interpretation of their insights, especially the data from interviews, and by understanding their self-awareness and understanding of spirituality. Such findings could not be readily surmised due to the large number of dissimilar spiritual and cultural groups in Western Australia and because each group teaches their members values in relation to body, education, health care, and roles in society, all of which become the embodied self for that person.

This embodiment can be illustrated in a sight I see each week at the local supermarket, the group I refer to are the Exclusive Brethren. Although I use this group as an example of embodiment, I do not mean to be judgmental, but rather show the effect on a community. The women usually shop for their large families on Saturday towards the end of trading hours when some lines are reduced in price. They live near each other, socialise only with each other, and marry someone from the same group, beliefs, and values as themselves. If one of the group should resign their membership and/or leave, they are not allowed to socialise or have anything to do with other members of their family or the spiritual group. Such strong control influences the environment in which they and non-members live. For example, in health, the women sometime continue having babies at an older age against medical advice (a practice which can stretch limited

health resources in a community). In one country town in Western Australia, when the Flying Doctor Service is called in to air lift a patient out to a large city hospital for expert care, the Exclusive Brethren members will not help the pilot (who as a child had been a member of the Exclusive Brethren) to load the patient into the plane. The refusal to help stems from the fact that once a member leaves this brethren group they are ostracized by all group members in the state of WA. This example of embodiment is used to illustrate the various examples that can be easily seen in Western Australia. Other groups also have observable signs of embodiment, but are not described in this thesis.

## Philosophical Basis of the Research Methodology

I explored several philosophical models in order to facilitate and provide a phenomenological framework for the design and conduct of this study. What I needed was a philosophy and design that would accommodate the following criteria embedded in Chapter One and in the first section of this chapter.

- The primary aim of health treatment is the caring process that helps a person attain or maintain health or die a peaceful death.
- There is a uniqueness of each person which needs to be respected to be compatible with the government's multicultural policy and the cultural embodiment of each of the various participants' protected.
- The understanding that each person knows what he or she wants in relation to the context of the world in which they live (that is, the acceptance of peoples' contrasting values and beliefs and cultural differences to understand their phenomenology of Self).
- Conversation/s, that is, words, pictures, and symbols used by people are the truth on which the study could stand, that is they are manifestations of their phenomenology of Self, including their spirituality.

I discovered that the philosophical assumptions of Martin Heidegger would be compatible with the desired outcome of the research and, therefore, could be used in the research design to protect the uniqueness and worthiness of the participants' beliefs. Especially the compatibility between Heidegger and Asian culture

(Parkes, 1990), as there is a strong Asian population in Western Australia. However, I wanted to do more, in that I wanted to bring about change in the spiritual education of health care professionals. Bakhtin's phenomenology of language theory proposes how to bring about such change by using a two-level textual analysis (Bakhtin, 1986). I adopted both Heidegger's and Bakhtin's philosophies, in a manner, which I believed, could provide the framework for the study. (Later, in Chapters Five and Six these philosophies are discussed in relation to the findings).

## Peoples' Epistemology from Experience

According to both Heidegger and Bakhtin (Bernard-Donlas, 1994; Plager, 1994), there is no privileged position for objective knowing, and all knowledge comes from the people (who are already in the world) seeking to understand individuals (who are also) in the world. In this way, I could be involved within the interpretive research cycle with the participants (Bernard-Donlas, 1994; Plager, 1994). I was able to view the participants and myself as sharing common practices, skills, interpretations, and everyday practical understanding by being in a common culture and language (Benner, 1994). According to Gadamer (1990), this relationship between researcher and participant assumes the role of "cocreators", in which there is a meeting of perceived knowledge between the two, and we would be co-creators of the epistemology or way of knowing the essence of spirituality in relation to health care.

## Peoples' Worlds

When thinking about the phenomena of spirituality and health care I needed to ask the question "how and what would be the participants' world?" in such situations. 'Being-in-the-world' is a Heideggerian phrase that refers to the way people act, and are involved in their world, for example, as parent, child, student (van Manen, 1990). In this study, people were foremost patients and clients of the health care

system, but also mothers and fathers, husbands and wives, sons and daughters, as well as green keeper and nurse, anthropologist and an Elder of a spiritual group.

According to Heidegger (Dostal, 1994; Gadamer, 1976), a person's "world" is "a priori", that is, it is the person's given cultural and linguistic practices and history. Language predetermines and prescribes the person's world, in that it both articulates and makes things noticeable. Language also creates the possibility for particular ways of feeling and of relating (Bernard-Donals, 1994; Gadamer, 1990). Heidegger used the term "thrownness" to express an individual's view of beingin-the-world at that time (and therefore already situated) (Gadamer, 1976; 1990). A person's existence encompasses the workings out of the possibilities that exist when a person is "thrown" into a particular cultural, historical, and familial world. In this manner, a person constitutes his or her own "world". Although, at the same time, he or she is constrained in ways by language, culture, history and personal values (Bakhtin, 1981; 1986; Bernard-Donals, 1994). This is evident in contemporary health care, especially in organisations where several multicultural groups request treatment. In Western Australia, a Muslim woman attending a maternity hospital for ante natal care will always be accompanied by her husband, for it is the husband who will make the decisions in regard to any necessary treatment. In some cases, the woman may not speak English and the husband acts as interpreter. For this couple, their culture determines their behaviours in that the male is head of the household, and no person will see his wife undressed in any way unless he, his mother, or her mother is present.

However, a person's world is not a purely intentional cognitive set of beliefs; neither is the environment viewed as an object (Gadamer, 1976; 1990; Bernard-Donals, 1994). It is a milieu of contextual factors, in which my research aim was to try to understand the essence of participants' experiences of spirituality and health care. This part of the philosophical framework allowed me to accept and respect each of the participants as unique individuals in their own world and their own perception of that world; and to them this was their "truth" that they were telling me.

## The Significance of Value in Peoples' Lives

Another essential facet of people (besides their view of their world) from the Heidegger and Bakhtin phenomenological perspectives, is that each person is a "being" for whom "things" have significance and value (Bernard-Donals, 1994; Gadamer, 1990). Things/situations/incidents can be made significant – and described as threatening, attractive, stubborn or useful, and so forth. This significance is the background for additional reflection, desiring and/or evaluating by those involved (Bakhtin, 1981). Both Heidegger and Bakhtin maintained that "things" are inseparable from the world and that people engage with these in order to protect themselves from being reduced to the state of "a means to an end" (Bernard-Donals, 1994; Gadamer, 1990). In this way, people in the phenomenological view have not only a world in which things have significance and value but also qualitatively different concerns based on their culture, language, and individual situations (Gadamer, 1990). This view is demonstrated in the way people value things in their life and their social environment.

Therefore, to understand a person's behaviour or expressions, I needed to study the person in context, taking note of the social constructs of the person's world and their thrownness (Benner, 1994; Denzin, 1994; Hodder, 1994). For it is only in context that the things a person values and finds significant are manifested and can be discovered. Understanding the relational and configurational context allowed me to appropriately interpret what was significant for each of the participants (Benner, 1994; Denzin, 1994; Gadamer, 1990). For example, a participant (Sophie) told me of how when she came to Australia with her parents, and went to school and learned English, she became the family's interpreter. It was this role that formed the bond between her parents and herself until they died some forty years later. This role was a significant part of her life and world and the world of her parents. The discussion of the participants' social construct world is explored in an essay as Appendix 17.

## People's Ability to Understand

Heideggerian phenomenology assumes that a person has the ability to self-interpret, in a non-theoretical non-cognitive way (Leonard, 1994). People are able to interpret a situation and act without consciously realising that they are doing it from within their particular linguistic and cultural traditions (Gadamer, 1976). In Bakhtin's theory of language, all verbal communication a person expresses is limited by the person's ability to articulate and is based on his/her personal background (Bakhtin, 1986; Bernard-Donals, 1994). This was evident to me when interviewing the participants, in that when I asked them a question they answered from within their own ability. For example, when I asked a participant (Geoff) what he thought was meaningful in his life, he could not answer. However, when I asked him was important to him, he could answer. He was limited by the words that I used because they were not part of his everyday language. When I used another word that was part of his everyday communication, he was able to respond.

Although the name of "hermeneutic phenomenological" method is the common method stated by various researchers for undertaking research studies that explore human behaviour, Bernard-Donals (1994) implied that it could not be used when Bakhtin's theory of language was used. This is because it doesn't adequently theorise "subject construction" to comply with Bakhtin's perspective, in order to bring about change. Because I wanted to incorporate the assumptions of Bakhtin, I contemplated using another method. However, according to van Manen (1990), hermeneutics is the theory and practice of interpretation. He states that, for Heidegger, the notion of hermeneutic understanding is not aimed at reexperiencing another person's experience, but rather it is to grasp one's own ideas of possibilities for being in the world. In this way, to interpret a text is to come to an understanding of the possibilities of being in the text. In fact, Heidegger's hermenuetics has been described as 'interpretative phenomenology' (van Manen 1990). This brought about my adoption of the 'interpretative phenomenological' method, although in a modified form.

## Interpretative Phenomenology

Interpretative research is a recent development to be used in both education and health care: an example includes Madjar and Walton's (1999) "Nursing and the experience of illness", a book of some seven studies by varied Australia and New Zealand researchers utilising phenomenology in the last few years. Because of the contemporary nature of the methodology, there is not one way or one set name for this approach. Although I believe it is immaterial as to the name of the methodology, it does have one standard epistemological feature. This feature is its concern with producing understandings about the significance of what is happening in a specific social setting, such as health care, from the perspective of the research participants. Of special note, the interpretative methodology includes the researcher as a participant in the research milieu, as the interpreter of the situation both at the time and on reflection (Denzin & Lincoln, 1994b; van Manen, 1990). To suit the needs of this study and the large amount of valuable methodology available in print, I did not completely accept or reject one particular stance; rather, I used a modified approach.

The modifications to the interpretative phenomenological method included my acceptance of some parts and rejection of others. In a way, the approach used is not purely that described by Benner, Hussel, Heidegger, or van Manen. Instead, some of these have been used with the addition of Bakhtin and Gadamer, to fulfil the goal of this study. This modified interpretative phenomenological approach takes into consideration the following points.

- Husserl (Benner, 1994; van Manen, 1990) believed that a researcher, when interviewing people, could "bracket" his/her own personal perceptions and ideologies. That is, I could state my own thoughts and biases then assume that these would not prejudice or bias my interpretation. This appeared unreal to me and not possible to achieve so I did not adopt this idea.
- Heidegger, on the other hand, did not believe that this was possible, and that
  my personal perceptions would colour the interpretation. This seemed more
  reasonable and honest to me, so I adopted this idea. To me, it would be better

- to state my personal perceptions at the beginning of the writing and throughout the whole process. In this way, I could reflect how these were affecting the interpretation process.
- Husserl, Heidegger, and Gadamer also believed that the essence or basis of a
  problem was the "truth" as far as that person was concerned. Consequently, I
  assumed that whatever the participants told me was their truth, which I
  accepted as such.
- Heiddegger said it was possible only to perceive people's communication, and that there may be various layers or depths in attempting to find the essence or basis. This I found to be quite accurate. On listening to the tapes of the conversations I had with the various participants, I discovered differing levels of possible interpretation. The first hearing of the tape-recording usually gave me intuitions, guesses and questions which I needed to clarify from the data. Subsequent hearings gave me greater understanding, with additional questions to be clarified.
- Bakhtin's philosophical theory of language emphasises the use of a two-level textual analysis in order to explore the social constructs of the participants' dialogue (Bakhtin, 1986). Because the first level of analysis is the same as that suggested by van Manen (and used in Chapters Five to Nine), the second level was undertaken separately to define some of the characteristics of the sample (see Appendix 15).
- Although van Manen (1990) doesn't name his research method as 'interpretative phenomenology', instead using the term "hermeneutic phenomenology", it appears to be a combination of Husserl's and Heidegger's concepts as listed above; and therefore I could adopt van Manen's approach (1990). Similarly, I could use Benner's (1994) or Denzin and Lincoln's (1994) way of collecting and analysing data, so long as I made no attempt to bracket my views, but to include them in the role as interpreter. These views were written in my journal, and then later written into this report (and denoted by the use of the Lucida Handwriting font).

In this way, I believed my interpretative phenomenology was compatible with the basic argument of this study and allowed for my interpretation of Heidegger's and

Bakhtin's philosophies. I therefore adopted its use, and the manner in which I did this is discussed in Chapters Four, Five, and Six.

## THE STUDY ARGUMENT

The following argument or set of premises of this research study have arisen from the discussion in Chapters One and Two, and the first part of this chapter.

- This interpretive inquiry is motivated by my concern that, amongst health care
  professionals, the diversity of Australian people's spiritual needs are not well
  known, resulting in peoples' spiritual needs being ignored or dismissed when
  seeking health care.
- The primary source of spiritual knowledge is the observable everyday activity undertaken by people.
- This human behaviour becomes a text analogue that can be studied and interpreted in order to discover the obscured meaning. In this mode, people's spiritual needs can be identified.
- Although health care professionals can facilitate the meeting of spiritual needs, it will ultimately be the patient or client who can say that their needs have been met.
- By analysing the study data (taking note of the rhetorical content, social context and material construction) using interpretive phenomenology, peoples' spiritual needs will be able to be identified, and suggestions made to meet these needs.
- I anticipate that the findings and recommendations could increase the health care professionals understanding of spirituality and to provide a framework for assessment and intervention.

Although I postulated this argument and hoped to enact these premises, I did not want to pre-empt any findings, so I needed a way of stating these hopes and checking if they occurred during the study. These hopes were not research questions, but rather 'assumptions' that I declared. In this way they became statements for which I had gathered no material evidence from the field, but

which I assumed would occur until such time that the material from the field did or did not support them. My use of assumptions is derived from the definitions of "assume" and "assumption" from the Collins Dictionary and Thesaurus (1994) "to take for granted or without proof" and "the act of taking for granted or supposing (p. 65)".

- Assumption One That a participant has knowledge about something and this is in relation to his or her own subjective experience. (See Chapter Five).
- Assumption Two When participants' tell of their present experiences, they will also remember the past and think of the future. (See Chapter Five).
- Assumption Three That participants' will have an underlying spiritual need or want or cry. (See Chapter Six).

These assumptions are discussed in subsequent chapters to discern the fit of the philosophical framework and interpretative research design with the data. That is, I discuss each assumption with the generated data to check if the findings could or could not support the assumptions. By exploring the relationship between the factors (of philosophical framework and design with the data), I hoped to interpret the findings in way compatible with Heidegger's, and Bakhtin's philosophical and phenomenological theories, the findings of which could be discussed and recommendations made. (see Chapters Ten and Eleven).

## RESEARCH DESIGN

The goal of an interpretive design is to understand everyday skills, practices, and experiences; to find commonalties in meanings, skills, practices and embodied experiences; and to find exemplars or paradigm cases that embody the meanings of everyday practices. By identifying paradigm cases (that is, situations or incidents) and exemplars that represented strong instances of particular patterns of meanings, I was be able to depict the participants in the situations and preserve the meanings and contexts. In this way, the paradigm cases and exemplars enabled me

to access the participants' everyday lived experiences and open up a new understanding of culturally diverse Western Australians spiritual needs.

Interpretive methodology seeks to develop the participants' explanations and understandings that they express as concerns, practices and meanings (Denzin, 1994). The design is based on the search for common meanings in the data, reflective interpretation of various parts to the whole, contemplating what further data could be gleaned from the information, and entering the inquiry cycle in the right way. Thus, the interpretive process moved back and forth between part and whole and between the initial concern or question and what was being revealed in the data of the study (Benner, 1994; Denzin, 1994; Van Manen, 1990). There was also the constant mandate to go beyond existing, available, publicly authorised interpretations of things to follow a more authentic and deeper analysis that was projected in the possibilities (Bakhtin, 1986; Bernard-Donals, 1994). It was through systematic analysis of the whole that I was able to gain a new perspective and depth of understanding. This understanding was then used to examine the parts of the whole, and then re-examine the whole in light of the insight gained from the parts. The interpretive process followed this whole-part strategy until I was satisfied with my depth of understanding. Thus, the interpretive process had no clear termination, except for when I felt that there was new information to be gained (Denzin, 1994; van Manen, 1990).

The initial study design involved a three- step process.

- 1. Gaining access to hospitalised people as participants in the study.
- 2. Interviewing the participants.
- Analysis (including interpretation) of interview data and artifacts supplied by participants.

#### Forms of Data

In undertaking interpretative phenomenology, I used the participants' behaviour as the text analogue, which I studied and interpreted in order to discover any hidden meaning. The data for the text analogues came from the numerous interviews I conducted with the participants, observation of some of their behaviours, and notes that I kept to record incidents and situations (Denzin, 1994; van Manen, 1990). Because peoples' everyday lived experience is so taken for granted as to go unnoticed, it is often through breakdown of a data text that the researcher achieves insight into the lived world of the interviewed participants. At the same time, it was important for me to realise that the taken-for-granted, everyday lived world could never be made completely explicit, that is, I would only be able to see what I had the capability of seeing, and that which the participants allowed me or wanted me to see or hear.

According to Bakhtin (cited by Bernard-Donals, 1994), textual analysis allows and supports social change. This is because the "language" (that is, the words of communication and conversation) in which the participants talk can influence change strategies when the researcher realises the significance of the language. In order to address this important step in the research design framework, I used Bakhtin's method of textual analysis at two levels. The first involved rhetorical analysis of interviews with the participants (Chapters Five to Nine), and the second involved exploring the social construct of the participants' language and worlds (Appendix 17).

According to Benner (1994), it is important that the participants' experiences are treated in a way that "they are not destroyed, distorted, deconceptualised, trivialized, or sentimentalised" (p. 3). In order for me to respect the integrity of the texts, I found that by listening to the recorded interviews in my car when driving, I was able replay these until I felt that I could understand the participants' perspective by imagining myself in those incidents and situations, and then interpreting this insight that I gained until no new interpretations arose (Denzin, 1994).

#### **Data Analysis**

I used transcribed interviews, observational notes, memos, and samples of human action as data analogues for the interpretive analysis (Denzin & Lincoln, 1994). The data analysis involved three inter-related processes, of undertaking thematic analysis (what was happening to the participant), analysis of exemplars (specific situations and incidents), and the finding of paradigm cases (patterns of meaning) (van Manen, 1990).

In the first stage, that is, when doing the thematic analysis, I needed to read each piece of data several times to arrive at an overall analysis of what was happening for that participant. I found car journeys an ideal time to listen and reflect on the recordings of participants' interviews. To raise lines of inquiry I found I needed to get "inside the data" and identify the theoretical background that grounded the study with the themes consistently emerging in the data (Benner, 1994; van Manen, 1990). Constant listening to the tapes and rereading the texts analogues allowed me to do this.

The second aspect of the interpretive process involved the analysis of specific episodes or incidents. That is, all aspects of a particular situation and the participants' responses to it need to be analysed together (van Manen, 1990). To do this, I selected all the data that reflected a certain type of incident or situation from all of the participants, and analysed the situation or incident as a whole group. This enabled me to see if situations and incidents were common to all participants, and to track any variations. For example, I wanted to know if all the participants actively sought or requested to have their spiritual needs met, and so I examined all the texts for situations and incidents where this occurred and where it could have occurred. This stage of analysis allowed me to see that, in some circumstances, the participants were not able to ask for their spiritual needs to be met. I then explored why this could have occurred. This stage of analysis allowed me to constantly interact with the data, that is, I used the text to raise questions

and returned to the text to find answers. This process questioning, finding the answers became part of my interpretation.

The third aspect of interpretive analysis included the identification of paradigm cases, which are the strong instances of particular patterns of meaning (van Manen, 1990). Paradigm cases embodied the rich descriptive information necessary for understanding how patients' actions and understandings of spiritual beliefs and related needs emerge from the situational context, including participants' concerns, practices and background meanings (Benner, 1994; Coward, 1990; Emden, 1998; Forrest, 1989; Oiler, 1986). Paradigm cases and exemplars are effective strategies for depicting the person in the situation and for preserving meanings and context. This access allowed me to interpret the participants' experiences of spirituality in relation to health care, and provided me with greater understanding about the participants. The first type of paradigm cases that I was able to identify were those when participants expressed anger towards the health care professionals in not having their needs met. These paradigm cases were easy to identify by the tone of the participants' voices and the words that they used to express their feelings.

## Computer Software

I used the "HyperResearch" package to facilitate the management of the large amount of qualitative data collected (Hesse-Biber, Dupuis, & Kinder, 1995). This enabled me to analyse sections of the data, code according to the content, and then store the information in the computer software package. The program also enabled me to display the data in a way that allowed the formation of emergent themes and propositions so inferences could be made. These coded data (units) were named and labelled to reflect their essential concepts, that is, all the data that pertained to the participants realising that they were ill were labelled "realisation of illness". Likewise, other variables were discerned and became important themes to be named and labelled (Morse, 1995b; Oiler, 1986; Poland, 1995). In order to understand how these data units related to each other, I raised questions and sought verification from the data (Coward, 1990; Forrest, 1989; Oiler, 1986). The

HyperResearch software had the ability to undertake these Boolean searches and to supply the data to match questions through artificial intelligence (Hesse-Biber, Dupuis, & Kinder, 1995).

#### **Documentation**

In addition, I wrote memos and drew diagrams to help describe the participants' perspective of their spiritual needs from the data. These memos were record keeping devices and enabled me to write down ideas and questions and come back to them at a later date to answer the questions. These memos also provided the information needed for writing the drafts of the various chapters of the thesis. The drawing of diagrams assisted me in visualising the relationships between themes and allowed me to make mind maps with notes of the various themes, concepts and contexts (Oiler, 1986; Strauss, 1987). An example of these is given in Appendix 4.

## Trustworthiness of the Design, Data Collection, and Analysis

According to Denzin (1994), the foundation for interpretative studies is based on purposive (theoretical) sampling, inductive analysis and contextual interpretations. Furthermore, the foundation for interpretation rests on triangulated materials that are trustworthy. Trustworthiness consists of the four components of credibility, transferability, dependability and confirmability. Although feminists, liberation theologists, Freirian critical theorists and neo-Marxists may criticise this method for not being sufficiently ideological, it is moving in the direction of incorporating more moral, ethical, and political dimensions (Denzin, 1994). However, some social scientists would argue that interpretative researchers have yet to engage fully in the new sensibilities arising from the poststructural and postmodern perspectives (Denzin, 1994). This has resulted in the previous criteria from the poststructural and postmodern views being challenged, as social scientists seek new criteria to use to test the authority of a study. It is possible that criteria, in time, will tend towards more moral, practical, aesthetical, political and personal issues (Denzin, 1994).

In the meantime, the problem of rigour in qualitative research continues to arouse, beguile and misdirect (Sandelowski, 1993). Although researchers have a much clearer understanding of the challenges involved in producing good qualitative work and of techniques that can be used to ensure its trustworthiness, there remains the danger of succumbing to the technique of making a fetish of technique at the expense of perfecting the craft and of making rigour an unyielding end in itself. Such a position could take researchers too far from the artfulness, versatility and sensitivity to meaning and context that mark qualitative works of distinction. When trustworthiness can become a matter of persuasion, whereby the researcher is viewed as having made the practices visible, it is less a matter of claiming to be right about a phenomenon than of having practiced good science (Sandelwoski, 1993). Consequently, I could make serious analytical errors in attempting to find temporal, informational, or intentional consistency among stories (Sandelwoski, 1993). For these reasons, although striving to achieve trustworthiness of the study I avoided engaging in rigorous procedural processes that might deprive the study of the art and sensitivity involved in handling the data. Rather, the following procedures for trustworthiness were used as guides to facilitate the process without minimising the very essence of stories and truth told by the participants. Furthermore, I gave my peers in the Doctoral Colloquium a copy of the exemplars and asked them to identify the themes that they felt were present in these examples (Appendix 15). This feedback was valuable to me as the members are from various multicultural groups presently studying in Western Australia. Although my peers stated the themes that they found were the same as mine, they were also able to identify other themes that I had not interpreted, as they were able to perceive the data from their own worlds. When I had finished the data analysis, I then presented the findings to the Colloquium group as an audit trail, to make sure I had not missed any important points of reference.

To ensure the trustworthiness of this study, the credibility or plausibility, transferability or contextual relevance, dependability and confirmability of the data needed to be addressed (Denzin, 1994; Lowenberg, 1993). Although these terms are also used in ethnographic research, van Manen (1990) believed they

could be said to be more beneficial in interpretative and analytical studies than mainstream ethnographic works.

#### Credibility

Credibility refers to the plausibility of the data, that is, whether or not the findings would be likely to be believed as reasonable. This was established through remaining in contact with the participants to obtain sufficient data to achieve saturation. In addition, I clarified with participants my interpretations of the interview data, in order to minimise any potential misunderstandings between their perspective and mine (Lincoln & Guba, 1985; Silverman, Ricci & Gunter, 1990). Although I interviewed each participant a minimum of three times, this excluded the times when I telephoned to clarify their point of view. Some participants I interviewed more than three times, until I was satisfied with my interpretation of the essence of what they had told me.

#### Contextual relevance or transferability

To ensure contextual relevance or transferability, I developed rich descriptive data that used not only the participant's words and sayings, but also described the context of the experience, stated the intentions and meanings that organised the experience, and revealed the experience as a process (Denzin, 1994). This allowed me to interpret when various incidents and situations may arise, and to draw conclusions about these, which I also checked with the participants. These rich descriptive units of data described the participants' perspective of their spiritual needs in the health care context (Guba & Lincoln, 1994; Lincoln & Guba, 1985).

#### Dependability

The dependability of the data was ensured by the documentation of clear descriptions of the methods undertaken during data collection and analysis, the recorded interviews and the use of verbatim transcripts (Poland, 1995; Sandelowski, 1993). In addition, the analysis was conducted in a systematic manner by using the software package HyperResearch to include or exclude data into various units or categories based on the labelled names and themes (Hesse-

Biber, Dupuis, & Kinder, 1995; Polit & Hungler, 1993). Such strategies permit other researchers to examine and follow the progression of events (Lincoln & Guba, 1985; Silverman et. al., 1990).

#### Confirmability

Confirmability was addressed by the development of sufficient data in all categories and themes and an audit trail. Interview data were obtained from a purposive or theoretical sample of participants who, in turn, told me distinctive stories of experiences related to their spirituality and health care. This allowed a wide breadth of Western Australia's multicultural population to be explored. I also provided clear examples of the data on which the conclusions are based in the writing of the findings. Examples were documented as an audit trail so that readers could understand how categories and analysis developed (Lincoln & Guba, 1985; Polit & Hungler, 1993).

To assist in this process of confirmability I also used a journal to reveal my underlying personal assumptions and preconceived ideas and changes in thoughts during the study period (Koch, 1994). I found that by keeping this journal as a file on my computer, and writing entries, pre and post interview, as well as when I reread the units of data during analysis, I was able to bring my personal views into consciousness and record them (Appendix 5). For example, when I went to interview Tom for the first time he wanted the interview to take place in the library of his place of employment. When thinking about this forthcoming interview, I realised that my feelings and prejudices about this organisation were so strong as to not want to undertake the interview in that environment. When I realised the true extent of my feelings I wrote these down and contacted Tom to see if the interview could be undertaken elsewhere.

However, Tom could not understand my fears of his environment so the interview took place. Before I conducted the interview I documented my feelings and how I thought these may effect my conversation with Tom. You see, Tom worked for a

psychiatric hospital, which has been the scene for untold Coroner's Inquiries (See Appendix 7) and the de-registration of nurses for professional misconduct by the Nurses Board of Western Australia. As a teacher of the subject of health law and ethics, I remain appalled at the standard of health care treatment to the patients in that hospital. In my journal then I wrote

I can not ignore the vulnerability of these powerless people, who may not have the perception of what is happening to them, and the so-called treatment that they receive....I have seen them so many times wandering aimlessly around the various wards and compounds, their faces, posture, and behaviours reflecting the hopelessness they feel and endure.

Even though I knew I was going to interview Tom away from the wards, I needed to ask myself: "What if I witness something such as substandard treatment or hear of such examples from Tom...How was I going to deal with these". On reflection, even though I was going to the hospital as a researcher, I decided that because I was a senior nurse I had my legal and ethical obligations to the profession, the hospital that employs the staff, to society and to the patients. Once I made this decision, I decided that if Tom told me something which reflected poor patient care, I would ask him what he was going to do about it, and then if he said he was not going to do anything I would later make informal inquires and suggestions to senior personnel (nursing and medical) to help and protect the patient concerned. At the same time, I would protect the anonymity and confidentiality of Tom. I felt I could do this quite readily through my position in the University and profession. I noted that once I came to those decisions and documented them, a lot of the anxiety I had experienced pre-interview was resolved. I then felt quite positive about conducting the interview in the hospital grounds.

#### EVALUATION OF PHENOMENOLOGY RESEARCH

According to Packer and Addison (1989), there is no such thing as an interpretation-free, objective "truth" account of "things" in themselves, and there

is no technical procedure for "validating" that an account corresponds to the timeless, objective "truth". This is because criteria such as plausibility, coherence, and consistency do not help to determine the degree of correspondence between an account and the way things "really are". Rather, they help to determine how well an account serves to answer the original concern that initiated the line of inquiry leading to the research in the first place. Interpretive inquiry always begins from practical concernful engagement, and never seeks to simply describe a phenomenon but is always concerned with some issue of human behaviour. In this case, it was the lack of knowledge and understanding by health care professionals of the spiritual needs of multicultural patients or clients.

Therefore, the ultimate criterion for evaluating adequacy of an interpretive account is the degree to which it resolves the issue and opens new possibilities for engaging the research problem. Disputes in interpretation based on the plausibility of alternative interpretations cannot be reduced to a-priori-derived, cut-and-dried criteria. In the interpretive approach there can always be another, perhaps deeper and perhaps more persuasive, interpretation of a phenomenon.

#### PROTECTION FOR PARTICIPANTS

Sensitivity and respect for the participants were hallmarks of this study, particularly during the data collection. I felt that it was important not to be heard or seen as patronising, judgmental or offensive while obtaining data (Knights, 1998). According to Berger (1974), those undertaking spiritual research must do so with humility as "the gods are not available to the scientist but through the contents of human consciousness" (p. 126).

Participants were advised of the voluntary nature of their inclusion in the study and the right to withdraw at any time, and permission was sought to tape record the interviews (Wallace, 1995). An information sheet was given to the participants, listing what their involvement in the study entailed, possible personal

responses, and those whom they could approach for advice and help. (see Appendix 6)

The culturally appropriate ways of communicating with Aboriginal people and others were respected (Brady, 1992). For example, when talking with the woman of Aboriginal descent I did not look at her directly when speaking. Likewise, I refrained from touching the Hindu woman. Such behaviours respected their integrity and communicated to the participants that I knew of and understood their cultural and/or spiritual need. I used appropriate communication skills, such as paraphrasing, to clearly establish whether the participant was in agreement with what I had thought she/he had said. I had decided that if a participant did not want me to tape record the interview this was acceptable to me. However, this did not eventuate.

Transcripts of tapes will be kept for five years following the study. However, in order to ensure confidentiality, actual tapes were destroyed on completion of the research. Confidentiality of participants was maintained at all times. Participants' names were not recorded with the data; rather, the participant chose a pseudonym which I used (see Chapters 4 and 5). I ensured that the book containing the actual names and pseudonyms was kept in a secure place separate from the data. I also ensured the participants' anonymity when citing extracts from interviews in both this final report and resulting publications.

It was in these ways (sensitivity to the participants, obtaining informed consent, respecting the culturally distinctive mannerisms associated with communication, and the maintenance of anonymity) that the moral principles of autonomy, justice, beneficence, and respect for human dignity were upheld, and therefore the study could be deemed ethical (Hawley, 1997b).

#### CHAPTER SUMMARY

The very diverse nature of the population of Western Australia caused me to adopt a philosophical framework and research design that would protect the participants individuality and uniqueness. The philosophical framework is that of both Heidegger and Bakhtin. Once the framework was identified, this was embedded in research assumptions so that they could be checked out during the analysis of the findings. To do this, an interpretative phenomenological approach was designed, and ways sought to protect the legal and ethical rights of the participants. The manner in which this design was enacted is described in the following chapter (Chapter Four).

#### SECTION TWO

Section Two comprises Chapters Four to Nine which present the selection, interviews and findings from participants of this phenomenological study, in order to identify their spiritual needs. Each chapter focuses on a distinct theme, and is written as a discrete entity, in order for the reader to readily comprehend the participants' lived experiences. The order of the chapters relates to the manner in which the study unfolded, and their titles reflect the main perspective of each phase in the enquiry. For example, Chapter Four is named "Taking Time to Smell the Roses", at a time when I needed to reflect the crucial stage of first interviewing the participants. During interviewing, I literally took the time to smell their roses.

The sequencing of the chapters is as follows:

- 1. The advertising, selection, interviewing, and analysis of participants' data (Chapter 4);
- 2. The participants' experience of being in the world and their subjective knowing (Chapter 5);
- 3. Their perspective of spirituality (Chapter 6);
- 4. Identified spiritual needs (Chapter 7);
- 5. The different levels of spiritual care that the participants received or would have liked (Chapter 8);
- Finally, the rite of passage that the participants underwent when receiving health care treatment and trying to have their spiritual needs met. (Chapter 9).

The chapters describe the findings as they unfolded through the research process, that is, the chapters follow the exploration path that I took as I interpreted the data, raised questions and sought answers. Each chapter commences with an epigram (or scenario) that had occurred sometime in my own practice, either as a registered nurse, nursing sister, clinical teacher, hospital chaplain, minister of religion, or university lecturer in nursing. The scenarios were chosen to illustrate the main theme of each chapter, and to provide the reader a view of the world of health care. For example, in Chapter Five the epigram is an example of nursing staff not realising the importance of a patient's spiritual needs. This relates to the overall theme of the chapter, which explores the participants' experiences (both positive and negative) in relation to their subjective knowledge of health care and spirituality. The inherent theme which is embedded in the chapters, was that of the participants asking "Why don't they take my spiritual needs seriously?".

The participants reported examples of the quality of care received from health care professionals. It was from these descriptions that I was able to interpret instances when their spiritual needs were either disregarded or some level of care was given. The names of participants - Athika, Ann, Geoff, Red, Rosie, Scarlet, Sophie and Tom - are pseudonyms chosen by the participants to protect their anomonity. The names of health care professionals in the epigraphs are also fictituous (except for my own). You will notice that various font styles are used to differentiate between the speakers. The *italic* font represents the responses and conversations from the various participants, and the *Lucidae* font represents my own reflections and questions.

#### CHAPTER FOUR

#### TAKING TIME TO SMELL THE ROSES

The Song of the Woman-Drawer by Dame Mary Gilmore

I am the woman-drawer;
Pass me not by;
I am the secret voice
Hear ye me cry
I am the power, which might
Looses abroad;
I am the root of life
I am the chord

#### INTRODUCTION

The overall aim of the study is to identify the spiritual needs of multicultural Western Australians and to discern how these needs may be met by health care professionals. The purpose of this chapter is to describe the selection of multicultural participants, the manner in which the interviews were conducted, and analysis of data obtained through the interviews. These actions were performed to identify the participants' thematic concepts, exemplars, and paradigm cases. The aim of interviewing people was to understand their perspective on spirituality, to retrieve experiences from their past, and to gain insight into their spiritual needs. The first section describes their selection, the

interviews, the manner in which I fostered trust in order to obtain descriptions of highly sensitive events about which only they could tell me. The second part describes the manner in which the interviews were undertaken, and the third section explains the data analysis.

#### SEEKING PARTICIPANTS

The aim of seeking participants from different multicultural backgrounds was to enable me to gain knowledge and understanding of their spirituality and related needs. In doing so, the participants would become known to me though their stories, to which I would respond, and they, in turn, would verify my interpretation of their experience.

Where am I more likely to find a captive audience to interview? Is there a hospital that has a large percentage of multicultural Australians?

The Australian Bureau of Statistics 1996 Census was consulted to ascertain which sections of the population were present in the various catchment areas of the large teaching hospitals and different geographical regions of the State. It appeared that multicultural people were hospitalised in scattered patterns throughout the State. From this I inferred that some hospitals may have a majority of British, Australians, some Italians, whereas another would have Australians, a few Chinese, Vietnamese, and Aborigines. That is, no one hospital would have a broad range of cultural groups. However, there was a strong possibility that two out of the three metropolitan tertiary teaching hospitals had a higher incidence of multicultural patients than the third hospital. Research proposals were sent to both hospitals, but these were not successful.

The refusals occurred because I was not a staff member of the hospitals. Hospital spokespersons stated that it was unethical for an "outside person" to undertake research within the hospital environment. I stated in my application to one hospital that I was prepared to work full time in the chaplaincy department for six to twelve months under the direction of the resident chaplains. However, that was not regarded as sufficient, because the concept of qualitative research was not acceptable. Instead, I was requested to undertake a quantitative study involving a more structured questionnaire and a control group (See Appendix 8 for copy of letter).

Scrubbing walls, scrubbing, scrubbing,
There must be another way to skin a cat.
Aha yes, yes, forget the patriarchal hospitals
And meet the people where they lives
Houses painted with different colours,
Gardens of concrete, brown dirt, or compost tumbling

All was not lost. I remembered that, when I had undertaken previous research of a spiritual nature, it was easier to interview the participants in their own homes after they had been discharged from hospital (Hawley, 1996). After discussing the issue with the Executive Director of the Office of Multicultural Affairs (who was interested in the study) and my research supervisor, it was decided that I should advertise for volunteers to be involved in the study.

#### **PURPOSIVE SAMPLE**

When analysing the material from the various spiritual groups in Western Australia I discovered that each group, church, or association fitted into one of four types (Strauss & Corbin, 1990). I felt it was important then to seek volunteers who would be representative of these types. Therefore the sample needed to be of people who were less than 55 years of age, with a health care problem (but not terminally ill), and who:

- 1. attended a Jewish synagogue or Christian church either frequently or infrequently; or
- worshipped (prayed or praised) a Higher Power that was not Jesus Christ or Yahweh (Jewish God), such as Buddhists, Shintoists, Hindus, or Muslims; or

- did not believe there was a Higher Power (Agnostic, Atheist, or Humanist), or underpinning their spirituality were the principles to "live a good life", "not to hurt others", "all people are equal" (Humanism, Communism, Marxism); or
- 4. had a mythical spirituality (Taoist or Aboriginal) or worshipped an aspect of creation/environment (sun, moon, and water, such as Wicca).

The manner in which the participants were chosen followed the concept of purposive sampling and is described later in this chapter (See Participants).

#### DATA COLLECTION

In January 1999, letters explaining the research and asking for volunteers were sent with an accompany advertising flyer to:

- 1. One General Practitioner (doctor's) practice in each metropolitan suburb. From the telephone book under the heading "medical practitioners" I chose one practice from each metropolitan suburb. If there was more than one practice in an area, I chose the doctor who (1) I professionally knew was more likely to support the research or (2) the doctor with the least sounding non Anglo-Celtic name. The rationales for these strategies being that (1) people who know the researcher would want to help (gratitude), and (2) patients and clients from non Anglo-Celtic backgrounds are more likely to attend a doctor from the same or similar culture.
- 2. The various multicultural groups within the State.
- 3. Multicultural and cultural specific health care services.
- Gender-specific health care services, for example, Men's Meeting House, Kwinana.
- 5. The spiritual groups who had previously supplied me with information.

I wanted as wide as possible a sample of participants from different genders, illnesses, ages, and cultures (Lonner & Barry, 1986; Parsons 1995). Such a broad canvas of the metropolitan region would ensure that all spiritual groups and cultures would be aware of the study. (Appendix 9).

Whose needs are being met? Need to always remember the aim of study. To identify and develop new definition of spiritual needs for the recipient of Australian health care, be that patient, client, consumer, or person.

In response to the advertisements over thirty people contacted me. All volunteers had spiritual beliefs compatible with one of the four groupings and were therefore regarded as possible participants. As each person spoke to me on the telephone, I noted details on a prescribed form (Appendix 10). This form noted the person's age, place of birth, their health problem, and what cultural and/or spiritual practices were important to them. These telephone discussions were important, as it allowed me to decide whether or not it would be worthwhile in using resources to conduct interviews with them. I needed participants who were able to reflect upon their experiences and discuss the issue of their spirituality and related needs. However, not all those who responded had a sufficiently clear enough conversation pattern to be interviewed. This was due to either their degree of illness, or command of the English language. In addition, non-English speaking people who were not able to fully understand the nature of the study were not interviewed as the cost of using an interpreter was beyond the financial restraints of this study.

Information given to the volunteers by me at the time of the initial telephone call included the purpose of the study, the benefits and risks, and provided the person the opportunity to ask questions (Benner, 1994). The volunteer was then told I would contact them when they were needed for the interview.

What about the people I can't use? I can't write them a letter and say thank you, but you couldn't talk very well, so I am not going to interview you. That would be utterly bad mannered!

If a person was not selected for interview a letter of thanks was sent explaining that the response rate was overwhelming and that I would not need to interview them. It was anticipated that I would need to spend approximately six months actively interviewing in order to gain sufficient data to achieve

saturation (Morse, 1995a). However, I actually spent 12 months, on and off during 1999, interviewing the participants. As a contingency plan, I decided that if I did not gain sufficient volunteers the first time then I would readvertise later. However, this was not necessary due to the large response to the first advertisement (Morse, 1995b; Strauss, 1987).

Not all people who responded (and telephoned) wanted to take part in the research, once they had more information. For some, the idea of telling a stranger about their spiritual needs in an interview was too personal and therefore they refused. That is, they told me that they didn't mind talking briefly on the telehpone, but they did not want to be interviewed. Similarly, some were not able to reflect on what gave them meaning and purpose in their lives. The reasons why people refused and were not chosen to be interviewed were documented so that if regular patterns formed, inferences could be drawn (Field & Morse, 1985). At the end of the 12-month interviewing period, the one crucial inference that could be drawn was the volunteers' ability to reflect and talk about their situation and incidents of spirituality and health care.

#### **INTERVIEWS**

In undertaking the interpretative phenomenology approach, the feelings, thoughts and behaviours of the participants in relation to their spirituality and health care become the text analogue (van Manen, 1990). This was studied and interpreted in order to discover the spiritual needs of these people when receiving health care. The data for the text analogues came from interviews, participant observation, diaries, and samples of human behaviour (Benner, 1994).

According to van Manen (1990), questions are the best-known tools of the interviewer's craft. Consequently, I spent many hours deciding on which were the most pertinent questions I needed to ask each participant. I needed to be cautious, so those events would not be too structured and so that I would not

lose the meaning of what the participant was trying to tell me (Field & Morse, 1985). I wanted the interview questions to have the capacity to guide discourse along certain tracks and not others and to affect pace and tone of talk (Strauss & Corbin, 1990). Used appropriately these would aid in eliciting well grounded accounts of their experiences. I also needed questions that allowed the context of the participants' responses to be viewed (Lonner & Barry, 1986). I felt that it was equally important for the participants' own rich language to be expressed, and the opportunity provided for them to explore their thoughts in relation to spirituality and health care.

When it was time to interview particular participants, I telephoned them and arranged a suitable time that was convenient to both of us. Again, I explained the purpose of the study, the benefits and risks, and provided them with a further opportunity to ask questions. After written consent (See Appendix 6) was obtained, general questions relating to the participant's illness and experience (taken from Kleinman, 1978) were asked by me in order to establish rapport (See Appendix 11). The participants were then asked specific in-depth, open-ended questions adapted from Fish and Shelly (1978), exploring their meaning of spirituality and their spiritual needs (See Appendix 11). These included the participant's use of activities related to their spiritual beliefs, accessories and/or artifacts (restricted dietary intake, dress, washing rituals, prayer postures, icons, prayer books, pictures, beads etc). It was anticipated that all interviews would be tape-recorded and transcribed verbatim (Poland, 1995). However, if this was not achievable and the participants did not accept this method, I was prepared to respect their wishes, and write verbatim account of the interview immediately after leaving.

I planned each interview with certain functions in mind which needed to be performed to create an efficient process. That is, at the first interview, written consent was obtained from the participant to be part of the study and for me to audio tape record the conversations. At the end of each interview, the tape was transcribed and a hard copy sent to the participant for corrections and/or

amendments. After each interview I listened to the audiotape with the transcript to check for completeness, that is, I added to the interview hard copy the recorded voice tones, emotions, and if necessary edited the copy (Benner, 1994; van Manen, 1990). Each interview tape was then labeled with a banded note of the tape number, date, participant name, subject and themes of the interview. Such actions would facilitate the 'audit trail' in order to increase the dependability and confirmability in establishing trustworthiness of the data analysis process (see Chapter Three).

The style of interview was a conversation with a purpose in which interviewing takes on the form of talk between friends or peers. That is, it was informal, coequal, interactive, committed, open-ended and empathic. However, the interview was not just a conversation, as the distinctiveness of the session was informed by its purpose and somewhat by its structure.

During the interview, I clarified information given by the participant by using active listening skills, including words of affirmation and paraphrasing. At the end of the interview, some participants were asked brief demographic questions if they had made no direct reference to these issues, that is, their culture or ethnicity, religion or spiritual belief (Guba & Lincoln, 1994). Before leaving the participants' homes I reminded them that I would contact them later to review the interview transcript, and that in the meantime they would receive a copy of the interview by post (Appendix 12).

Additional data was collected, such as observations of the participants' environment and artifacts in relation to spirituality. This enabled me to raise questions during the interviews to gain a fuller understanding of the participants' current environment as related to their spiritual needs.

Three or more separate conversational interviews were undertaken with each participant (van Manen, 1990). Each interview was conducted according to the ethical guidelines as stated in Chapter One, tape-recorded, transcribed and

analysed. The first conversation openly explored the participant's meaning of spirituality and their health care problem. The second conversation addressed the confirmation, clarification and elaboration of my interpretations of the first session, and the third interview confirmatory of the overall findings. The planned questions that I asked in the first interview were reiterated in the second if the participant wanted clarification. However, overall my questions changed subtly from participant to participant and over time. For example, if the participant was ill at the time of the interview I needed to be aware of their energy levels and whether or not to ask specific questions so that they would not be harmed. For example, with my first interview with Rosie I could see that she was still clinically depressed, and so I did not want to ask her any questions that may cause her to harm herself. I asked Rosie to tell me whatever she wanted to about her experience. This then allowed her to skip any areas that may have been painful for her, while I listened empathetically.

Also, I ensured that my questions were commensurate with the educational development level of each participant. For example, Geoff did not have the vocabulary to explain his situation and experiences to me as another participant could, so I used basic explicit questions for Geoff, whereas Athika discussed with me her ideas about the socialisation of spirituality (see Chapter Six).

As the study progressed, I changed the direction of some of the questions so that I could obtain specific information from some of the participants in order to fully understand about a situation or incident (Erickson, 1998; Morse, 1995a). For example, I asked Tom, a registered nurse, why he thought certain aspects of communication occurred between patients and nurses.

The preparation of summary sheets of the interviews (immediately after the interview) were used to capture thoughtful impressions, reflections and consolidation of ideas for further investigation or analysis (Koch, 1994). Data from these summary sheets guided subsequent data collection, suggested new

or revised codes for units, and reoriented me to the setting on returning to the data (Morse, 1995b). Ongoing analysis during data collection allowed me to alternate between thinking about the existing data and generating strategies for collecting new data (van Manen, 1990). (See Chapter Three)

Once the initial interviews with all participants had been conducted and I had performed a preliminary, or level one, analysis of the data, I returned for additional interviews. At the second interview I sought clarification about issues arising from the first interview and provided opportunity for elaboration. The third and final interview enabled me to ascertain the participants' perception of the data as a whole and to engage them in considering the meanings emerging from the study. Final confirmation of the information was obtained when participants assessed my analysis of the transcribed interviews. They were asked to consider whether the analysis reflected their recollections, and whether they wanted to make any comment. This process of 'member checks' (Strauss, 1987) assisted in optimizing the credibility of the findings and facilitated trustworthiness (see Chapter Three).

By the time of the third interview (when I had provided the overall findings to that time), participants seemed to feel quite comfortable about agreeing or disagreeing with my interpretations of the various themes. This allowed me to make any necessary changes to the names of some themes. For example, Sophie, Athika, and Red suggested the use of alternative word/s to refine (or more accurately describe) a theme and relationship. It was at the third interview that the unexpected occurred with three participants (Athika, Red, and Sophie). They introduced new material, which added further dimensions to the data already collected. For them, this was the ontological authenticity of their interviews (Laidlaw & Whitehead, 1995). That is, their claim to have learned about their personal experiences in relation to health care and spirituality. For me, I needed to conducted subsequent interviews (either by visiting personally or talking with the participants on the telephone) until no new relevant data became available.

#### **Establishing Initial Rapport**

The first interview session with each participant was crucial. I needed to take time so that rapport was established. To do this I allowed sufficient time to enable me to ask questions, and for the participant to answer in a non-hurried manner (Flinders & Mills, 1993). When I first arrived at a participant's home and had introduced myself I always made a comment that would establish a conversation. I named this period as "taking time to smell the roses" and it was invaluable to what followed in later conversation and the actual interview. In taking time to smell the roses, I demonstrated to the participants that I was genuinely interested in them, and was not there to do just an interview. The metropolitan area of Perth experiences warm sunny weather, which is conducive to gardening. Consequently, taking time to smell the roses, was something that was quite often literally done. Telling the participants that I noted their lovely roses or vegetables invariably evoked an invitation to tour the gardens. Morning or afternoon tea was usually then offered and so, by the time it was ready for me to tape the interview, a good and relatively open relationship had been established. At the first interview, each participant was asked to identify a name that they would like to be called for the duration of the study and resulting publications, that is, they invented a pseudonym by which they wanted to be known.

After each of the interviews I stepped aside, to write for a while, trying to make sense of what I had learnt, before rejoining the research setting to conduct another interview in order to test and retest the ideas I was developing (Benner, 1994). In this way, the credibility of the findings (and trustworthiness) was optimised through the process of 'progressive subjectivity' (see Chapter Three). During this stage of the study, I needed to keep the whole of the field of participants in mind. According to Lindof (1995), by doing so I could go to a participant as a resource for the information needed. When the concepts and propositions were corroborated in essential aspects by participants, I gained confidence in my own ability to model an

interview. When participants verified (and did not disconfirm) my interpretations, the meanings also became enhanced (Morse, 1995a).

The importance of establishing rapport between the participant and myself was to increase the 'authenticity' of the data (Guba & Lincoln, 1994). Rapport began with clarity of purpose. Participants were given clear, succinct reasons why they were contacted during any communication with me, including the aim and value of the study, and how the interviews were conducted. The participants were told that, unlike other more formal styles of interviewing, this experience was to be more like a conversation, and they would be able to raise their own topics and expand into those if they wished. Because the set questions were of utmost importance, the participants were told of these at the beginning of the first interview session. I had found in the past that usually participants appreciate knowing what they are expected to do to get the job done.

The whole purpose of the interview questions was to help the participants introspect effectively, and so I used general, non-directive questions at the beginning of the interview. The open questions helped establish good rapport, as they gave participants a chance to display their expertise and experience, as they unraveled their knowledge of certain routines, procedures, or activities. If the story was told too quickly or too vaguely, I waited until participants had finished telling their story. I then asked additional questions about their experience to get the greater detail that I needed in relation to spirituality and health care (Lonner & Barry, 1986).

#### Good Person Concept

I had learnt from previous research that my disposition during interviews was important at all times, as I had realised that the efficiency of this took place only at the pleasure of the participant. Thus, I needed to be regarded as a 'good person' (Adler & Adler, 1987). By being a good person, I would enhance confidence and build trust with the participants. To be a good person I needed

to give the participants the benefit of the doubt, getting along by going along, and not being overly querulous or contentious (Emerson, 1983). I also found that being a good person involved the general social competence of knowing when to be quiet and when to be gregarious, when to share information and when not to interfere but let the participants stumble over their own words so that I would not put "words into their mouth" (Anderson, 1995). The real advantage of being a good person lay in the scope of social situations and relationships that it opened. For example, I found that I was invited to a Chinese New Year celebration at a local Buddhist temple, a weekend retreat of meditation at another Buddhist Temple, a Sikh convention, and to join the Elder Troth of Western Australia. These relationships added further depth to the information I received from the participants and the spiritual groups.

The opportunities to be a good person occurred in the writing of the letter to organisations to seek participants, on the telephone when possible participants phoned to seek more information, arranging the interviews, during the course of the interviews, and through a follow-up letter thanking participants for their time. Creating the good person relationship was vitally important, as without it I would not have been able to get the information I would have liked or needed (Flinders & Mills, 1993).

#### **Ethical Outcome**

To be ethical in nursing I need to uphold the principles of autonomy, beneficence, justice and non-maleficence (Hawley, 1997b). This ethical behaviour applies equally to research and education, in that I needed to be cautious and primarily uphold the principle of non-maleficience, that is, to do no harm (Hawley, 1997b). I was very concerned that I did not want to harm any of the participants by my questions. In order to protect the participants I told them that there were no right and wrong answers about spirituality. Also I told them that they did not have to answer any question that made them feel uncomfortable.

According to Erickson and Lin (1990), people who think they have little power and no respect in an educational setting will usually not take the risk in giving answers that they think may be wrong. Because the participants knew I was from a university, I did not want this to occur. Therefore I needed to give them special encouragement and safety to be imperfect. That is, I accepted everything they said as being true for them, and told them prior to the interview that I would not doubt their stories of experience. In this way, they knew I would not be judgmental or critical of the things that they told me. I believe this gave the participants permission to reveal whatever they wanted to tell me. It was anticipated that these actions would increase the probability of high credibility and facilitate the trustworthiness of the data (see Chapter Three).

Although the sample was a convenience one, it was also purposive (Strauss, 1987). That is, the order in which I interviewed people had a pattern that was related to how questions arose from the within the study.

Whom shall I interview first? Yourself you silly pumpkin then you will know if the questions will work or not. It will also clarify your own beliefs and bring them into awareness (bracketing) so that I realise what they are and therefore less likely to be confused with the participants' responses!

Consequently I interviewed myself, and reflected on the same open-ended questions I was intending to ask the participants (adapted from Fish & Shelly, 1979, p. 64). That done, I felt quite happy about proceeding with the interviewing participants because the questions appeared to elicit the information I thought I needed. However, the real advantage of answering the questions myself is that it helped me to identify and name my own opinions and beliefs. Because I did not believe that I could fully bracket (see Chapter Three) this information, at least by bringing these thoughts to consciousness and documenting them I would be more aware of their existence.

#### **PARTICIPANTS**

The first person I interviewed was Ann, who was in her early 30s with Australian (part Aboriginal) and English parentage. Ann's health care experience was 'traumatic childbirth' when delivering her daughter Mary in a maternity hospital. Ann was university educated and had what the Western world would call a traditional spirituality in that she worshipped the Christian God and Jesus Christ. Ann's mother had left her father when Ann was sixteen years old and her father died several years later. On interviewing Ann, I discovered that her spiritual needs were related to her Christian belief. I then asked myself:

Would a non-traditional person have similar spiritual needs? I need to interview a non-traditional or non-Christian person.

That meant that Red was interviewed next. Red was a "true blue" Australian, university educated, who had travelled extensively in his twenties and thirties. He married in his early 40s and was now 54 years old with no children. Red's spirituality was related to his Australian culture. Although Red had what he termed a 'Socialist' perspective of spirituality, in fact there were some strong characteristics of Humanism present in his story. At the time of the first interviews, Red had a painful trapped nerve condition (that is a physiological condition). His spiritual needs were different from Ann's.

Are spiritual needs dependent upon the person's sex, psychophysiological state, or spiritual background (including culture)?

Need to explore spiritual needs from another male person's perspective. However, this time someone who had a psychological/emotional condition, rather than a physiological.

Tom was 50 years old and not born in Australia, but in Singapore of Chinese heritage. He was not university educated, although he had several trade certificates. Tom described his health problem as being "burnt out". He worked as a mental health nurse, and his job included the assessment and treatment of people (at the psychiatric unit) who were suffering from a severe psychiatric episode at the time. This role sometimes involved the forensic nature of nursing when he needed to assess and treat people who had committed a civil or criminal offence. In these instances, the person was remanded to the hospital from the Ministry of Justice where the lawyers or judge thought the offence committed by the person may or may not be connected to a mental health/psychiatric problem.

Tom's spiritual needs were different from Red's in that they were of a deeper need, that is, more uniquely personal and reflected his religious beliefs of The Society of Friends (Quaker). Tom's need was that he wanted peace within himself, his story also included the spiritual care that he gave to people with psychiatric illnesses.

Were the spiritual needs related to the length of time of the health problem? Red's health problem was short, Tom's health problem was long in duration. Need to interview a male with a long-term physical problem.

Geoff was interviewed next. He had a long-term health problem of Non-Hodgkin's Lymphoma and was in remission at the time of the interviews. His spirituality was similar to Red's (love of Australian environment), but also to Tom, in that he too wanted inner peace. Geoff did not have a traditional view of spirituality, and said he had never been to a church service. Instead he gained purpose and meaning of life through his relationship with his family, and his farm and animals.

Does the sex of the person make any difference to their spiritual need? A female with a non-traditional view (opposite to Ann) needs to be interviewed.

Scarlet was chosen; her health problem was similar to Ann (traumatic childbirth), but she did not have a traditional view of religion and was what she termed "a pagan Romany (gypsy)". Scarlet came from a wandering life through Europe (United Kingdom, Spain, Italy, Germany, The Netherlands, etc), as Romanys do not have their own country, but have their own culture. Her spiritual needs reflected not only Ann's but also Red's, Geoff's, and some of Tom's. This suggested to me that traditional or non-traditional views did not alter the spiritual needs, neither did the characteristic of male or female.

# A question that remained was whether physical illness affects spiritual needs differently from mental illness. I need to interview a person with a serious mental health problem.

This would be a difficult interview, as mental illness still has social stigma in Western Australia, and therefore I knew I would find it hard to find someone who was willing but also had sufficient trust in me as a researcher and person. The possible participant also needed to be sufficiently recovered in order to be able to reflect on their experience and problem. No such person had responded via the advertisements. I felt it was important that I interview such a person if possible. Therefore, I contacted someone whom I believed met the interview criterion, and to whom I had given spiritual care on previous occasions.

This woman had previously been hospitalised with severe depression when she had been harming herself. I had originally met her when she requested to see me for spiritual care while in private psychiatric hospital. We had kept in contact since her discharge, and I remained giving her spiritual care when she requested it. This in itself was a unique situation, as I was not her Parish priest, nor that hospital's chaplain. Instead she knew of me, as an ordained woman minister, and requested I see her. This situation involved her right to seek help outside of the parameters of her own normal priest and hospital chaplains (which she had felt did not meet her needs). Consequently, I telephoned the woman, told her about the study, and asked if I could interview her. She

replied "since it is you Georgie I will agree, because I know you understand me. But I would not do it for any one else"

## What have we done to mentally ill people? That they would feel like this? Have we as priests or nurses hurt them so much?

Rosie was in her late 40s, and came from Europe. She had a certificate in nursing, and worked part time in a nursing home. Her family had a history of Bi-polar disorder (fluctuations between depression and manic behaviour). Rosie herself had been diagnosed with depression some years before the episode during which she requested to see me. Her recent episode was probably bought on by work stress, as she had injured her back at work; her doctor put her on workers' compensation, but her employer would not recognise her injury, so she continued to work.

Rosie told an emotional story of the difficulty in trying to get protection for herself when she was physically harming herself. This had involved taking overdoses of sleeping tablets and deliberately burning herself. It was a friend at work (who was also nurse), who realised the problem and arranged for her to be seen by a psychiatrist who admitted her to the private psychiatric hospital. (\$3,000 per week, fortunately she had private health insurance). When I saw Rosie in hospital she had "angry red wounds to her arms and legs" where she had burnt herself with cigarettes (during her episodes of harming herself at night when she could not sleep). She also had experienced two episodes where she had taken much greater than the recommended dose of sedation in an effort to get to sleep. She had known that the doses might kill her, but she was so desperate to get some sleep that she did not care. Listening to the audiotapes of Rosie's experiences were disturbing and I found myself crying on several occasions. Her feelings of being betrayed by her employer were evident (in not acknowledging her injury), as were her ineffectual methods of trying to obtain help for her unstable mental state. Rosie's graphic details of repeatedly burning herself with cigarettes, but not feeling the pain, demonstrated to me the complex anguish and the burden of the pain of hopelessness that depressed people must feel.

When I couldn't sleep I quite often went for a drive in the car, but Fred [husband] thought that was too dangerous as he would be asleep and not hear me go out...so he would hide the car keys at night so I could not go out..........

The only other thing I could do then was walk around the house and out into the back garden for hours on end. I felt I did know who I was and what I was doing, life was just a great black abyss. [pause]

I felt so unreal at the time, as though I wasn't me, but I didn't know who I was. So I would burn myself with the cigarette to see if I could feel if I was alive or not. (character 23241 to 25878 of ROSIE.TXT).

Originally, when Rosie had requested to see me when she was in hospital, my spiritual care to Rosie had been to be with her and to empathise with her for her situation and illness. Because Rosie was also an Anglican, I anointed her with Oil (specific ritual) and prayed with her for healing. Later during her hospitalisation, I went with walks with her outside of the hospital though a beautiful nearby park (she was not allowed to go by herself, in case she harmed herself). The care at that stage was walking side-by-side holding her hand (to give physical comfort through touch) and presence.

At interview, Rosie's spiritual needs encompassed Geoff's in that she too wanted that peace within herself. However, it was a different intensity; with Rosie, the need was urgent and imperative so that she would not commit suicide. As the interviews unfolded, I discovered that Rosie's father died when she was ten years old and her mother at sixteen years. She told of the anguish and pain of not being allowed to see her parents when they were dying, and the refusal of her older brother and sister over the years to tell her anything about her family history of mental illness and ancestry.

So obviously, the spiritual need of "peace" is not specific to either male or female. Could it be due to Western religion? (Tom was a Quaker, Rosie was Brethren/Anglican.) It was

## time to interview some one with a non-Western view of spirituality.

Athika, was a Hindu woman, university educated, with a health problem of hypertension related to work stress in an academic environment. She had strong family and cultural ties to India and meditated each day. Her spiritual needs at the time were not that different from Tom and Rosie in that she too wanted peace and tranquility in her life. Athika's story also included the manner in which she gave spiritual care to people living with cancer.

#### What about a person with multiple health problems? Each of the previous participants had only one health problem. Would spiritual needs change if a person had several problems?

Sophie was interviewed. Sophie was from Norwegian parents who came to live in Australia when she was very young. However, such was their poor language skills that Sophie frequently needed to interpret in English for them, until they died. Sophie suffered from arthritis of the spine and hips, and had experienced a coronary occlusion. She was a heavy smoker, a social drinker, and suffered anxiety and depression for many years until her children reached adulthood and left home. Her spirituality was related to the fact that she had rejected the Christian dogma she received as a child, and her own experiences in trying to find meaning and purpose in her life. Her spiritual needs included the ability to love herself, hope, trust in others, and acceptance by others. In telling her story Sophie also told the story of her husband Alf, who had brain damage (related to chemicals that he had inhaled at work), suffered a stroke, and had previously been addicted to alcohol and cigarettes.

## What type of person and health problem is left? Can't think of any at the moment

I decided that Sophie was to be the last participant to be interviewed at that stage, and to continue analysis of the data of these eight participants. If I discovered that more participants needed to be interviewed, this would be done

at a later stage. However, this did not become necessary, as the participants did not just tell a story about themselves. Instead, they included stories of their loved ones, of experiences in different hospitals and numerous health care professionals. Such experiences included:

- health care for childbirth, mental and psychiatric illnesses (depression, manic-depression, and anxiety), immunology (lymphoma), stroke, detoxification of alcohol, arthritis, coronary occlusion, hypertension, peritonitis,
- operations such as repair of hernia, bowel obstruction, eye surgery, orchdectomy and orchopexy (removal of testes from inguinal canal into the scrotal sac), caesarian, appendectomy, and oopherectomy.
- treatments such as radiotherapy, chemotherapy, and physiotherapy
- hospital experiences in both large and small public and private acute hospitals, private and public mental health/psychiatric hospitals, intensive care and coronary care units.

This range of health problems, different types of treatment, and both public and private hospital experiences, appeared to me to offer satisfactory coverage to achieve saturation in the data (Morse, 1995a & b).

As much as I dislike placing people in boxes, I needed to ascertain that the participants I had chosen did represent both the different spiritual groups in Western Australian and also various multicultural groups. The manner in which the participants could be related to these groups are as follows:

- 1. Non Christian religious: Hindu Athika (Indian)
- 2. Judeo-Christian: Anglican Ann (Australian Aborigine and Anglo-Celtic):
- 3. Philosophical: Socialist Red (Australian)
- 4. Mythical, Pagan or heathen: Pagan Romany Scarlet (European)
- 5. The other participants were aligned to two or more of the above groups, these combinations were:
  - a. Non Christian/ Judeo-Christian: Anglican, Brethren and Buddhist Rosie (Irish)

- b. Philosophical / Judeo-Christian: Humanism and Society of Friends – Tom (Asian Chinese)
- c. Philosophical / Mythical: Humanist, Mythical Geoff (Australian)
- d. Christian / Mythical : Lapsed Roman Catholic Astrology –
   Sophie (Norwegian).

Having done this I was satisfied with this stage of my purposive sample.

#### SUPPORT INFORMATION

During the process of interviews I made field notes and wrote in my journal. The field notes were brief reconstructions of events, observations, and conversations that took place when I went to conduct an interview. To do this task properly I wrote them up immediately after each interview. I had allowed myself time to do this immediately afterward. I did not discuss the interview with my supervisor or anyone else until the notes had been written, in order to avoided contamination of ideas (Koch, 1994; Morse, 1995a). The field notes described the concrete particulars of the interview and the relationship between the participant and myself. (Appendix 13)

In fact, the notes represented my 'learning curve' at the time. For although I did know something from my nursing experience, theological background, and the review of the spiritual groups at the commencement of the study, the information presented by the participants was so unique that it was, for me, like a new or different discipline of study. It was in the notes that I asked myself questions such as: What is going on here? What has happened for this to occur? Is this a significant incident or event? Are there artifacts involved? Are there other activities that make up this event? For example, when a Hindu person is dying in hospital what rituals should be performed and by whom (Benner, 1994).

My journal provided a chronological key to information in field notes and participant data files. The journal helped me with the rising tide of data by serving as a place to record field visits, names of persons met, and participants interviewed. It also included my thoughts about procedural problems and options. Although others (Strauss & Corbin, 1990) suggest the use of a separate diary to include emotions, I wrote about them (emotions, doubts, private prejudices, and other thoughts) in my journal. I could not see the benefit of having one journal or diary in which to write, and another to commit my thoughts and feelings to paper.

These documents formed a paper trail to sustain trustworthiness of the data analysis (see Chapter Three). By themselves, these documents would have had limited significance, but when related to other evidence, they had much to offer me. In this way, they became part of the talk I was observing and they helped me reconstruct participants' past events (Morse, 1995a).

#### DATA STORAGE AND ANALYSIS

I used the computer software package "HyperResearch" to store the data from the interviews and aid in the analysis (Hesse-Biber, Dupuis, & Kinder, 1995). During analysis, sections of the data were identified, coded according to the content, and stored. The coded data (units) were labeled to represent the essential concepts, variables and important themes of the study (Morse, 1995; Oiler, 1986; Poland, 1995). Questions were generated about how the data units and themes fitted together, and verification sought from the data (Coward, 1990; Forrest, 1989; Oiler, 1986). The advantage of this electronic package was that it ensured that no pieces of data were lost and that coding for various pieces of information could overlap without loss of clarity. Once themes were recognized across the various participants (see Appendix 14), Boolean searches were undertaken, questions and assumptions tested (Hesse-Biber, Dupuis, & Kinder, 1995). In addition, it was possible to undertake analytic induction at the same time (Erickson, 1998).

The findings of this study (Chapters Five to Nine) emerged from the data analysis. These findings started out as surmises and questions, which came to mind as I listened to the participants' stories and the recordings of their interviews and as I read the hard copies. I reviewed all the data for comparison, in both recursive and progressive processes, for analytic induction (Erickson, 1998). That is, I reviewed all the evidence to a particular question and/or assumption that I had obtained until all the relevant data had been identified and compared. I then did the same for each assumption and/or question that I raised (Sandelwoski, 1996). When I found data to collaborate each assumption or question, I then went back to the participants for them to validate the findings.

Of great importance in the data analysis were the exemplars (van Manen, 1990). These consisted of one or more parts of a participant's data (record) that were shaped (or constructed) to advance the developing conceptual argument. Exemplars were very important to the crafting of a rhetorically persuading research text, in that they were embodiments of the inductive construct that was occurring at the time. I used exemplars to test a claim, and to evaluate how plausibly the data explained the descriptive act, and how well it explained new data for participants when appraising its truth-value. According to Benner (1994) and van Manen (1990) potent exemplars bring out the salience and the inherent order or contradictions of an event. Without exemplars, the claims of a theme or word would be empty and unpersuasive. To do this I used examples from the data that lent insight into spirituality and health care to help me understand the study (Erickson, 1998).

#### Finding Exemplars

When coding Ann's first interview data, I suspected that there were themes of anger and unresolved grief. On examining the data for exemplars I found this one concerning her anger:

We had one nurse from hell! She said things as if "I hope you are not thinking of staying here tonight because you can't".... Then she changed her mind and said "You can stay but we don't have any bedding for you" and so he [husband] had to sleep on the bare floor.

And then she didn't show me how to breast feed, just grabbed my nipple and shoved it [baby] on; into the baby's mouth and you know, you're not some sort of person anymore, you're just a piece of flesh! (p. 3-4 of ANN.TXT)

These exemplars vividly describe Ann's feelings at the time of the incidents. It was examples such as these that allowed me to raise possible interpretations of the text and present them to the participant for verification.

#### Coding of Data

The coding experience gave me an opportunity to think through the data, and to infer what the information might mean. The construction of exemplars enabled forward movement in this process. Finally, analysis prepared me for quitting the interviews and starting the writing of draft chapters. In all of this, the analysis of data and continuing investigation of participants went on simultaneously.

#### Levels of Coding and Analysis

Different levels of analysis were performed, at the same time as raising questions and testing out assumptions (Erickson, 1998). Level One analysis included the identification of paradigm cases, themes, and exemplars for all the interviews. Level Two consisted of examining all the themes and exemplars for corresponding or universal themes. Level Three involved the working out of relationships between the themes (van Manen, 1990).

#### Level One

When undertaking Level One analysis, the paradigm cases, associated themes, and exemplars for all the interview cases were identified (van Manen, 1990). Each participant had different paradigm cases (a scenario or incident that may contain one or more themes), as each person was unique in their personal experience of health problem and related spirituality. Likewise, the arising

themes (related to one concept) were different, as were the exemplars. For example, from interviews with Ann several paradigm cases were identified (i.e., major health problem, spirituality and related needs, and other emotional and spiritual needs). From the data of the first interview with Ann, two main themes emerged from the paradigm cases.

- Anger towards the HCP in not demonstrating care and compassion. In addition, Ann's attitude was very fatalistic, very passive while hospitalized, as she used words such as "God's will" and did not confront staff. However, on discharge from hospital Ann sought and asked for help (from mothers' groups, child health nurse, and psychologist) and thereby became quite active in her care.
- Unresolved grief concerning her father's death (and anger still towards her mother from not being there and helping). In addition, she still has questions about the death, which are unanswered 12 years later.

These themes evoked the use of strong and emotive behaviours by Ann, such as hurt and pain, fear of death, anger from lack of support, anxiety, denial, and acquiescence to God's will. The findings caused me to ask questions of the data and to find answers. In this instance, I wanted to know if I had noticed only some strong feelings and ignored others in the data.

## These strong descriptors/feelings would have opposites? Are they present in the data?

That is, I needed to search for disconfirming evidence in the data (Erickson, 1998). A search for the antonyms of the descriptive words through the data found that Ann had not used the words at all during the interview. The words that were searched for included: empowered, ask, help, comfort, pleasant, unafraid, inner peace calm, assurance, and acceptance. Although this searching was unsuccessful, it did assist me in knowing that I had correctly identified the main thrust of the interview. That is, Ann had used predominately negative and/or passive feelings, and there was very little evidence of positive and/or active feelings associated with her spiritual needs during the traumatic birth of Mary.

#### The meaning and use of codes

When comparing the various participants' descriptions of their feelings, some of these could be quite readily grouped. For example, one participant's behaviour had prompted me to use 'passivity', whereas with another participant's behaviour I had used the descriptor 'disempowered'. The manner in which I used the descriptors and situations in which I used them are as described.

- 1. The words 'powerless', 'passivity', 'dis-empowered' (antonyms of 'empowered'). Some participants were very passive about their spiritual beliefs and their understanding of both the health care professional and their own beliefs/truths. For example, some participants were extremely passive in some instances and did not seek any help for their health care problem, saying, "it is God's will". This may have been due to their lack of spiritual maturity or stage of faith, or because of their concrete thought patterns and lack the intellectual ability to reflect, or due to their psychophysiological condition (Hawley, 1998). The opposite of a passive person is someone who has gathered as much understanding as possible about their health care problem and feels and acts in an empowered way in their knowledge and understanding of the situation. A Hindu, although s/he may not wish to accept narcotic analgesia when approaching death, is empowered by his/her religious conviction (in that they are doing the right thing to enter the next stage of their life through reincarnation). With the Hindu person, there is nothing passive about their decision or refusal of treatment. It is an active declaration of faith.
- 2. The words or themes of 'lack of support' (antonym of 'ask'). In some situations participants realised their vulnerability or passivity, and at the same time recognised that the health care professional was not openly supporting them. That is, there were no words of assurance or acknowledgement of their situation by the health care professional.
- 3. <u>Likewise</u>, the use of 'hurt and/or pain' (antonyms of 'help', 'comfort', 'pleasant'). This occurred when the participant was hurt by the health care professional. That is, the situation at the time was made worse by the

- health care professional hurting or offending the participant to the extent that they felt pain because of the health care professional's behaviour.
- 4. The theme of 'fear of death' (antonym of 'unafraid'). From my experience, the only person who does not fear death is the person who wants to die. This may be a person with a terminal illness or a condition that is not compatible with life (eg, severe burns, complete quadraplegic, psychiatric illness). There was no participant in the terminal or end stage of a disease. However, one participant had contemplated committing suicide to the extent of harming herself. It is the suicidal person who can not think of anything else but the pain inside of themselves, and not being able to take any more pain, s/he decides to die. Others fear of death may be due to not wanting to leave their loved ones. Therefore, the anxiety or fear of death felt by Ann was understandable, when she did not want to die while having the operation just after her baby was born. In my experience when information is given to a person about the dying process, their anxiety is reduced. Likewise, loved ones are also relieved to know what will happen as death approaches. That is, the person becomes weaker; they will sleep more often and gradually lapse into unconsciousness. However, if a person is concerned about death when facing an operation their fear is only resolved when they have survived the anesthetic and operation and woken up. Giving the person the statistics of how few people die because of an anaesthetic only partially helps.
- 5. 'Anger' (antonym for 'inner peace'). Anger arose when the health care professional did not explain provide information, gave incompetent care or "stuffed up"; that is, when the participants' felt that the health care professional or the health system did not match the care the participants felt that they should have been given.
- 6. 'Anxiety' (antonym for 'calm' and 'assurance'). The situation of facing uncertainty (Hawley, 1997c) that is, not knowing what might happen next, or if recovery is possible can produce stress and anxiety in any human being. Although stress may provide the means for flight or fight, there is probably a percentage of anxiety involved. For example, Geoff was

- able to fight the Non-Hodgkin's lymphoma and, with treatment, go into remission. However, he still had anxiety about the disease returning.
- 7. 'Denial' (antonym for 'acceptance'). Denial was once thought to be a non-coping mechanism. However, today, it is acceptable that people can at times deny aspects of their illness, so that they can stay focused and positive about the outcome. In this way, denial occurs when the participant does not dwell on the negative aspects of their illness or situation.

After making sure that there was uniformity in word usage when labeling cases, themes and exemplars the data analysis progressed to Level Two (Benner, 1994).

#### Level Two

Level Two analysis involved examining all cases, themes, and exemplars to identify the themes that were universal or common to all participants (van Manen, 1990). The individuality of each participant's interview contributed to the variation that occurred. Again, questions needed to be asked and answers sought.

# What are the common threads to the participants' feelings, etc.?

The spiritual themes common to all participants involved their perspective of spirituality, their manifestations of spirituality, meaning of life, and purpose in life, personal reflection and prayer and/or, trust, hope, understanding, respect, and their fears. Other themes included their health problem/s, the uncertainty they were facing, their knowledge deficit, emergency treatment, and the relationship between their significant other and the health care professional.

#### Level Three

Level Three analysis consisted of working out the interrelationships between the themes (van Manen, 1990). It was clear that the participants' spiritual themes were affected by their "health" themes. That is, the participants' spirituality, meaning of life, and purpose in life, their personal reflection and prayer and/or meditation were affected by the nature of their health problem, the uncertainty they were facing, their knowledge deficit, whether or not they needed emergency treatment, and the relationship between their significant other and the health care professional.

When undertaking the analysis and by talking with the participants during their third interview session, I realised that the names of some themes needed to be altered to enable them to more accurately describe what was happening in the theme. In this way, the theme "understanding" was changed to "empathy". Likewise, "respect" became "valuing". As the participants said, it would be nice to be valued and cherished by health care professionals. However, in reality it is only loved ones who we can ask to cherish us. The health care professional has a different relationship with us and, therefore, to be valued would be the highest expectation that we could ask for as consumers of health care.

Some themes needed to be combined, as the participants used the terms in the same context and they said that they meant the same behaviour. The themes that needed to be amalgamated were "fear of dying" and "fear of abandonment", to become part of "empathy", in that the participants wanted empathy from the health care professionals when they experienced such fears.

In total, 24 individual themes were identified and supported by the participants. These were: past health care of hospital experiences; past spiritual or religious experiences; present health care problem/s; and present spiritual situation/s; participants' meaning of life, and purpose in life; trust, love, peace, and hope; identification of the participants' health care problem; realisation of dissonance between normal routines/daily rituals and/or feelings of anxiety or fear due to present condition, asking for spiritual care, receiving or not receiving that care, and reflection; acknowledgment, empathy, and valuing.

These themes, when grouped together with similar themes, told their own story of spiritual concepts or processes. These included Being, Spirituality, Spiritual

Needs, Journey or Rite of Passage, and Levels of Care. The way in which these themes were grouped together follows.

- The participants' past health care of hospital experiences, past spiritual or religious experiences, present health care problem/s, and present spiritual situation/s, constituted the Bakhtin and Heidegarrean concept of Being (see Chapter Five).
- 2. The themes of spirituality and meaning of life and purpose in life constituted the concept of spirituality (see Chapter Six).
- 3. The themes of trust, love, peace, hope, became the spiritual needs (see Chapter Seven).
- 4. Three themes became the levels of spiritual care, that is, acknowledgment, empathy, and valuing (see Chapter Eight).
- 5. The themes of identification of health care problem, realization of dissonance between normal routines/daily rituals and/or feelings of anxiety or fear due to present condition, asking for spiritual care, receiving or not receiving that care, and reflection. These arose from the inter relationship between the themes of spirituality, spiritual needs, and the health themes. Together, they constituted the participants' journey or passage (see Chapter Nine).

As mentioned previously, the findings of this study were presented to each of the participants for their comments (Appendix 16) and were deemed true and trustworthy (See Chapter Three). On reading the final draft of the findings the participants' comments included:

It makes sense the way you have put it together. (p.16 TOM.TXT)

You interview us, and we gabble on, but somehow you make sense of it all, and write it as it is but in a way, that makes sense. (p.18 SOPHIE.TXT)

I don't know how you have done it, but the way you have taken what we have obviously all said and shown how spirituality and health problems together can cause problems for patients. I can see that the private health care system could do with some improving. But I don't know what the poor buggers in the public system can do about it, as they haven't time to scratch themselves

these days. However, that should not stop them being aware of the problem. (p. 35 RED.TXT)

This is so true, it is what happens in our hospitals. I'm not working in the nursing home anymore, but I know what happens still. Even when I was in the private psychiatric hospital where the care is excellent, I said to them, you could try harder to help a person spiritually. (p. 45 ROSIE.TXT)

Tom, Geoff, and Scarlet did not make any comments, and when specifically asked if they disagreed with any of the findings they said no. I think that the cognitive ability (of abstract thought) needed to follow the threads from what they told me in interviews, and then joined with what other participants had told me, and then for me to make an interpretation on these, was beyond some participants. The part of verification that excited all the participants was when they could recognise a quote from them in the final copy. None of the eight participants showed any concern that one of their responses might have been different from another participant's. For example, when Red read comments made by Ann about God he appeared to accept her spirituality without being judgmental, cynical, or dismissive of her spirituality. Likewise, Ann made no comment about Red's spirituality.

It should be noted that another researcher could ask different questions to what I did during the analysis of the same data and may find material to support that answer. However, those questions did not occur to me and I admit that I may not have found everything possible in the data. What I have done is to identify the spiritual needs of culturally diverse Western Australians to the best of my ability at this stage.

#### SUMMARY OF CHAPTER

Discussion through interviews cannot reproduce transparently an event, process, concept or object. Even when interviews cannot lead a researcher directly to an event, or at least a completely accurate record of an event, they do enable me to learn about things that cannot be observed directly by other

means. In this study, eight participants were interviewed for their perspectives on spirituality and related needs. In addition, the participants spoke about other people, situations and experiences, so that the stories the participants told were not limited to their own personal experiences. Table 3 contains a summary of the participants. Three or more interview sessions were conducted with each participant. Data analysis involved three progressive levels of identifying paradigm cases, themes, and exemplars, comparison made between all participants, and the working out of the relationships between the themes. Although not all participants were as articulate as others were, the overall findings were poignantly revealing and surprising in their originality. The depth of emotion expressed by the participants during their interviews was heart-rending at times, to the extent that I felt privileged to have been trusted by them to express their innermost feelings. In addition, I discovered that well conducted conversational interviews with an articulate participant can uncover details that I could not possibly witness or observe through questionnaires and statistics of quantitative research. However, the findings could be used in the future to assist in the construction of a questionnaire about spiritual needs (Morse, 1995b).

Table 3: Summary of Participants

Participant	Health Problem	Treatment	Parents/culture	Place of Birth	Spirituality
Ann	Traumatic birth Father died	Operation	Aboriginal/English Mother lives in Aborginal community	Australia	Anglican/Christian
Athika	Hypertension Peritonitis Cancer people-	Medication Operation Teaches meditation	Cosmopolitan	India	Hindu/cosmos
Geoff	Lymphoma	Operation and radiotherapy	English/European	Australian	Creation
Red	Pinched nerve Undescended testes Hernia Mother died	Rest/physiotherapy Operation Operation	Australian	Australia	Humanist/Socialist
Rosie	Manic depression Father died Mother died	In-patient	Irish	Ireland	Brethren/Anglican/ Buddhist
Scarlet	Traumatic childbirth Separated from baby Mother died	Operation	Romany	Southern Europe	Pagan Romany
Sophie	Anxiety and osteo. Heart failure Husband had stroke	Medication	Norwegian	Norway	Ex Roman Catholic/ cosmos
Tom	Burn out/depression	Time off work	Chinese	SE Asia	Quaker/cosmos

#### CHAPTER FIVE

## THE ESSENCE OF BEING A PERSON

#### AND

## WHY DON'T THEY TAKE MY SPIRITUAL NEEDS SERIOUSLY?

I had been visiting Ted for some months, both at home and in hospital. He was suffering from cancer of the lung, which had spread to the liver and elsewhere. He would be leaving a wife and three teenage children to grieve for him after he died. We all knew he had only a couple of weeks left to live, and the family and I had been trying to tie up the loose ends that Ted was worried about. One day when he was in hospital we were talking about his funeral (at his request) and what he would like and how he wanted me to conduct the service. The screens were around the bed to try to make the time we had together private. We had discussed what organist he would like and what hymns. We were moving on to the Bible readings and who would read them when suddenly...the bed screen was lifted up and a nurse said, "here is a bottle [urinal] for when you need one later on". I was dumbfounded; that this health care professional did not take her patient's spiritual needs seriously.

#### INTRODUCTION

The main purpose of this chapter is to explore the participants' essence of being a person. This chapter does not give an empirical description of the participants and

their worlds, rather it seeks to find the Bakhtin and Heideggerian understanding of what it means for them in being a person. The concept of being a person includes the way in which people know things, that is, their subjective knowledge and meanings gained from their worldly experiences of culture, family, and situational practices about health care and spirituality and meanings (see Chapter Three).

I do not believe I can accurately describe the participants and their experiences, and therefore, I have tried to uncover the meaning of being from my own interpretation (see Chapter Three). In this way, some new light will be shed on the phenomena of being a person and spirituality and health care.

Another purpose of the chapter is to set "the stage" so to speak for subsequent chapters. In this way, the Bakhtin and Heideggerian notion of being a person provides for the reader the participants' nexus of knowing experiences in their worlds, in relation to spirituality and health care. Possible ways of knowing were expressed as assumptions in Chapter Three in order to ground the philosophical beliefs into the research design. At that time, I argued that the assumption statements were without evidence; it is now time to enquire into these statements in order to find the essence of the participants' being.

This first section of this chapter discusses the first assumption: that a person only knows something in relation to his/her own subjective experience (and what the meaning or essence of that experience was for the participants). This includes their cultural, familial and situational worlds. The situational world incorporates the participants' experiences of health care, spirituality, and the intertwining of these two phenomena. The second section discusses assumption two: that when participants tell of their present experiences, they remember the past, as well as thinking about the future and this is included in their subjective way of knowing. The final section discusses the third assumption: that the participants have an underlying need that is, their cry or problem. Underpinning these assumptions is

the premise of the uniqueness of people, that is, each person is an individual, with different experiences from the next person. The overall aim of this chapter is to enquire not only into the assumptions, and compare these with the participants' stories, but at the same time try to interpret what the participants felt is the essence or meaning of being a person.

## PARTICIPANTS' BEING IN THEIR WORLD OF SPIRITUAL AND HEALTH CARE EXPERIENCES

This section of the chapter addresses the first assumption:

Assumption One That a person only knows about something in relation to his or her own subjective experience.

To gain an interpretation of the participants' ways of knowing I examined the stories of all eight participants. According to Bernard-Donals (1994), and Gadamer (1990), peoples' way of knowing, and their individual or unique world, includes their own set of values and beliefs in relation to their experiential nexus of cultural, familial, and situational practices and meanings. In order to enquire into this assumption the participants' cultural, familial, and situational practices and meanings are explored separately (Benner, 1993; Bernard-Donals, 1994; Gadamer, 1990; Van Manen, 1990).

## The Participants' Knowing their Cultural Worlds

The eight participants' experiences of their cultures was unique to all of them in that each had different stories to tell about their individual and personal circumstance (Dostal, 1994; Gadamer, 1976). Five of the eight participants were born outside Australia, and had either immigrated with their parents or arrived later as an adult. The participants who were born outside of Australia were Athika,

Rosie, Scarlet, Sophie, and Tom. The Australian-born participants were Ann, Red, and Geoff. Each participant's culture is as follows:

- 1. Athika's culture is cosmopolitan in that although she described her spirituality as Hindu Indian, she had lived in South Africa, the UK, USA, India and Australia. When I first asked Athika what her culture was, she replied "which one?". She then went on to explain the various countries and cultures in which she had lived. Athika said that she felt her beliefs and practices could not be attributed to one specific culture. Rather, each residing country with its different cultural characteristics had contributed to her unique way of knowing through experiences.
- 2. Scarlet was also born overseas in that her parents were Romanies (Gypsy) and she came to Australia with them as a child. Scarlet is very proud of her Gypsy heritage and culture, and endeavours to try to practise those customs as much as possible. These include attending Romany gatherings, horse shows, celebrations and learning as much as possible from documents and listening to the older relatives.
- 3. Rosie was born and educated in Ireland and came to Australia in her twenties. Her voice has an Irish accent. She said that she likes to party on St Patrick's Day, and is partial to Irish foods. However, if you ask Rosie what her culture is she will reply "Australian".
- 4. Sophie's parents are from Norway and she came to Australia with them as part of the white European wave of immigration in the 1940's. Sophie regards her culture as Australian, as she said that she has lived the majority of her life here.
- Tom too came to Australia as an immigrant; his mother culture is Asian.
   However, he said that he no longer practises any customs or holds strong Asian beliefs.

The varied cultural experiences gave these participants knowledge of another country as well as of Australia, and allowed some to have the advantage of knowing, appreciating and manifesting parts of this culture while living in

Australia. The different cultural backgrounds also allowed the five participants to be uniquely different from each other, and the meaning I gathered from this was that such individual ways would give rise to different ways of subjective knowing for each of them (Bernard-Donals, 1994). The experience that these five participants had in common with each other was the fact that they had been part of Australia's immigration programme at some stage (see Chapter One). However, even with this experience there were subtle differences in that they each came to Australia at different times and from different countries.

The remaining three participants (Ann, Red, and Geoff) were born in Australia to Australian parents. Their cultural backgrounds include:

- Ann was born in Victoria, her father (born in England) had died some years before and her mother now lives in an Aboriginal Community in the Northern Territory.
- Red grew up in Queensland, as one of twin boys. He attended school there and later went to university. He came to Western Australia as an adult and since married a third generation Australian.
- 3. Geoff was born here in Western Australia and had lived all his life in this State, except for the odd holiday to the eastern States or South East Asia.

The Australian-born participants, although fortunate in growing up in Australia, where there is no shortage of food, and health and education are available to all people, have not had the experience of being able to compare this way of life with another culture (Mackay, 1993; 1999). That is, these participants' knowledge from cultural experiences was different from participants born overseas, in that they did not have that knowledge gained in childhood of growing up in another country. They also did not have the experience of trying to establish themselves in a school or employment or abode in a country where the culture was foreign to them. These experiences could have been both positive and negative as the treatment towards each new wave of immigrants to Australia creates some hostility. (See Chapter One). Although there may be similarities between the participants'

countries of origin, say Ireland and Australia, variations still exist, such as politics and government, education, and health care.

For all eight participants, cultural experiences included their personal relationships within their cultural group, as well as those with loved ones and family. This family and cultural group also involves community participation, which although directed towards the self is frequently done with others. This includes the different festivities related to specific days such as Christmas and Easter.

## The Participants' Familial Knowing

All eight participants had experiences of familial incidents, which gave them subjective knowledge of those experiences (Bernard-Donals, 1994). These experiences included those with their parents, siblings, and with their partner and offspring (if they had children). Some people in Australian society may be estranged from their family, but the eight participants in this study stated that they enjoyed their familial relationship with another person and other family members. The meaning I interpreted from these findings was that each of the participants was loved by someone, and they in turn loved someone. When love is reciprocated in this way, a person feels important to the other person, and this in turn gives them a purpose and meaning in their life.

Each participant volunteered information about their parents and whether or not they were alive; in fact each spoke openly about these relationships without me asking a direct question. Six participants (Geoff, Red, Rosie, Scarlet, Sophie, and Tom) had neither parent alive; both of Athika's parents were alive, with Ann's mother alive and father deceased. The death of parents I took note of because sometimes I find that when a person's own parents have died they become more aware of their own mortality and question their own purpose in life and its

meaning(Bearon & Koenig, 1990). This made me wonder if their spiritual needs may be different from those who parents were alive (see Chapter One).

#### Sexual relationships

The participants' familial relationships did not conform to the Australian statistical norm of "married with 2.3 children" (Australian Bureau of Statistics, 1996). That is, not all participants were heterosexual and married with children. One male participant was homosexual and lived with his partner. Of the seven heterosexuals, five were legally married (Ann, Athika, Red, Rosie, Sophie) and two had long-term de facto relationships with another person (Geoff, Scarlet). To emphasise the diverseness of participants' experiences these familial situations are listed:

- 1. Ann and her partner Sam had been living together for some years before deciding to get married, and they now have the one child, Mary.
- 2. Athika and her husband have both been married before, with Athika being stepmother to one child from her husband's first marriage.
- 3. This is Red's first marriage, his wife's second, and they have no children.
- 4. Both Rosie and her husband have been married before and have three adult children between them from previous marriages.
- Sophie and her husband have been married for over 30 years and have four adult children.
- 6. Geoff has been living with his defacto wife for 15 years, both have been previously married and she has 3 daughters from her first marriage who live with them.
- 7. Scarlet had been married and now lives with a partner, she has two adult children from her marriage who live with her and a younger son (born by caesarean operation as mentioned in this study) from a relationship prior to her present partner.
- 8. Tom has never married and lives in a sexual relationship with his male partner. (In Western Australia, homosexual relationships are deemed legal if

males are over the age of 21 years and females over the age of 18 years. However, under the present Marriage Act homosexuals cannot marry each other. Instead, they can instruct a lawyer to draw up a legal contract of commitment, which both can sign. In this way, their joint ownership of housing, goods and chattels is deemed legal.)

My interpretation of these familial experiences led me to believe that they were all different to each other and no two participants had a similar relationship to the others. This finding would appear to support the assumption that the participants had developed different ways of familial knowing in relation to their personal circumstance (Bakhtin, 1981; Bernard-Donals, 1994).

## The Participants' Situational Knowledge

In enquiring into the participants' knowledge in relation to their experiences, the phenomena of this study also needed to be explored, that is, their knowledge in relation to health care and spirituality. This notion is supported in the literature of Gadamer (1990), in that the situational meanings of experiences that participants attached to these are also part of their unique way of knowing (Benner, 1994). The situational practices and meanings that I was interested in were those pertaining to their health problem and spirituality.

#### Health care experiences leading to knowledge

All eight participants told stories in relation to their health problems and treatment that included childhood illnesses, previous operations, illnesses and deaths of loved ones; not only their own personal experiences, but also those of their parents or others that they knew. The situations included both positive and negative experiences, which the participants portrayed by their feelings and described in their stories of various situations. For example, the following story from Red relates to a negative health care situation:

About ten or twelve years ago I went for a hernia operation for about five days I s'pose. One nurse used to tick me off for upsetting one of

the poor nurses. I said, I was just trying to help. I thought she was a stupid old bag actually.

I said to a friend who was an educator type of nurse, you'd better start teaching them, that they ought to start listening to their patients because this one knew everything. And I thought, right, go to blazes. I remember I didn't want a cup of tea after an operation. I said, can I have a glass of orange juice? No, no, that's solids and I said, no, no, no, if I have tea I'll throw up. It was just the smell in there, you could see it was going to happen. Anyhow, I said, okay, so I forced a cup of tea; and I had a cup of tea and threw straight up in front of them and I said, now can I have my orange juice?

They went out and brought me some juice and it went down no worries at all. And I was angry inside, that, why don't you listen to people? Don't you believe people have idea, but we're just the poor peasants outside that don't matter? (character 15792 to 16856 RED.TXT)

From this story of Red's it may also be possible to interpret the meaning that he doesn't like nurses (and perhaps other health care professionals) who do not listen to what patients say. To me as a nurse researcher, who knows that only very thick fruit juice could be regarded as solid food, I find the nurse's attitude rigid, lacking not only common sense but also thinking ability. It would have been perfectly acceptable to give Red a glass of fruit juice in this situation. Red's story also allows me to understand his dislike and anger that the nurse was not listening to him. I too would feel the same. Such an incident forms part of his personal or unique way of negative knowing about nurses and other health care professionals who do not listen to patients. Although I could interpret this situation as nurses being uncaring, there is also the essence of power by knowledge. That is, the nurses thought themselves right because of their training and therefore had this power over the patients who did not have their knowledge.

Not all participants were able to tell of positive experiences related to their health treatment or care; in fact only three did. This, in itself, is worrying, in that the participants were not able to easily reflect on any positive experiences that had happened to them. That is, they either did not have any positive experiences or, in

their minds the negative experiences were more readily remembered. The following story is from Rosie when she was severely depressed and trying to commit suicide.

When my husband took me to the psychiatrist and he said I needed to be admitted to the private psychiatric hospital, I knew I had to go but at the same time I didn't want to as I was worried about how the staff would treat me.

The psychiatrist told him [my husband] to take me straight to the hospital, then go home, and collect the things I would need. Well, my husband took me to the hospital and I was admitted, and the staff apparently were really very nice. I can't remember much about those first few days, as I was so ill. But my husband told me later that the staff were nice in that he felt quite comfortable in leaving me there for treatment. (character 26000 to 26580 ROSIE.TXT)

He said he was not worried, and that the staff seemed so caring. Also, that there was enough staff around all the time to stop me from hurting or harming myself, until the medication had time to take effect. Later I did realise how caring they are when they suggested I telephone you [the researcher to go as a chaplain or minister to see the patient] and ask you to come and see me. (character 26680 to 27160 ROSIE.TXT)

But at the same time I couldn't have my own way all the time. I can remember that I wanted to have a sleep one day after lunch and not go to therapy. However, my nurse came and said to me that I needed to go to the therapy group and have my sleep later. (character 28420 to 28606 ROSIE.TXT)

If this experience is an example of positive caring, then it can be interpreted that such incidents are composed of several factors such as adequate staff, non judgmental attitude by health care professionals towards the patient's illness, and trying to assist the patient in gaining comfort and peace through spirituality. My meaning being that there is possibly no one factor that can be classified as positive or good caring, rather several features need to work together or interrelate.

The two experiences, one negative from Red and one positive from Rosie, are used as examples, in order to describe the uniquely different experiences of knowing about health problems and care from the participants' perspectives, the

essence and meaning of which illustrate the factors that incorporate poor or negative care and those that facilitate good care. Here, poor care comprised (a) an unequal relationship between health care professional and patient in relation to knowledge power, (b) negative attitude of health care professional, and (c) incompetence due to inaccurate knowledge of fluids and solids for the postoperative patient. Good or positive care incorporated (a) the easy rapport by health care professionals with the patient about her illness, (b) sufficient staff to give effective care, and (c) the effort to try and help even more, by suggesting that she phone me to visit her.

## Spiritual Experiences Leading to Knowledge

In talking about their knowledge of spirituality and being spiritual, all eight participants had situational incidences to tell of that were part of their stories (Benner, 1994; Van Manen, 1990). Again, some of these stories were negative and others positive. All of the participants were able to tell of both negative and positive situational incidents. Examples of some of the negative spiritual experiences from the eight participants included:

The various religions have caused me to have a lot of emotional baggage over the years, which I have had to get rid of. (character 477 to 486 TOM.TXT)

The so-called Christian religions in England and Europe have messed up some gypsies by saying their culture and way of life is wrong. (character 520 to 637 SCARLET.TXT)

My mother was told she could not celebrate in the Holy Communion/Lord's Supper, and not sit in the pews in the front of the chapel because she had a glass of sweet sherry after she had finished laying out a patient whom she had looked after for months. You see drinking alcohol was a sin in the Brethren Church. Therefore, she had to sit at the back of the chapel with the sinners and not have communion. She decided not to stay and left the Brethren church, never to return. She did go to the Church of England years later and

was Confirmed into the Church before she died. (character 3524 to 3982 ROSIE.TXT)

If you don't believe in the Virgin Birth and all those creeds, you are excluded from the Christian Church, although some of it may appeal to you. You have to work it out for yourself. I can't believe in those creeds, so I don't go to church anymore. (character 25768 to 15966 SOPHIE.TXT)

The Russian bloke Lenin said that religion is the opium of the masses and I've often thought he's right. (character 22151 to 22272 RED.TXT)

Aboriginals were told by the "whites" that their spirituality of Dreamtime and their relationship to the environment was heathen. So they excluded all of their culture and indoctrinated them with Church of England and Roman Catholic beliefs. I mean that was daft, those two Christian religions were for people of different cultures than the Aboriginal. (character 11120 to 11420 ANN.TXT)

Within these statements of negative knowing are the participants' personal or unique gripes about aspects of religion that they do not like. Such stories allow me to interpret these as having negative meanings for the participants. The essence of these stories reflects the damage that religion can do, to either a person, a group, or whole culture, when there is a lack of understanding and a rigidity to teaching and doctrine. For example, I told Sophie about the The Religious Society of Friends (Quakers), who do not demand that people believe in the creeds, and also the Sea of Faith (an international ecumenical group that believes religion has been created by humans, and that people need to develop their own spirituality). Sophie had dismissed all Christian teachings because she could not believe the creeds; however there are other avenues open to her (such as the two groups I told her about), where she could develop her spirituality in the company of others. The rigidity on the part of the church she attended could have been bent a little, and church members visited her at home to see why she had left. In which case she may have been told that the creeds were written in ~360 CE and that she is not the

only person who has difficulty in believing them to be true, as they reflect peoples' understanding of Christian belief in the fourth century.

Positive spiritual experiences of knowing were told by all eight participants, although only three examples are given below. The reason why these three are given as examples is that they also describe how experiences form various parts of the participants' lives. For example, the story from Rosie relates to an aspect of childhood, for Athika her experience occurred when she was a young adult, and for Sophia it is in relation to middle age.

Rosie's childhood experience describes how she was bribed and rewarded for good behaviour at Sunday School.

As a child, I was quite bright and so on Sunday afternoons, I would go to Sunday school and recite their memory verses. I got paid for those (three pence each for each correct verse I recited), on most days I could get 2/- which was a lot of money in those days. More than what my parents could afford to give me as pocket money. (character 3524 to 4167 ROSIE.TXT)

Athika's story of positive knowing told of her ability to manifest part of her spirituality. This centred on her ability to meditate and say positive mantras to herself to stay alive and not die.

When I was extremely ill in hospital and .... I used meditative repetitive self-help talk. I closed my eyes and it was really the only way I survived that situation because I was very ill and the medical care was very bad and it took a while for things to be re-organised and operations; you know, I'd already had one operation, another operation to be organised and, and for me to be moved into a different hospital and it was pretty horrendous. I think that it was that technique helped me greatly. I know more about the technique now than I did then because that was many years ago, but it almost seemed instinctive. It was almost like survival technique because there were so many things going on around me and nothing was happening with relation to my health care. Nothing positive was happening the health care professionals were not doing anything. They had told my mother to come to the hospital as they thought I might die. So, meditation

perhaps decreased worries etc and kept me focused on living. (character 20265 to 21317 ATHIKA.TXT)

#### Sophie's story:

When I was going to the charismatic meetings I was asked to pray for someone, lay my hands on someone and pray for them in tongues. When I did this, I felt as though a silver sword pierced my head and down through my arm into my hand and into the woman. She started crying. It terrified me; afterwards I thought I couldn't do this any more. So I didn't go to any more meetings — the power was scary. However, I did find out that she her husband had been an alcoholic. They had six children and she was pregnant again. And when I laid hands on her and prayed her husband gave up drinking and became the model husband. She gave birth to a lovely little girl. I saw her one day in the street and she told me all about it. I couldn't remember her, but she recognised me, came up, and thanked me. (character 18463 to18975 SOPHIE.TXT)

In this story, Sophie describes the positive nature of being able to help someone through prayer but, at the same time, of the anxiety of the situation that scared her. This fear or anxiety was sufficient to cause her to not go to any future charismatic prayer meetings as the potential power available through her scared her.

The three examples of positive spiritual knowing help us to understand the idea that both spirituality and health are intertwined. For example, Rosie, was paid for knowing her scripture verses (spiritual) which improved her wellbeing (health) by having the money for things which her parents could not afford to give her. Athika's ability to meditate (spiritual) helped to sustain her physical nature when she was close to dying. Sophie's prayer (which is a behaviour or manifestation of spirituality) was for the alcoholic husband (health problem) to be made well or healed.

The examples of spiritual knowing with those of health knowing are part of the wider or broader concept of situational experiences and meanings that are part of each participant's unique way of knowing from their subjective experiences. Also,

it can be seen that spirituality does not occur in isolation of health care, rather the two phenomena can be intertwined and need to be explored together and not separately.

## The Intertwining of Health and Spiritual Experiences

Although health experiences and spiritual experiences have been separated in order to show the reader the discreteness of situational knowing, what invariably occurred within the data was that the components of health and spirituality were intertwined. When examining the situational incidents of both health care and spirituality together it occurred to me that additional factors could possibly influence the participants' experience of knowing. I identified the following three factors that I believe contributed to the knowledge of these participants.

- 1. The classifications of care and treatment.
- 2. Their personal understanding of the situation at the time.
- 3. The attitudes and communication skills of the health care professionals. Because all eight participants cited one or more of these factors as added stress for them, it seems pertinent to describe these more fully.

#### The classifications of health care and treatment

Health care has many divisions and classifications, such as geographical (urban and country), levels of care (primary, secondary or tertiary), public (government) or private organisations, type of care (acute or long-term). However, in this study, the differences that I needed to interpret were those between emergency treatment and non-emergency and when complications occurred from either the emergency or non-emergency treatment. Non-emergency treatment is planned so that the patient or client knows what is going to happen to them. The doctor explains the situation, the benefits and risks of the treatment and asks patients or clients if they want the treatment. It is then up to patients or clients to accept or refuse that treatment. Emergency treatment is not planned, rather it is done in response to a crisis that has occurred for the patient. Also, by law the health care professional

does not need to ask the patient or client's permission to carry out the treatment. In addition, complications can occur as a result of either emergency or non-emergency treatment.

#### Emergency treatment

In this study, two participants (Ann and Scarlet) needed emergency treatment. An example of emergency treatment is when a woman is in labour and it is realised that she needs to have a caesarian operation, as she is not able to give birth to the baby via the vagina. This was the emergency treatment Scarlet had for the birth of her son. However, in Ann's case the afterbirth or placenta did not come away naturally from the wall of the uterus, and pass out through the vagina after the birth of Mary. In this situation, an emergency operation was needed to remove the placenta. To leave the placenta inside that uterus would have resulted in severe infection and haemorrhage and possible death of the mother. In Ann's situation, the health care professionals tried to give her an epidural anaesthetic, so that she would be conscious but feel no pain when the placenta was removed. However, Ann said that the epidural did not work, so she needed to wait on an operating room trolley in a corridor of the perioperative unit until an operating room was free, to have a general anaesthetic.

The midwife had me doing all sorts of things so that the placenta would be expelled. At one stage, she had me sitting on the toilet with her pressing down on my abdomen to try and press the placenta to move. Then she tried other things but still it wouldn't come out. She said to Sam and me that I would need to be transferred from the independent delivery cottage across to the main hospital to have an epidural anaesthetic and for the doctor to manually remove the placenta. I didn't want that to happen as I wanted to be with Sam and our new baby Mary. But the midwife said it was something that had to be done immediately like an emergency as it was wrong for the placenta to stay inside the mother. So I was transferred and I didn't see Sam and Mary for about another six hours, as the epidural anaesthetic didn't work and I needed to have a general anaesthetic. Character 4026 to 7991 ANN.TXT)

I strongly believe that the emergency treatments for Scarlet and Ann were additional situational experiences that became part of their knowing. It would appear that the two participants in these situations were not given time to comprehend what was occurring and neither did they have the necessary mental and physical resources to assimilate/synthesize any information that they were given. In these positions, they did not have the time to give an informed or true consent or permission. An extract from Scarlet's first interview gives an example of her emergency experience and way of knowing about such situations.

I had to have an emergency caesarian operation to give birth to my son.... It was dreadful...I felt as though I had been raped.... I was hauled this way and shoved that way as though I was just a carcass of meat on the production line in a factory. .. That is no way to treat a person's spirit. All that bullying.... leaves the spirit battered and bruised. (character 8962 to 9698 SCARLET.TXT)

Emergency caesarians are always rushed, and that is why they are termed "emergencies". The operation is needed to quickly remove the baby from the mother so that either the mother or baby (or both) will either not die, or the baby suffer from permanent brain damage. However, sometimes the gravity of the situation is not fully explained to the mother and she suffers as a result of the rush to save the baby. Whether or not Scarlet would have commented on her rough treatment if she had known that by being gentle with her the health care professionals would have compromised the safety of her child, is not known.

While these stories from Ann and Scarlet serve as examples that emergency treatment may alter a person's perspective of situational knowing, they may also tell of the participants having insufficient understanding of the situation they were experiencing at the time.

Post Script: Since the final interviews with Ann and Scarlet have taken place, a State Government funded inquiry is investigating claims of negligence and poor

standards of care by doctors and nurses at the hospital where they have both given birth.

Although emergency treatment appears to affect the manner in which the participants' have knowledge, as it did with both Ann and Scarlet, these situations can also be illuminating and knowledgeable for the health care professionals as well. Scarlet told of her experience of knowing more than the normal or usual patient by using some of her Romany power to remember treatment while anaethetised. She later informed the specialist of her experience.

After the emergency caesarian. I told the doctor everything they had done to me in the operating room. He couldn't believe what I was telling him. You know how they come and see you the big guy with the junior doctors and students. So I told them you need to always care for the body, as it is sacred, even when the person is unconscious the care should be respectful with no pulling around etc. You see the Romany mind can remember what happens to them when they are unconscious like having an operation and it can still hurt them if they are not treated right. (character 9225 to 9526 SCARLET.TXT)

Some people might say that Scarlet was untruthful or bluffing about her experience, however I do not think it can be so easily dismissed, as there is so much about the human brain that we do not know.

### Complications suffered by the participants

Any health problems have the potential to increase in severity not only due to the actual problem, but also because of complications. Inflammation and/or infection and haemorrhage are two such complications that are not unusual. It was these complications that affected both Ann and Scarlet, both directly and indirectly. Ann suffered two infections of the lining of the uterus and haemorrhaging. Scarlet, after having the emergency caesarian operation, was separated from her baby son who was transferred to another hospital so that he would not contract a life-threatening infection that had closed the nurseries at the hospital where she

had given birth. An example of incidences when a participant experienced additional worry or concern or anxiety in regard to complication of their health problem and treatment is as follows.

Then I ended up with an infection afterwards, so I had to have antibiotics and I was really worried about my baby Mary having the antibiotics when she was only two days old. (character 8957 to 9148 ANN.TXT)

That is, the antibiotics the mother received would pass through the breast milk to the baby. The usual side effect is gastric-intestinal irritability and diarrhoea, causing the baby abdominal pain, discomfort and excoriation of the skin around the anus. However, her worry did not end then.

I ended up with another infection later on too, so for a time there I thought it was just going to go on and on and I'd never be well again. (character 9148 to 9366 ANN.TXT)

These extracts are from Ann's first interview that occurred when Mary was six months old. Up until that time Ann did not want to be interviewed, as she felt too unwell to do so.

The manner in which I was able to interpret some situations as being additionally stressful or worrying to the participants, was that they used either a voice tone that inferred deep concern, or used adjectives that described the experience. For example "I was really worried" was said by Ann when describing her postnatal infections. In addition, when telling me of that particular experience the participants' faces reflected worry in a non-verbal way of communication. Scarlet's face expressed anger at the interview when she told me about the need for her baby son to be transferred.

Since I had been an emergency caesarian they said my baby would need to go to the special nursery for 2-3 days for treatment. I understood that these things sometimes happen but you don't expect it to happen to you. But the bloody special nursery at the hospital was closed as some babies had developed a bug in there and died. So no new babies were to be admitted until the bug had gone. (character 8673 to 9050 SCARLET.TXT)

This meant that my baby had to be transferred [loud angry voice] to the special nursery at the children's hospital, but I had to stay at the women's hospital for treatment. Whoever thought up that arrangement needs their bloody head read! But do you know I am quite sure it was only my baby and the Aboriginal babies that were transferred. They probably made room for the "upper class babies" at the women's hospital. You know I still get angry with that. (character 9225 to 9526 SCARLET.TXT)

While Scarlet was angry about the complication that resulted in her baby being in one hospital and she in another, it appeared to me that she also lacked some understanding of the situation at the time. For example, the "upper class" may not have needed special nursery facilities and therefore they were able to stay with their mothers in the same hospital.

### Personal understandings of the situation at the time

When reading the interview transcripts I also noticed that when the participants did not have sufficient knowledge of the health care system or treatment and/or their spirituality this placed them at a disadvantage and possibly affected their experience. I believe this factor of insufficient knowledge affected at least four participants (Ann, Athika, Geoff, and Rosie), and in quite different ways. An example of such an incident follows.

I now have an action plan for my feelings and behaviour. [pause] I didn't have one before so I didn't know I was depressed. [pause] All I knew was that things were not right. So I went to the doctor. [pause] I even went to my doctor and told him I was mistreating and injuring myself and he didn't tell me I was depressed and should go to hospital. He didn't even prescribe any medication. [pause] So I came home again and tried to struggle on. [pause] But I still wasn't sleeping at night and all I cope with was to sit around and smoke. I just had no energy to do anything. [pause] When I did sleep I still felt tired when I woke up...it was all so terrible the pain inside. I tried to pray for God to help me, but I couldn't even pray. (character 24647 to 25878 ROSIE.TXT)

In this situation, Rosie stated quite clearly that she did not know what was wrong with her. Like most people she went to her General Practitioner and told him of how she was feeling. For some unknown reason he didn't tell Rosie about her depression or give her medication to ease her mental and emotional pain. Perhaps it could be said that not only Rosie had insufficient knowledge but also her doctor?

Ann, on the other hand, had someone looking after her who did have the knowledge (midwife), but Ann's understanding of what the pain of childbirth would be like and reality were quite different.

Nobody tells you how horrible the pain of childbirth is and being my first I didn't realise that the pain would so bad... it was quite horrendous... I hadn't expected that much pain. The midwife was good in that when I asked her if this was what the pain of childbirth was normally like she said that it was. And she did give me lots of encouragement, saying things like, "not much longer to go now etc". But I also thought that the pain was the curse from God because Eve disobeyed God, and thats why all women suffer too much pain at that time. (character 2453 to 4021 ANN.TXT)

Geoff didn't know a great deal about Non-Hodgkin's Lymphoma, and neither did he or his partner obtain any information. Why this occurred is not known. I would have thought that the hospital or surgeon who performed the operation to remove the lymphoma would have given him a brochure or told them about the Cancer Foundation, where he could have obtained information. Whatever the reason, he was unaware of the severity of his condition and the likelihood of possible death until he went to a wellness course (conducted by Dr Ian Gawler in Victoria) after he had his operation and completed the radiotherapy.

They didn't tell me anything about the cancer much, I didn't know how severe it was until I attended the wellness clinic in Victoria...my specialist had not told me... and I didn't know, so they told me all about it in Victoria, they said patients should get as much information as they can about their illness as that empowers them. (character 2482 to 3821 GEOFF.TXT)

The difference information and knowledge could make is perhaps seen in the following quote from Rosie. This occurred at her second interview, when I asked additional questions concerning the need for knowledge:

The first time I went to X Clinic [private mental health hospital] they taught me how to recognise when I might need help that only professionals can give. So that is really my action plan now- it is on my fridge. Actually the second time I needed to go in was about 9.30pm one night. I had told my husband that I didn't feel well. So he telephones the hospital and the nurses spoke to me and told me to go in. I had no fear about going back the second time, as I knew I would be well looked after. I wasn't there more than half an hour and my psychiatrist came to see me. He immediately changed my medication, and gave me a sedative to settle for the night, so that I could rest. I didn't have to suffer on my own like it happened the first time. (character 30600 to 31190 ROSIE.TXT)

Rosie mentions the difference knowledge made to her in that she did not suffer as much the second time she needed to be hospitalised. Because she knew what was happening and what to do, she used that information to seek early intervention for her suffering.

Rosie's additional worry was also related to her health problem, but was not caused by the doctor not communicating, but rather her own family medical history.

My family has a history of mental illness. My brother suffers from the same manic-depressive disease that I have, and I recently found out that my father died in a psychiatric institution. All this makes me worried, as I wonder what is going to happen to me.

My brother is a religious priest and he has had to give up his parish, as he became so irrational at times.... And the money he would spend (which he didn't have of course). (character 22869 to 23193 ROSIE.TXT)

The meaning of Rosie's story for me signifies the experience of additional worry on top of her suffering from manic-depressive illness, her worry that she might experience more manic episodes and be like her brother, spending money which she doesn't have; or in needing to be institutionalised for all of her depressive episodes (and trying to commit suicide and needing protection like her father did).

These are three examples of participants' experiences of worry that possibly had an effect on their experience of knowing and their perception of health problems and treatments and spirituality. Athika offered the example of the power of knowledge:

The difference knowledge makes is tremendous. I think information is a very powerful tool for empowerment. Whoever said knowledge is power was correct. (character 1416 to 1546 ATHIKA.TXT)

These examples helped me to understand that knowledge cannot be taken for granted. That is, the health care professionals need to have knowledge, but there is also the need to communicate that knowledge to patients and clients so that they are more informed and less vulnerable to pain and suffering. Like a lot of things that can cause patients and clients concern, it is usually not one factor that they say caused them to feel that way, rather it is a cluster of reasons. In this study, the participants' vulnerability appeared to have come from the classification of their treatments, that is, whether or not it was an emergency and if complications had occurred, their personal understanding at the time, and insufficient knowledge. When examining the previous examples of insufficient knowledge, I had originally thought that this pertained only to the participants. However, when Rosie's doctor did not treat her for depression, I then started to re-examine the data for examples of the attending health care professional's attitudes and communication skills towards the participants.

Do health care professionals' attitudes and communications skills influence the care patients and clients receive? If so how?

# Attitudes and communication skills of the health care professional towards the participants

On reading the transcripts again, I realised that the health care professional's attitudes and their communication skills (or lack of) appeared to be an influencing factor in contributing or alleviating the participants' experience of vulnerability. That is, the influence of positive or negative attitudes and communication skills may either have helped the participant or not. Three of the participants spoke of situations in which they felt supported by the health care professional's positive attitude towards them and their ability to communicate with them.

The first example is from Tom who works as a mental health nurse in a psychiatric institution. His work involves caring for the "criminally insane" (those who will harm or kill other people, because of their mental disorder), and other patients with a mental disorder who may kill themselves. Tom described to me how he frequently gets exhausted in his work and "burnt out" (his description). The relationship Tom has with his general practitioner is rather like mutual respect.

My doctor and I have come to an understanding.... When I feel as though I can't cope any more with work he gives me a medical certificate for time off work.

Sometimes when I go to him for other things he asks me questions about various mental illnesses, I can usually gather from those conversations that he has a patient who he thinks may have the illness and he sought of "runs it past me" to see what I think. (character 2962 to 3522 TOM.TXT)

Another example of the general practitioner helping a participant by his attitude and communication skills was Sophie's doctor. He told her about a local support group she could attend to ease the burden in looking after her ill husband.

They started a support group to help the carers of those looking after someone sick in their own home. Since Alf has had his stroke, I look after him each day. It's twenty-four hours a day, so it is quite good to get a break, go, and talk about it. (character 584 to 782 SOPHIE.TXT)

Geoff and his wife were also told of a group that would be of use to them.

My general practitioner suggested to my partner and me to a private organisation that conducted residential wellness programs for people with cancer. The program was holistic in that we both learnt the importance of diet and meditation etc. (character 4829 to 5031 GEOFF.TXT)

The outcomes of supporting the participants both in attitude and also by communicating information to them by the health care professional was seen to be of a positive value and may have contributed in a positive way to their health.

Within the data were examples, for all eight participants, of incidents or situations in which the health care professional displayed a negative attitude and lack of communication skills. These were incidents in which either the health care professional may have had poor communication skills or their attitude towards the participant was not one of demonstrating hospitality or of being welcoming and trusting in nature. All participants spoke about situations in which they felt the health care professional had poor communications skills. These included:

Not listened to.... Spoken to as though I was not a person. We were not regarded as people. Gang mentality, Excluded... that nurses really had a way of making things uncomfortable for patients.

Geoff's experience of his health care professionals not giving him sufficient information and communicating with him raised concerns for me. This was mainly caused by his specialist doctor not communicating effectively with him.

I needed to have radiotherapy after the tumour was removed. I felt so tired I wondered if I was going to feel better again. I mentioned it to the doctor, but he never said anything. (character 2482 to 2628 GEOFF.TXT)

When Geoff told me about his tiredness I questioned him about the activity he was doing at the time. I discovered that he had gone back to work as a green keeper while having radiotherapy as an outpatient, hence his tiredness. I asked

him why he went back to work and he said that his specialist did not tell him he should not be working. In addition, the specialist had not told him to rest at home in between radiotherapy treatments.

Of particular concern to me was his possibility of developing serious burns to the radiotherapy area on exposure to the sun (from working outside). The skin that the radiotherapy rays pass through becomes so sensitive that people are told not to use soap on that area of skin. Geoff had been told not to use soap, but he was not told to keep his face and head out of the sun. While Geoff's additional worry was his tiredness during radiotherapy, my concern is the lack of communication between the specialist doctor and himself that created the additional worry in the first place, of not knowing why he was so tired. In addition, Geoff's activities could have resulted in heat exhaustion and severe burns to the face and head.

# Insufficient time spent with participants coupled with poor communication skills

When poor communication was combined with other behaviours by health care professionals such as rushing, not spending sufficient time, noisy atmosphere, in too much of a hurry, they were rough, did not use eye contact, they did not make the participants' worlds a very nice experience at times. An example of poor communication combined with not having sufficient time for patients and lack of understanding of their feelings was given by Ann. At the time of this example, she had given birth to Mary, and needed to be transferred to the operating suite to have an operation to remove the placenta, that is, the afterbirth, which is normally expelled though the vagina.

Soon I was wheeled away and Sam [her partner] didn't know I was having a general anaesthetic or the operation. It was only when I got to the operating room that they told me I'd have to have one because the epidural hadn't worked. And it was pretty scary. I'd heard about people dying under a general anaesthetic and at that stage I was praying. I was praying that I just wanted to enjoy my baby, you know,

and I didn't know things like, why did they put socks on my feet, you know, things like that that are really scary, and being wheeled into this room flat on my back and there's all these, like lights and people.

And to have such a private thing of giving birth to Mary, and then to be such a public thing, you know, who knows what they did when I was unconscious for the operation. With my feet up in the air in stirrups, my legs wide open and them with their hands up me trying to get the placenta out, I mean, you know, it was horrible.

Then when I woke up afterwards, my throat was really sore and I was trying to get the nurse's attention. The nurse was around but I couldn't see her. I wanted to hallo to the lady on the next trolley, but I could hardly say anything because my throat was so sore. Finally I got someone's attention and finally they wheeled me out, but I only found out afterwards that they put tubes down your throat when you have a general anaesthetic.

Luckily, Sam had just bumped into the Anaesthetist who said that I'd had a general anaesthetic and that was the only time he'd known that something had gone wrong! Then I was wheeled to the postnatal ward and saw him and Mary. It was great and that was about, that was about six hours after she was born.

So he didn't know what was happening to me for all that time! He had been so worried and everyone had been too busy to tell him anything. (character 4026 to 7992 ANN TXT)

Ann quite clearly describes her feelings of being scared and worried because either the staff did not have time to communicate with her or did not know how. At that same interview with Ann, she also told me of an example of the health care professional having a negative attitude towards her.

There was this senior nurse, I think she was a manager. She argued with Sam (male partner), as he wanted to stay the first night after I had given birth. First of all the nurse said he could not stay, then she changed her mind when he argued. He ended up staying, but the nurse would not supply any chair or bedding so, he slept on the bare floor. (Character 8557 to 8957 ANN.TXT)

The realisation that nurses could still treat patients in this way really worried me! I took the question as to why nurses might do this to Tom who is a registered nurse.

#### Possible reasons for poor nursing behaviours

When I was interviewing Tom (who is a nurse), I asked him why he thought nurses might still treat patients in an impolite way. He cited an incident when he was a student, when he felt the curriculum was at fault:

I had a clinical teacher who did not believe that nursing students should talk with the patients. She had caught me talking and listening to an elderly woman who needed to have a below-knee amputation for diabetic gangrene. This poor little old lady was really worried and anxious, and the clinical teacher said that I wasn't to talk with the lady, that had to be done by a registered nurse. I mean that is so ridiculous, you can't all of a sudden be registered and have the skills to communicate — it takes practice. (character 15675 to 16027 TOM.TXT)

I asked Tom if he felt things had changed in the time since he had been a student.

Nurses are now taught better communication skills and so are the medical students. Nevertheless, I sometimes think you will always get some criticism when you want to try something new to help patients, or even change anything. (character 16997 to 17187 TOM.TXT)

I asked Tom if he would like to give me a contemporary example.

At work a group of nurses has joined to pool their knowledge to provide complimentary care to patients. However, they are criticised by some of their peers...some people are just resistant to change, I think it is part of human nature. I don't think it is something unique to nursing, as you see it in doctors as well. (character 17200 to 17460 TOM.TXT)

The long-term effect of situational experiences and knowing was not explored in this study. However, twelve months after Ann and her partner Sam had their baby, Mary, they still remember very passionately the situational experience that gave rise to their subjective knowledge of childbirth. In the following example, Ann describes this subjective knowing:

I couldn't face having another baby. If I found myself pregnant again, I don't know what I would do. ... Mary will just have to be an only child.

Georgie, I really just couldn't face that sort of experience again. It wasn't just the pain of childbirth [lack of knowledge], it was

Although not all eight participants experienced all of the additional factors that could affect their health care problem and related spiritual needs, what did occur is that each participant experienced one or more. That is, one participant experienced one, three participants experienced two, two participants experienced three, and one participant experienced all four. These situational incidents and factors affected the participants' subjective knowing of those experiences. It could be said that perhaps these incidents might have compounded the stress they were experiencing due to their original health problem.

## Summary of Assumption One

In enquiring into the assumption, it was found that each of the participants in the study had had a different cultural experience from the others. All participants had different individual cultural, family and situations. The implication that I interpreted from this is that each patient that a health care professional treats is quite possibly very unique, and that therefore, there can be no single best way of providing health care. In the ideal situation, health care needs to be individualised. Furthermore, it would appear that the participants in this study acquired their individual ways of knowing about spirituality, health care professionals and hospitals through their subjective experiences. That is, they subjectively knew about health care and spirituality, from their culture, family and situations that they had experienced.

The essential meaning of what I interpreted from the participants' experiences of health care appeared to illustrate several factors that incorporate poor or negative care and those that facilitate good care. Poor care is composed of (a) an unequal relationship between health care professional and patient in relation to knowledge power, (b) negative attitude of health care professional and (c) incompetence due to inaccurate knowledge of fluids and solids for the postoperative patient. Good or positive care included (a) easy rapport by health care professional with the patient about her illness, (b) sufficient staff to give effective care, and (c) an effort to try and help even more, by suggesting that the participant phone me to visit her.

In some of the situational experiences the eight participants considered themselves vulnerable. On exploring the data to identify any factors that could contribute to this feeling of vulnerability I found that there was a cluster of situations that could cause stress. These identified stessors were additional worry, emergency treatment, insufficient knowledge, the attitude of the health care professional and communication skills. The extent to which these stressors could affect the participants' feelings of being ill and their vulnerability is not known. However, it should be remembered that, for some people, the mere fact of having to depend on someone else to care for them could be sufficient stress to provoke feelings of vulnerability (Rawlins, Beck & Williams, 1993; Black & Martisson-Jacobs 1993). When this is added to by any one of the cluster of events, such as emergency treatment and or complications, insufficient knowledge, and negative attitude or poor communication skills by the health care professional, it may increase the participants' vulnerability and anxiety.

# Is this why I sometimes feel very vulnerable and anxious when needing health treatment?

The data provided by the eight participants when they talked about their health problems and spiritual needs, however, not only mention their present situation, but also their past, and their hopes and/or anxieties that they face for the future.

This concept of time (having been-ness and future as being expectant – see Chapter Three) will be assumed and explored in the next part of this chapter.

Assumption Two

When participants tell of their present experiences, they remember the past, as well think about the future and this is included in their subjective experiential way of knowing.

On face value, it appeared to me when reading the transcripts that perhaps the participants' ways of knowing also included a blurred concept of time, that is, the notion of time could also include past occasions, present situations, and future expectations or possibilities. In this way, time was not regarded as a set time of a day, week or month, but rather unlimited or a lifetime. According to Bakhtin (1978) and Dostal (1994), peoples' ways of knowing not only include the past and present experiences ("having been-ness"), but also what they surmise about their future experiences ("being expectant"). For example, if I need to go to hospital and have a general anaesthetic, I would think about undertaking that experience. In doing so I would remember the previous times (having been-ness) I have had general anaesthetics and wonder what the next experience would be like (being expectant). That is, I remember the first time I needed to have an anaesthetic as a child and was given drops of Chloroform onto a mask held over my mouth and nose, and me frantically screaming for my mother (having been-ness). I can relate this to future experiences I may have by telling myself that Chloroform is no longer used. However, other past experiences of general anaesthetics may be still related to any experience in the near future (as those influencing variables have not changed). That is, I am asthmatic and allergic to some of the medications and gases used in anaesethics (being expectant). From my own experience then, it would appear that this assumption could hold. However, I cannot speak for the participants and so their data needs to be explored. To do this the data of each of the assumption components will be examined separately and then together as a

whole, that is, the manner in which the participants refer to their past, present, future, and the way these are expressed together in the data. Once again, I will also try to interpret the meaning or essence, at the same time as inquiring into the assumption.

## **Having Been-ness**

On reading the data and listening to the participants' stories, I understood the having been-ness situations to be in the past and present when the participants did not infer that they were expected in the future. Again, when listening to the tape of the participants' interviews and reading the transcripts, these incidents or situations included both positive and negative experiences of spirituality and also health for the participants. Tom, when speaking about his "having been-ness" spiritual experiences, had this positive thing to say about the spiritual group to which he belonged:

I find discussion with the people at The Society of Friends very helpful. You are free to believe in what you want, you don't have to say the creeds and have definite views about life after death like you do in the Roman Catholic, Orthodox and Anglican churches. (character 23114 to 23328 TOM.TXT)

Another example of "having been-ness" spiritual experience that I interpreted as being negative included the following story described by Rosie at her first interview:

People at church didn't seem to want to help me. It isn't as though they didn't know me, or that I have just turned up for help. I have been going for 13 years. It isn't the first time I had been ill either. You would think by this time they know me when I was down and try to help. God help a person who goes to church for help! (character 22002 to 22260 ROSIE.TXT)

In this situation, Rosie reflected on how the people at church were treating her. I also interpreted in this incident that Rosie was also expressing her anger at her perception that the people at the church were not helping her. In both of these

experiences, neither Rosie nor Tom stated that the events were in the past. Rather, it was inferred, as they did not state it was in the past or make an inference that it may occur in the future.

## Being Expectant

The eight participants spoke of "being expectant" as something that might occur. It was something that the participants anticipated happening in the future or it might be in the future. Again, both health and spirituality experiences and stories were intertwined. Participants' feelings towards the future were told in their stories, and it could be seen how the "having been-ness" could be reflected in the future. That is, the past and present positive and negative experiences were portrayed in the participants' anxieties, fears, and hopes for future spiritual needs and health care problems and treatment. An example of this projection was given by Ann:

I have decided I don't like them [hospitals] anyway. (character 326140 to 326183 ANN.TXT)

When considering Ann's experience of traumatic childbirth and when her father was dying this comment is not surprising.

Red spoke of watching his mother dying of cancer (over a period of two years), and how he hoped that he never has to die that way with such pain. He also told of the difficulty of watching someone you love die:

You feel so bloody helpless....I have an old mate down the road, whose wife died. She decided she didn't want any more treatment in hospital and came home. He said, he felt so bloody dreadful, but he wanted to have her final wish of dying at home, so he put up with it. He said he never wants to have to do that again, so he has stayed alone and lives by himself all these years since she has gone. (character 32000 to 32319 RED.TXT)

From this situation of Red's friend I could interpret that the elderly man found death of his loved one too painful a grief to experience again, and knowing this decided not to seek another companion or partner.

Participants also spoke of the future in respect to their personal spiritual views. Examples of these included:

A friend was involved in the Voyager space program, I think it was Voyager II. It had taken shots of Pluto and all these shots of earth and it sent them back to Pasadena in California. There was a photo in the "Australian" the earth was there and the sun. It had been enlarged slightly, so you can see it. I thought if people thought about how they were on the small blob [earth] they could really be spaced out. Because we are just so insignificant. And in that context, we are insignificant. Totally, we're just a little bug. Like you go into your backyard, put it under a microscope; that's what we are, in the total universe. For that split second I thought, gee whiz, you could get quite scared about that if you thought about it. Like, how insignificant you really are. (character 29267 to 29898 RED.TXT)

From this conversation with Red, I interpreted that his future spiritual perspective encompassed the idea of cosmic universe, with the earth as one of many planets within a much wider system. I also realised he was scared that there is no God, and there is no one in the universe to reach to.

On the other hand, Ann's future spiritual perspective included that of earth having a heaven in which deceased loved ones lived with God and Jesus Christ:

I believe my Dad went to Heaven, wherever that is and I believe they are alive in the same realm as where Jesus is, wherever that is. Alive as in a spirit alive. You know, if I think about some of the things that happened and I wish that I could have said sorry to them. If I say sorry in my mind I believe the answer comes back, it's okay, you know, you don't have to worry, so alive in some unseen area. (character 16790 to 17111 ANN.TXT)

Although these two participants had different views about their own perspective of their place on earth, they still acknowledged the future aspects of life and perhaps life after death.

Within the participants' stories, it could be seen how, for some, the "having beenness" could affect their "being expectant" perspective of health and spirituality.
Some of the participants (Geoff, Tom, Red, Athika) mentioned "having beenness" and "being expectant" together. For example this except, from Geoff's first
interview.

Geoff: Ah, ah, ah, I've had cancer in the past,

Researcher: Right.

Geoff: I'm in remission now.

Researcher: Uh huh.

Geoff: Yes well it is easy to think that I don't have cancer or that I am cured, but I have to have check ups with the specialist every 3 months to make sure everything is alright. (character 537 to 776

GEOFF.TXT)

In the excerpt, I interpreted that Geoff is telling about his past health care experience, what is happening to him at present, and what the future holds for him. This story provides a picture of Geoff's knowledge of his time world. That is, he has had a type of cancer (the past); he has been told that he is in remission (present) and his future holding both hopes and anxieties. Hopes that the cancer may not come back and therefore he is cured, and anxiety and fear that the cancer will come back. His unsaid story is probably that he knows the cancer will come back again and that is why he has the three monthly checkups. For Geoff, his past health care and lack of care for his spiritual needs may possibly impact on his present anxieties and any future treatment.

I cannot surmise or tell from the data whether perhaps participants always infer about the past, present and future together when talking about their ways of knowing. As Rosie was not able to do this at both her first and second interviews, I cannot uphold the assumption. While the example of the excerpt from Geoff did

uphold the notion, this could have been due to the fact that he was very well at the time of the interview and able to cognitively think in what is known as formal operational thought. According to Rawlins, Williams, and Beck (1993), in cognitive formal thought people are able to think about what is happening to them in the present, but also remember the past, and think of possibilities for the future. However, people whose intellects exclude them from formal thought and restrict them to concrete thought, are only able to consider the present. That is, they are not able to reflect about the past and do not think of the future (Rawlins, Williams, & Beck, 1993).

In previous research I had undertaken on how patients pray in hospital, I noticed that when people were very ill they could only cognitively think in concrete operational mode, and therefore only focus on what was happening to them at the time. That is, they did not have the psychophysiological wellbeing and ability to think in formal thought (Rawlins, Williams & Beck, 1993). I found that a competent adult patient needed to attain a certain state of psychophysiological wellbeing before they were able to think, talk and pray in formal thought. That is, patients who were very ill either mentally or physically could only think of what was happening to them in the present time and only in a limited manner (Hawley, 1998). This might explain why I could not find sufficient evidence in the data to support the assumption that the participants, when reflecting and speaking of the present, think of the past and what the future might hold. Some participants in this study felt vulnerable or perhaps powerless when experiencing various attributes of health care such as emergency treatments, complications, having insufficient knowledge to empower themselves, and the health care professional exhibiting negative attitude and/or poor communication skills coupled with worry about their future, which are all stressful factors. It is therefore not surprising that the assumption could not be upheld, when it is a well known fact that stress and stressors greatly affect people's thinking abilities.

# Assumption Three The participants have an underlying need. Or what is their cry or problem?

According to Benner (1994), when health care professionals examine data to undertake interpretative phenomenology it is useful to try to ascertain what it is those participants wanted. That is, within the stories that the participants were expressing, what is their explicit difficulty or problem that they faced at that time, and therefore what were they asking for. In this study, the participants' worlds were portrayed by them as the intermingling of different experiences that gave rise to feelings of vulnerability, anxiousness, lack of certainty, lack of understanding, mistreatment by nurses/doctors, and confusing spiritual thoughts (that could be both negative and positive). Their stories reminded me of many incidents that I had seen as both nurse and chaplain when I would ask myself "why don't they treat the patients better?". The participants' tales were very telling with their cries of anguish woven and hidden in their stories. This need or cry was common to all eight participants, and appeared to be "why don't they (nurse/doctor) treat us better? ... Why don't they take my/our spiritual needs seriously?". There was a repetitive cry from all of the eight participants that many health care professionals were not aware of their spiritual needs.

Although not all the participants directly articulated those exact words, their stories inferred the meaning of the cry that was echoed repeatedly throughout the data. An example of this cry includes this story of experience by Tom, as he told of the lack of spiritual knowledge of the Aboriginal Dreamtime by the health care professionals in the psychiatric hospital where he worked:

There was a case at the hospital a few years ago now, where a young, Aboriginal boy was transferred down from the North West, or the Kimberley area, he was quite young and he was schizophrenic, and he came down without family and other bits and pieces and he was in ward X because he was suicidal etc. He went on a regime of medication and ECT and even after this, while still on his medication,

he was still saying, you know, that he wanted to, you know, he was going to die, and they did the usual precautions. Anyway, because they thought he was getting better they relaxed the precautions of, you know, not observing him etc, and um, he killed himself. It was only after that that the um, that they discovered that the black crow (pause) was a spiritual sign for him that he was going to die. I mean when you think of how many black crows there are around here.....There was another case too....

You know we have had a whole family that has lived here since the hospital was founded in 1902. They have said 'I don't want the crows here, I want the Willy Wagtail', she gave it a name and I didn't realise at the time what she was going on about. At the time we (the nurses) were encouraging, thinking get her out (outside of the ward) there, trying to get her to think and talk and do something different. I didn't do anything about it getting the Willy Wagtails [a different type of bird that symbolise life and happiness].... How could we? I didn't realise that Willy Wagtails are a happy spiritual sign for Aboriginal. However, if this family still has the same feelings about crows and the need for Willy Wagtails... It's rather a biggish one to tackle. (character 17482 to 18856 TOM.TXT)

Tom's stories clearly portray the lack of spiritual knowledge he and other health care professionals have in respect to Aboriginal culture. The patient in the first story may have lived if the health care professionals were more aware of the spiritual care that he needed. To me, it is an example of why many people say, "Why don't they take my spiritual needs seriously?". The sad thing about this story is that it is not isolated. After a series of recent cases before the Court, the Coroner directed this hospital to learn more about Aboriginal Culture, and also to find ways in which indigenous people will have their spiritual needs looked after when hospitalised with a serious mental illness.

### CHAPTER SUMMARY

This chapter explored three of the assumptions stated in Chapter Three related to the essence of being a person. This Bakhtin and Heideggerian notion of being a person provides for the reader the participants' nexus of experiences in their worlds, in relation to spirituality and health care, including culture, family, and situational practices about health care and spirituality and meanings. All eight participants' cultural experiences included stories about their country of origin and the relationships with loved ones and family at that time. They were involved also in community participation; although directed towards the self, it was frequently done with others. The participants' familial experiences included their parents, siblings, and those with their partner. All eight enjoyed their familial relationship with the other person and other family members.

When examining the situational incidents of both health care and spirituality, it occurred to me that additional factors could possibly influence the participants' experience of knowing. I identified factors that I believe contribute to the situational knowing of these participants. These include the classification of the treatments (elective, emergency treatment, or complications), participants' understanding at the time, and the health care professionals attitudes and communication skills, including not having sufficient time with the participant.

The essential meaning of what I interpreted from the participants' experiences of health care appeared to illustrate several factors that incorporate poor or negative care and those that facilitate good care. Poor care is composed of (a) an unequal relationship between health care professional and patient in relation to knowledge power, (b) negative attitude of health care professional and (c) incompetence due to inaccurate knowledge of fluids and solids for the postoperative patient. Good or positive care included (a) easy rapport by health care professional with the patient about his/her illness, (b) sufficient staff to give effective care, and (c) an effort to try and help even more, by suggesting or facilitating spiritual care.

The second assumption of participants being aware of past and future thoughts when thinking about the present could not be substantiated. This concept of time, of having been-ness, and being expectant becomes an area for further exploration

or research in future studies. The third assumption that I made that participants would have an underlying need was discovered to be "why don't they (health care professionals treat us better ......why don't they take my spiritual needs seriously?"

### **CHAPTER SIX**

# THE MEANING OF SPIRITUALITY: AN INTERPRETATION

While a chaplain of a cancer support group I was requested to see a lady who was dying with breast cancer in an oncology ward of a public hospital.

Joyce was 35 years old and the breast cancer had spread into her bones, liver, and lungs. When I went to see her, she was in great discomfort with pain in her neck. Joyce was having difficulty obtaining alleviation from the pain, and so I asked her how she relaxed at home when she was in pain. She replied that she usually lit a candle and meditated. We hadn't long started when a nurse came into the room and commanded us to extinguish the candle, as she thought a fire could start. Although I had positioned the candle where this could not occur, the nurse was adamant that the candle would not be lit. When I said the lady would like the scented candle to meditate by, the nurse cruelly replied that if that was what we wanted to do we should go to the chapel! The difficulty was that the patient was too ill to go to the chapel. On glancing at Joyce's face I could see defeat so clearly written. She also motioned me not to argue with the nurse.

So I sat with Joyce and tried to give her comfort, by holding her hand and praying and reading to her. However, clearly this was not the same as meditating with her candle, as the smell and sight were absent.

There was another factor in this scenario and that was that the doctors had wanted to operate on Joyce and place a bone graft in her neck to reduce her pain and discomfort. She had refused this, saying that she only had a short time to live and her pain was controllable with analgesia and meditation with scented candles. I wondered if Joyce was being denied her spirituality (scented candle to meditate by) because, she had refused the operation. Alternatively, perhaps it was out of the spiritual realm of the doctors and nurses to understand the power of spiritual comfort afforded by the scent and the sight of light and prayer.

### INTRODUCTION

The purpose of this chapter is to explore the essence of the participants' spirituality. In the previous chapter (Chapter Five) I explored the participants' experience of knowing about health care and spirituality, and the essence of being a person. This provided the background to enable me to explore and interpret their spirituality. This chapter, although exploring the participants' spirituality, also describes the difference between spirituality and religion.

To explore the participants' spirituality I have taken what they told me was their spirit and, after examining their responses, I have written the interpreted descriptions. When talking about their spirituality each of the participants' responded in an individual way. This has given rise to some similarities as well as variations. I have described the participants' beliefs in relation to their meaning of life and purpose in life to ascertain if there are differences between that and their spirituality. This was because some researchers, such as Benner Carson (1989), implied that they were the same and that there are no differences (See Chapter One).

In Chapter Two, I identified the components of spirituality as: the focus of spirituality, beliefs and truths, person's perception of those truths, manifestations of spirituality, and methods used to access their spirit. Although I was mindful of these core components I did not want to rush in and assume that when the participants spoke about spirituality I would find reference to these. Instead, I was more interested in the participants' meaning of religion compared with spirituality, and whether patients and clients could have meaning in life and purpose in life that was not of a religious concept. It was not until I had written three drafts of the chapter that I asked myself whether there was any correlation between the model I described in Chapter Two and what the participants were telling me about their spirituality. I then went back to the data and, using the same codes that I had for Chapter Two, I was able to discern the participants' focus, beliefs and values, the manner in which they accessed their spirit, and their manifestations of spirituality. This I named "Spiritual Nature".

The first section of the chapter presents the participants' definitions of spirituality, their perceived differences between spirituality and religion, and their meaning in life, purpose of life and spiritual development, and movement associated with a person's spiritual development and/or journey. For some participants spirituality involved a relationship or connection with a god/s or higher power; for others life did not have this connection. The second section enquires into the spiritual nature of the participants; that is, their beliefs and values, how they accessed their spirit, and also the manifestations of their spirituality. These components are the same as the model of spirituality developed in Chapter Two (page 50).

#### PARTICIPANTS' SPIRITUALITY

The participants gained their subjective knowledge of spirituality from their cultural, familial, and situational experiences (see Chapter Five). These included both positive and negative experiences. When the participants spoke of these, I

could discern the inter-twining of both the health and spiritual factors in these experiences. Furthermore, there were certain circumstances that rendered the participants more vulnerable and/or powerless in having their health care and spiritual needs met. These included the type of treatment they were receiving, their personal understanding at the time, and the attitude and communication skills of the health care professional towards the participants and/or their significant other. Within this context, the participants discussed their spirituality in greater depth with me, and it is that which forms the basis of this chapter.

The very idea of discussing spirituality was, for the participants, something with which they all had difficulty. When I asked the question, "Could you tell me about your spirit or spirituality?", they all paused and thought about the question before answering. The responses they gave were similar to each other, but at the same time varied. The similarities were based on their descriptions of the personal nature of spirituality but varied because each participant had slightly different ways of describing and articulating what they meant by the concept. The similarities of the answers from all eight participants included the echo that spirituality was difficult to describe but was also part of each person. The way in which five participants described their spirituality is as follows:

Each person would have a spiritual side of him or her. (character 1796 to 1833 ROSIE.TXT)

It is the part of me that is not physical. (character 13957 to 13989 SOPHIE.TXT)

(character14471 to 14511 RED.TXT)

Something deep within me that causes me to be a better person, more caring, more feeling person. .... It pulls us forwards all the time. (character 12747 to12858GEOFF.TXT)

Spirituality is the bigger part of life; it is the whole picture. It is difficult to describe, but it is not just me, as I am just part of the

picture, but spirituality and our beliefs of what that is, is the whole Caboodle. (character14390 to 14471 RED.TXT)

Spirituality is part of life and me... That inner being of me. My Inner being.... It is an innate quality. It is the inner voice that I respond to. (character 1896 to 2010 ATHIKA.TXT)

The remaining three participants had definitions about spirituality that were closely similar to those already described.

The idea of spirituality being connected to other phenomena in the cosmos was expressed by the eight participants. These excerpts from Tom and Scarlet are perhaps the clearest to understand:

Part of our spirituality is the way in which we are connected to the earth, we are part of creation, and our spirit is part of the cosmos. (character 22888 to 23144 TOM.TXT)

My spirituality enables me to communicate with the good and bad or evil spirits. It is entirely up to me, if I want to be nice to someone, or place a curse on them. I have that power through my spirit. (character 3130 to 3260 SCARLET.TXT).

All eight participants spoke of the positive nature of their spirituality, and only Scarlet told of the potential harm she could exert through her spirit. Although all participants took a few minutes to describe their definition of spirituality (at the time of the first interview), Tom's definition perhaps encapsulates the breadth of the phenomena that the others may have been trying to articulate:

Looking at spirituality is like one of those glass balls or mirrored balls you see in entertainment centres. I am looking directly at the ball, I see a little, and you might see a little, but we don't see the whole. As the ball moves around, we each see a different aspect. We also have the potential to move too, and see different things along the way.... (character 7477 to 7705 TOM.TXT)

To me this excerpt describes the dynamic and different facets of spirituality and the potential for spiritual growth, that is, we all have our own personal perception of spirituality, and we may not see the same things as another at the same time, but we all have the potential for spiritual development and growth (that is, movement). Nevertheless, before any further exploration of the participants' spiritual natures can take place it is important to clearly state the participant's opinions concerning spirituality and religion. In this way the reader then knows the difference as "a priori", and can follow the further development in the chapter more readily.

# Differences between Spirituality and Religion

In Chapter Four I stated the various spiritual groups to which the multicultural participants could be possibly aligned as:

- 1. Non Christian religious: Hindu Athika (Indian)
- 2. Judeo-Christian: Anglican Ann (Australian Aborigine):
- 3. Philosophical: Socialist Red (Australian)
- 4. Mythical, Pagan or heathen: Pagan Romany Scarlet (European)

The other participants were aligned to two or more of the above groups, these combinations were:

- Non Christian/ Judeo-Christian: Anglican, Brethren and Buddhist –
   Rosie (Irish)
- Philosophical / Judeo-Christian: Humanism and Society of Friends
   Tom (Chinese)
- Philosophical / Mythical: Humanist, Mythical Geoff (Australian)
- Christian / Mythical: Lapsed Roman Catholic Astrology Sophie

This classification became useful to me as a starting point when I wanted to discover any possible differences between spirituality and religion. All eight participants were careful to point out their conjecture of what they believed was the difference between their spirituality and any religious belief that they held:

I'm not the religious type, but I have a spiritual side of me that gives me a meaning for this life. (character 12860 to 12940 GEOFF.TXT)

We've got so hung up with this idea of religion being spirituality whereas religion to me is... is someone's set of doctrines or, or

dogma of some sort attributed to a....., a religious denomination, it..... it...., it's totally different from spirituality. (character 13957 to 14175 SOPHIE.TXT)

My spirituality is part of me, but my religion is what appeals to me, so that I find expression for my spirituality. (character 9862 to 9956 ANN.TXT)

I think individuals can be very significant in another's spiritual life, I think they can act as guides in various ways, but no individual, religious priest, church etc has a right to fully direct the life of another person. It would be difficult for people to experience their spirituality if it is submerged in religious regimes. Spirituality must have some meaning for them, whereas religion might not later on, it all depends. (character 3905 to 4241 ATHIKA.TXT)

In these responses, I not only interpreted the difference between spirituality and religion, but also how people can be confused between the two. Although a person can find expression of their spirituality through a religion or relationship with a god or higher power, it is not a necessary requirement. Furthermore, one person can help the spiritual growth of another, but no person (or organisation) should have direct control over another person's spirit.

# Spiritual Development

Not all participants spoke about how they thought their spirituality might have developed; in fact, only Athika and Sophie raised the concept of how they thought this occurred. I did not raise the idea of spiritual development as a direct question to participants, as I thought it might embarrass them if they did not know anything about the subject. Although it may not have embarrassed them, they could have interpreted it as a daunting question, and I did not want to destroy any fragment of the rapport that had been established in the other interviews. I was afraid that if I asked a question that they could not understand or fathom, and which I could not articulate in basic communication, they would be "put off" during the interview. The two participants who did speak of spiritual development were Athika and

Sophie. These excerpts from their interviews, when they spoke about spiritual development, are so extremely diverse that they could possibly be at either end of a spectrum (from physiology to socialisation). In the first excerpt, Athika talks about the role of socialisation in relation to spiritual development:

Most people are able to access their spirituality. However, how they go about accessing, depends on how they've been socialised and the experiences that they've had after that initial socialisation. It would include life experiences, things that have occurred within that person's lifetime. Travelling, I think, can be an advantage, meeting people from different cultural scenarios, interacting with lots of people, taking time to reflect on experiences I think is probably even more important, rather than having multiple life experiences. I also think individuals can be very significant in one's life, with regard to spirituality and while they themselves may not be ah, perfect individuals (I don't believe there's such a thing) I think they can act as guides in various ways, consciously or unconsciously. (character 10720 to 10405 ATHIKA.TXT)

In this excerpt from Athika, she mentions the importance of using reflection on her experiences to assist in spiritual development, the place of travel in order to see different cultures and to question ones own values and beliefs, and also the use of a spiritual guide or director. Alternatively, Sophie's concept of spiritual development appears to be related to the physiological elements of our bodies, and the place of ions in cellular and tissue function. I could be reading more into her excerpt than she intended, as she had a very basic education, which did not include chemistry and physics, however, that does not always limit peoples' ideas and concepts

I have come to the conclusion that we have a lot of electricity in our bodies. Electricity is a pure element, you can't get anything more pure than that and I thought I wonder if that is what is called spirit. Moreover, when we die, our electricity is no longer earthed, and it is released. Therefore, this could be what is referred to as our spirit, leaving our body. (character 14348 to 14648 SOPHIE.TXT)

I like Sophie's explanation of how our spiritual being developed, each time I read it, it brings a smile to my face because it has what I call a bushman's quality to it,

in that it was basic, yet at the same time provided her with an answer and rationale to a question about which many people would not even think.

These disparate ideas of spiritual development or growth from Athika and Sophie led me to think that perhaps there was no one way or single consensus of what the participants thought about their spirituality. This finding adds further strength to the assertion that the participants have knowledge about a phenomenon because of their experience related to that phenomenon. Although the participants may have similar ideas about spirituality per se, of an inner being and also, at the same time connected with the cosmos, this is where the similarity might end, and other parts of spiritual nature may vary. The only way I would know was to raise questions and examine the data to see if these occurred.

Is there something in the data that implies movement associated with spirituality?

Perhaps growth?

The concept of spirituality as a phenomenon did not appear to be something static, rather it involved movement. This idea came from four participants:

Spirituality is also like being on a path as in a journey. (character 3000 to 3046 ATHIKA.TXT)

Spirituality is also involved in how we grow. It may appear as, it's something that's there and logically it seems that I'm going this way but I may go that way or go there or go up and then go down. (character 5620 to 5778 TOM.TXT)

What is important is that we stay open to our spirit and just let it happen. (character 29156 to 29216 SOPHIE.TXT)

I think [a person's spiritual journey] it is pre-social...... A pre- or in a primary status of socialisation, and it can be difficult for people to sometimes experience their spirituality. (character 10876 to 14471 RED.TXT)

I have to have inner peace before I can do anything outer. It doesn't always work that way. I have had many times felt without that inner peace. For a long time too. It's only later in life that it that I've come round to it. (character 6581 to 6761 TOM.TXT)

These opinions of spiritual movement are diverse, in that for some of the participants movement is associated with growth and development, whereas, for others the movement involves the concept of being open to the spirit and to work with the spirit to gain inner peace.

# What is the meaning in life and purpose in life for these participants?

I asked participants about their spirituality first, then I asked them what gave their life meaning and purpose. I did this because previous research within the Judeo-Christian tradition and Humanism stated that spirituality was that concept which gave meaning in a person's life and gave them a purpose in life (Benner Carson, 1989).

The answers that I received from all participants in relation to the meaning and purpose in life involved the idea of loved ones supplying that meaning and purpose. Although six participants believed in a god or higher power of some sort, that in itself did not supply all that was necessary for meaning and purpose in life. It was the love of another person or persons, which gave life meaning and purpose.

The participants who did not believe in a god or a higher power of any sort gave the following explanation of what gave their living meaning and purpose:

Respect for others and from others, hope in the future, and always having your family and friends. (character 11000 to 11081 RED.TXT)

Having a relationship with others and being kind to others. (character 12598 to 12648 GEOFF.TXT)

This was not dissimilar to those participants who had a belief in a god or higher power:

I like visiting the people I know in Vietnam - Father Peter and the school. Last year we took pencils for the children so that they could write. I had a letter from Father Peter who said that the floods had destroyed much and they needed some reading books to teach the children reading. Now that I am starting to feel better, I shall arrange to collect some reading books and send them to him. (character 10619 to 10939 ROSIE.TXT)

The meaning I gained from Rosie's excerpt was that because she believed in a god, she in turn wanted not just to love and care for her own family, but also God's family at the school in Vietnam.

Included in all the participants' concepts of meaning and purpose in life was the idea of creation. It is interesting to note that there was no difference between the idea of creation for those who had a belief in a god or higher power, and those who did not. The participants who did not have a belief in a god or higher power enjoyed the contact with creation and other people within the environment (Red and Geoff):

I walk each day with the wife in the bush not far from here, there is something about creation and the environment that is special. When I was ill and in hospital I couldn't wait to get out and to be in contact with the outside, garden, and the farm again. (character 13821 to 14026 GEOFF.TXT)

I love the Australian landscape, it means so much to me. Helping each other when the other person has a need is also very important. (character 1748 to 1856 RED.TXT)

When your species is threatened you all pull together and help each other to survive. (character 1905 to 1975 RED.TXT)

Similar, answers were given by those participants (Scarlet, Sophie, and Tom) who had a belief in a god or higher power:

I like to create things and creation — writing poetry, doing pottery, painting they all serve to help me find meaning about this life. And I love my garden, the wind, and those people I love around me. (character 28485 to 28649 SOPHIE.TXT)

Staying connected with the earth, being grounded with the earth, being gentle with your body and with those you love so that the spirit is protected. (character 3130 to 3253 SCARLET.TXT)

I have a special place in my garden where I meditate and reflect on the day..... I find the garden a very peaceful environment, it helps me to love other people. (character 30312 to 31128 TOM.TXT)

Although these participants appreciated creation and the environment, there was also the meaning of love within their excerpts. In fact for these participants, the experience of love and loving another gave them meaning in their life and purpose.

# What is the meaning and purpose in life through a God or Higher Power?

Regarding the meaning and purpose of life and their spirituality, the six participants who had a belief in a god/s gave additional answers. When talking about the meaning and purpose of life these participants also spoke about the notion of faith and belief. For example, the following response from Ann reflects this belief and faith in a god or higher power.

My relationship with God is the core of everything. Our bodies will fade away; intelligence doesn't really mean anything in a sense, so to me my spiritual relationship with God gives my life meaning and purpose. (character 11138 to 11174 ANN.TXT)

This does not mean to say that those who have a belief in god/s or higher power did not find meaning in their life and purpose in life through loved ones, as all of them did.

# Is the notion of spirituality related to the participants' meaning of life and purpose in life?

In this study, only one participant voluntarily spoke about their spirituality being connected to her meaning in life and her purpose in life (Ann). However, on specific questioning four other participants believed spirituality helped give their life meaning and purpose (Tom, Rosie, Sophie and Athika). The manner in which the participants' spirituality was tied to their meaning and purpose in life included this description from Tom:

I have to have inner peace before I can do anything outer. It doesn't always work that way. I have many times felt without that inner peace. For a long time too. It's only later in life that it that I've come round to it. (character 8136 to 8912 TOM.TXT)

This idea of spirituality being a contributor of meaning and purpose in life was congruent with the other three participants' beliefs.

# Can spirituality give meaning of life when connected with a higher power?

Although the notion of spirituality was a person's inner being, within a cosmic world not all participants felt there was a connection to a god or higher power of some kind. Two participants doubted if a god or higher power could exist, whereas the remaining six participants felt there was some sort of connection to a god or higher power. Two of these participants had a notion of "a God" which reflected the Judeo-Christian tradition (Ann and Rosie). Whereas, for the other two participants, "god" was a power that facilitated a person's spirituality, and could heal through prayer and meditation (Tom and Athika). Similarly, Scarlet's and Sophie's relationship of spirituality and meaning of life and purpose in life was connected through the stars and heavens of a higher power of some sort. Sophie prayed to "her star and her inner self". Scarlet prayed to her ancestors in heavens above and her inner self. Scarlet's notion of heaven was not the Christian

idea of god residing in heaven, but rather celestial beings which were once her ancestors here on earth and other heavenly bodies.

# Can spirituality give meaning to life when there is no connection to a higher power?

Those participants who did not believe that there was a god or higher power, which provided the relationship between spirituality and their meaning and purpose of life, were Geoff and Red. Both men had similar views about the nature of the world:

My meaning of life involves the bigger world I s'pose, is the environment, it certainly includes people because the environment's not static, it's not just a picture, it's ah, it's movement, it's, well it's the air, it's the wind too. Its the whole total complex environment (laughs), Like everything relates to everything else in life. It's a total, it's a totally closed thing, like even the artificial monetary system we work on. It's circular; it always comes back. Now the wind's blowing because ...it's warmer inland than it is off the seas, so the wind dries convection, so it's all total, and I'm just the poor little bugger (laughter); in some part of a biological process in the total earth environment. (character 27599 to 28191 RED.TXT)

In summary, the participants' meaning of life and purpose in life contained three components, loving some-one else, creation/environment and the ability to create; and, for those who had a belief in a god/s or higher power, the connection between who they are and that god/s or higher power. It was the third component for those participants who did not believe in a god or higher power that was absent. This did not mean that these participants had no meaning and purpose in their life, for they certainly did. For the participants in this study, spirituality was something within each person, whereas, meaning of life and purpose in life was more directed towards those loved ones and creation around them. Also, if the person had a belief in a god/s or higher power this influenced their meaning of life and purpose in life, in that depending on their beliefs and the faith in those beliefs directed the connection between a god or higher power and those beliefs.

### SPIRITUAL NATURE

All eight participants understood their spirituality to be part of their inner being that was unique to them, and each person had an individual "spirit" which was as individual as their own self. This idea of the phenomenon possibly accounted for the variations in the participants' definitions of spirituality. But was there more about the participants' spiritual nature that I had not explored? I needed to ask more questions and to see if there were answers in the data.

Would the components of spirituality I identified in Chapter Two be the same for the participants' spirituality?

In the model of spirituality that I identified in Chapter Two the components were focus or orientation, beliefs and truths of an organisation if a person belonged to one, the person's own perception of those beliefs and their values, how they accessed their spirit, and manifestations of their spirituality. Using these codes as discussion points I explored the participants' data.

#### Focus or Orientation

When I sought the data for the code of "focus of spirituality" from all of the participants, I found that I had not asked this of them as a direct question. However, from their individual data overall I can discern for some of them what their focus was, and it included:

My inner spirit and a god within the cosmos. I can't believe in Jesus Christ, but I do think there is something out there that I relate and communicate with. (character 25768 to 26268 SOPHIE.TXT)

I believe in Jesus Christ as the Son of God, and this is my focus. It is God's Holy Spirit which is part of me. It is in my religion that I find expression for my spirituality. (character 11240 to11379 ANN.TXT)

The focus of my spirituality is god/s. But who is God? I don't know. How many gods are there? I don't know. (character 32000 to 32085 ATHIKA.TXT)

At her third interview Athika added the following (with the rider, "I will tell you this Georgie as I now know you understand, but I wouldn't tell a total stranger this, or even some of my friends"). I definitely believe there is some type of higher power out there in our cosmos. I have seen so many people made well and healed by communication with that higher power. (character 32085 to 32331 ATHIKA.TXT)

I believe in God and Jesus Christ and the Holy Spirit, but I also respect other peoples' gods. I can't say they are wrong, all I can say that mine is right for me. (character 7155 to 7427 ROSIE.TXT)

The meaning I gain from these responses is that, although people say they have a spirit that is their inner being and is connected to the greater cosmos, there is no definite focus of their spirituality, except when they belong to an organisation which supplies the name of that focus for them. For example, Ann, Rosie, and Tom belonged to churches within the Judeo-Christian tradition, and Scarlet was an Elder of the Pagan Romany Association. Whereas Athika had her own focus, which she had not yet named, and likewise Geoff and Red's focus was possibly aligned with something which they also could not name. My understanding of this means that when health care professionals want to ask patients and clients about their spirituality, they may well receive a negative or a confused answer to the question/s, "do you belong to a spiritual group? And, what is the focus or orientation?" This means that the model I developed and described in Chapter Two can be used in a theoretical way only to discern a person's spirituality.

### Beliefs and Values

Beliefs and truths of the patient's or client's spiritual organisation was a component of the model, and the following component was the patient's or client's perception of these beliefs and truths. I did not ask the participants in this

study what the beliefs and truths of their spiritual organisations were. However, in coding for beliefs and values in the participants' data, I could discern the following which possibly align more or less with their perception of beliefs and truths. The participants' opinions about the word, or term, "spirituality" in relation to beliefs and values, included the following:

It is what I believe in. I don't like to use the word spirituality if I have to, because of its connotations, I would rather use the word 'beliefs': "What do you believe in?"- To me that fits my secular view of the world much better. (character 4183 to 4370 RED.TXT)

The things that are important to me that I value such as family, friend and the environment, that is what gives me purpose in life. (character 12598 to 12704 GEOFF.TXT)

Involves looking after mankind. (character 17338 to 17530 RED.TXT)

For me it's the teachings of the church and that is why my spiritual life is important. (character 11340 to 11491 ANN.TXT)

I value and believe in my spirit. It is everything to me, as I have got older I have got wiser in the spirit it is part of me. (character 26268 to 26365 SOPHIE.TXT)

My interpretation of the participants' beliefs and values related to spirituality is that they are deeply personal, at the centre of their being (which may be connected with another power such as god/s in the cosmos), but most importantly it is what provides them with a purpose to life and with meaning in looking after each other.

# Accessing their Spirituality

Accessing the focus of their spirituality was another code and component in the model of spirituality. When I coded for this within the participants' data, I found that the manner in which the eight participants accessed their spirituality and reflected was similar. That is, they all used a quiet time for speaking to their inner self or god or higher power. To me, that is prayer, as I define prayer as any communication or attempted communication with a god or higher power (Hawley,

1998; Hawley & Irurita, 1998). In previous research, I discovered that people can find companionship through prayer with their god or higher power, and so I was eager to see if the participants in this study had found the same thing. Not all participants talked openly of the characteristic of companionship with the spirit, however those who did, found it vitally important in their lives. The participants who were able to talk about it were Athika, Rosie, Scarlet, Sophie, and Tom. Such conversations included this one from Sophie at her last interview.

Spirituality is something that you can cultivate and grow, as long as you are prepared to talk with the inner wisdom, journal and evaluate what is going on in your life. Listening all those things is important. And as you get older and more in tune with that inner wisdom, you can have fun with yourself, and joke and generally have more confidence. You know since I turned fifty I have really enjoyed life. Okay, so Alf has had his stroke and my arthritis is not good but I have this fantastic inner life that I would hate to be without. However, it takes practice to learn to listen to your spirit. I couldn't imagine my life now without the companionship and guidance from my Spirit. (character 26300 to 26860 SOPHIE.TXT)

### Meditation

Four of the participants, Athika, Rosie, Geoff and Tom also used meditation to access their spirit. The technique that the participants described included:

- 1. Limiting the amount of stimuli in a given situation.
- 2. Focussing on an appropriate thought or objects at the time. These could be items within a room or objects and people outside of the room, or a concept anywhere (it really didn't matter, as long as there was a point of focus). In this way the central point of the meditation could be objects, or natural creations or a person or people.
- 3. Using the visual focus was thought to be important, as the participants said they could then still participate in the world, but limit the amount of stimuli.
- 4. Breathing techniques were essential and part of the accessing process was through these breathing techniques (concentrated breathing).

Although this passage describes the way in which the participants accessed their spirit, it was also a manifestation of their spirituality. That is, they needed to be

able to reflect and meditate to connect with their inner being, but at the same time the reflection and meditation was a behaviour or manifestation of their spirituality.

### Prayer Writing

Two participants (Ann and Sophie) spoke of writing in their journal as communicating with their spirit, and something that they needed to do. The excerpts from Ann and Sophie are as follows:

Now that Mary has been born I don't have time to journal anymore and I really miss it. It is a different experience from prayer. I suppose it is like praying, but with journalling you have a record of what you have been saying and God's answers, whether they are in spoken word, dreams or in writing. Because I have written it all down, I have a record. It is then easy for me to see God's purpose and meaning in my life. (character 13729 to 14067 ANN.TXT)

I don't know what I would do if I couldn't write in my journal each day. It is like my lifeline with my Spirit. Although I talk with my Spirit as I have told you before, but writing is different. I know that as I write and communicate with my Spirit, if I sit quietly and meditate afterwards, I might start writing again, and that will be my Spirit communicating with me......how do I know it is my Spirit? Well the writing is expressed differently from the way I would write things. In addition, the words just appear on the paper, I don't know what they are until I read them. (character 26860 to 27331 SOPHIE.TXT)

What about the manifestations of their spirituality? This was another component and code in the model, which I need to check with the participants' data.

In addition to praying, which is both a way of accessing the focus or orientation of their spirituality, and also a manifestation of spirituality, other manifestations that the participants talked about included different ways of performing everyday behaviours in relation to the self and others. For example, the eating of food or fasting, hygiene, the manner of dressing, and manners towards other people. Rosie and Scarlet spoke of how they sometimes fast, and of eating specific foods to celebrate different feasts. Athika, spoke of the inclusive nature of the Hindu religion, in that all people are free to attend ceremonies whether or not they are

Hindu. She also described her dress as representing and expressing parts of her spiritual nature. For example, the Bindi (coloured spot on her forehead), tells people that she is a spiritual woman. Similarly, her hair parting (in the centre of her head) demonstrates to other Hindus that she is a married woman to whom respect should be given.

Scarlet also told of behaviours that were manifestations of the Romany spiritual nature. These included rituals to protect one's own or another person's spirit. Scarlet told how Mondays were usually her quiet day in the Romany community, the days later in the week and the weekend were busy performing rituals for other Romanies, especially cleansing of evil spirits from the Romany's home environment. In relation to rituals, Scarlet also told me that they believe that a person's spirit becomes one with the physical body, shortly after birth, therefore love and protection at that time were important. Likewise, when a person dies, respect needs to be shown towards the body while the spirit ascends out of the physical nature on the death of the person. She said it was important for health care professionals not to turn their back on the body of dead person until they had left that room. For herself, she could not turn her back on the body until she left the hospital building. When Scarlet was telling me this, she told of her experience of needing to withdraw from the Intensive Care Unit in the largest tertiary hospital in Western Australia, and walking backward until she reached the outside of the building on the ground. She told of the looks and giggles she got from other people who saw her doing this. However, she said the giggles stopped when the people saw the rest of the Romany group doing likewise, it was just that she went first being an Elder of the community.

Rosie showed me her shrine that provides the focus when she meditates, but at the same time it is also a manifestation of her spirituality. Rosie was fortunate to have a room which she designated and named "The Prayer Room". At the doorway people removed their shoes and inside she had placed chairs and large floor

cushions on which to sit and pray. The focus of the room was what I would call a shrine, which was a low table on which she had placed various icons (one being a crucifix, a statue of Buddha, and the other a framed prayer which was also standing), several natural articles (stones and sticks) which she liked and a container in which to burn incense. The framed prayer I had given to Rosie when she was very ill and was trying to commit suicide. At the time, she could not pray by herself because of her severe psychophysiological state, but she could get comfort by reading and saying the simple prayer to herself (Hawley & Irurita, 1998). It was not an expensive item to give someone, rather it was one of several prayers hand written in calligraphy by the Order of Poor Clares, that I had previously purchased, and intended giving away as presents. When the situation with Rosie arose, I placed the prayer in a standing photograph frame, and gave it to her. In this way, the prayer could stand somewhere in her hospital room and she could pray whenever she wished.

Manifestations of the participants' spirituality were as varied and individual as their knowledge of spirituality, beliefs and values, and the ways in which they accessed their spirit or focus of their spirit. However, because the manifestations are like outpourings of the participants' beliefs and values of spirituality, they are more noticeable, because they are something that someone else, such as I, can notice and witness (if given the honour to do so).

I think caution needs to be exercised when using the model as described in Chapter Two, primarily because the participants in this study possibly would have difficulty in understanding the components and the interrelationship between them. Although I can see the potential of using the model in education when teaching students and health care professionals about spirituality, the actual model would be too daunting to show the average patient and expect answers from them. In this study, I showed the model to only two participants, when we were discussing spirituality at their third interview. These participants were Athika and

Red. At the time, Red was having trouble expressing his views about spirituality, and so I showed him the model and said this might help you to discuss what it is that you are trying to tell me. He liked the model in that it explained the concept of spirituality for him, and the various components of spirituality. He then introduced new material into the discussion, which meant he needed further interviews to clarify those new ideas and concepts.

I also showed and described the model to Athika at her third interview (which coincided with her return from a trip to India) after she discussed the possible variables of spirituality. She then she spoke about her spirituality, in relation to her meaning of life, and purpose in life including the way in which her behaviours manifest her spirituality:

I am increasingly convinced that for me, the meaning in life is both conferred and inherent or inferred. The same goes for spirituality, for example, I confer meaning in a situation or to a situation or behaviour and it has an inherent spirituality thrust gives it meaning. In this way, we create our own lives and they are created around us. This is my belief — others may or may not concur. (character 33000 to 33320 ATHIKA.TXT)

Spirituality has movement, in that it is a process. A preparedness for situations, a continual learning process openly observing with others and interacting and reflecting with each other and our environment. Coming to conclusions and reacting and acting and evaluating. It also involves listening to an inner universal wisdom-which requires being quiet! (character 33320 to 33623 ATHIKA.TXT)

Within this statement, Athika tells of the wholeness of spirituality, of encompassing the meaning and purpose in her world, the manner in which she creates her meaning and also how she absorbs notions of spiritual nature, which she can then evaluate and manifest if she desires.

### CHAPTER SUMMARY

The meaning of spirituality for the participants is that their spirit is the inner part of themselves, which is not related to their physical nature. Their beliefs about their Spirit include helping others and enabling them to be a better person (and motivator). They were also of the opinion that their spirit is part of the greater cosmos and connected with creation and the environment. Their meaning of spirituality also includes the notion that development and growth is possible.

It was the participants' loved ones of family and friends that give them meaning in life and purpose. For those participants who believe in a god or higher power and those who do not, there is no significant difference in that meaning of life through the loving of others. The difference in that those who have a belief in a god or higher power love their family, etc., within the context of their god or higher power. Whereas, those who do not believe in a god or higher power just love their family and friends without that religious context.

The participants' spiritual nature was explored in relation to those components I described in the model of spirituality in Chapter Two, including the focus, beliefs and values. The participants accessed their spirituality by having a quiet time, and praying to their inner self or god or higher power and reflection. They felt this was worthwhile to practise, in that a person can gain inner peace through their own spiritual fulfilment. Other manifestations of their spirituality involve respecting the physical body for the entering and departing of the spirit at birth and death, fasting, eating of specific foods, dressing and hairstyle.

### **CHAPTER SEVEN**

## SPIRITUAL NEEDS OF TRUST, HOPE, LOVE AND PEACE

# Sergeant D. Kíkorí, Papua. January, 1967

It was a hot and humid tropical day, and as I looked from the front verandah of the office, I could hear the local indigenous people crying from a long way down the river. As they got closer, the crying and wailing got louder. The chief mourners and local dignitaries came first in line, followed by the coffin being carried by four bearers and then the rest of the mourners.

Every now and then, the bearers would change over, and four other friends of Sgt. D, would take over the carrying of his coffin. I wondered why they changing over all the time.... I didn't think the dead body would have been that heavy, as the Sgt. had been a small man. Then the wind changed and I smelt the pungent putrid odour of the decomposing body in the coffin. As the funeral procession came in front of the office on its way to the burial ground, I paid my last respects to Sgt. D and gave my condolences to his family.

The stench of the body was horrific; I had to fight down the bile that was reaching the back of my throat. The thought of vomiting in front of the mourners helped to stop the action; as to deposit the contents of my stomach at their feet would have been disrespectful. The funeral party moved on again, and as

much as my curiosity wanted to see the actual burial there was no way I could join the mourners and fight the smell of Sgt. D's decomposing body. Returning to the verandah of the office, I scurried around the back of the building, and leaning over the closest drain let nature take its course (of emptying my stomach).

During the night, I woke to hear the sounds from the funeral wake and I thought of the possibilities of Sgt. D dying in Australia with acute alcoholic poisoning, and the care he and his family would have received. But I was no longer in Australia, but in a country that sometimes had no matches or toilet paper in its largest supermarket 500 km away. As the wailing continued, I wondered about Sgt. D's spirituality and I thought what his needs might have been. Would those needs be the same as the white Australians I had nursed back home?

#### INTRODUCTION

The purpose of this chapter is to describe the participants' spiritual needs. It is from their definitions and concepts of spirituality that I identified their needs. To do this, I accepted that their knowledge of spirituality is gained through their individual life experiences of spirituality and religion. In Chapter Six it is noted that participants pointed out the difference between spirituality and religion in which they said spirituality is part of their inner being and related to the cosmos. They believed that they can access the focus of their spirituality by communicating and reflecting with their "inner self" or with their spirit or ancestory spirits. Prayers to the spirit/s involves meditation, verbal communication, non-verbal communication, writing or journalling, and reflection. The participants' manifestations of their spirituality encompassed their spiritual beliefs, which gave outward expression of that which they believed gave meaning and purpose in their life (time with family and friends, and enjoying creation and the environment). For the participants who have a religious belief their spiritual manifestation includes expressions of their faith. It is from the participants'

expressions of spirituality, development, means of accessing and manifestations that I am able to search the data for material that supports their belief of spirituality. This data I name "spiritual need", that is, it is needed to maintain the participants' beliefs and concept of spirituality.

The first section of the chapter is concerned with the spiritual need of mutual trust, followed by the second section which is concerned with hope. The third section discusses the spiritual need of love, and the fourth and final section discusses the spiritual need of peace. Each of these spirituality needs is described separately.

#### SPIRITUAL NEEDS

In order to identify spiritual needs of the participants I believed it was necessary for me to first state my own definition. To me, a need is something that is necessary, like a prerequisite for something to occur. A need is so vital that a person can not do without it; is not an item or behaviour that is superfluous. That is, I believe a spiritual need is a behaviour or situation that is necessary to sustain their spirituality.

The first clues as to what these needs might be came from the participants. They arose during the first interview, when often they stated that they wanted something. For example, Tom said that he wanted inner peace, as did Rosie. By examining the transcripts and listening to the audio-tapes, I was able to identify those specific things and/or behaviours which needs to sustain their spirituality and the context of their spirituality (see Chapters Five and Six).

The spiritual needs I identified include the behaviours or things involving not only participants, but also of others towards them, including health care professionals, family and loved ones. These behaviours or things became known to me as the

spiritual needs of mutual trust, hope, love and peace. When I thought I had identified the needs I went back to the participants and asked them if they concurred with my findings; which they did. The spiritual needs for all the eight participants in this study the same, irrespective of their race or religion: that is, they all needs and wanted mutual trust, hope, love and peace.

#### **Mutual Trust**

The spiritual need for trust was the first and easiest spiritual need to be identified. This occurred because, within the transcripts, there are expressions of anger towards those health care professional who did not demonstrate this behaviour to participants. Participants feel that their own spirit enables them to care for others, that is, they can trust the health care professional, so why could not the health care professionals trust them? The spiritual need of trust includes the need to be able to trust the health care professional, the trust of the health care professional in patients, trust in and from family and friends, and for those with a belief in god/s or higher power, trust in that power. For the participants trust is having confidence in the health care professionals' that they would do the right thing by them and trust the participants at the same time. All eight participants voiced a need to be able to trust the health care professional. Participants' responses about needing to trust the health care professional includes:

I found I also needed to be able to trust the staff so that they would look after me during the operation and not let me die... I was so scared of dying...I thought I have been through so much...don't let me die now. (character 16059 to 16226 ANN.TXT)

Being able to trust in the doctor or nurse or whoever the professional is, is most important. Red, Rosie, and Tom (character 17338 to 17454 RED.TXT)

Although it can be readily understood that people should be able to trust the doctor or other health care professional they are attending, what this study also found is that participants want the nurse/doctor to trust them too. As Sophie explained:

Integrity is most important. We trust them (doctors), but that trust is quite often broken by them (doctors and other health care professionals). (character 18888 to 18970 SOPHIE.TXT)

#### An example of this is given by Red:

I was in pain and lying on the floor at home when the locum doctor came to see me. But he would not examine me or give me something for the pain until I got up and wrote out a cheque to pay him! I suppose he acted that way because of something that happened to him before. I suppose someone took him for a ride and didn't pay him. Then I wonder what doctors are here for, to care for patients or get rich. (character 14518 to 14838 RED.TXT)

All participants had tried to find a general practitioner whom they can trust, that is, someone who would respect them as a whole person, including their spirituality. As Scarlet explained:

I need a doctor that respects my spirituality, someone that is gentle with my spirit. He or she needs to take time for me and not be rushed and hurried. There has to be that time for open communication between the two of us, so that there is time for explanation, the showing of empathy through gentle touch and examination. There must not be roughness, as that does not show respect to the person as a unique individual. It is not just the adult person either; when giving birth your baby's spirit and yours are the most important thing. You need to be gentle with you baby's spirit, protecting it with your loving, it is most important as the baby's spirit has to come and enter their body. (character 6351 to 6916 SCARLET.TXT)

One of the participants worked in gerontology and she described the lack of trust that occurred between her boss, a health care professional, and herself:

I injured myself at work, but my boss said that I had not. In fact, she wrote a letter to the insurance company saying that my injury was because of an accident I had when on holidays in Vietnam. Yes I did have a small accident (grazed leg) when I was on holiday but that was not the injury I sustained to my back while lifting a patient at work. I felt so betrayed by what she did. She made me feel worthless, I had been working there for years, and filled in when others sick and everything else! She betrayed me and breached the trust we had built up between the two of us over the years. (character 23241 to 23714 ROSIE.TXT)

Another cited example of lack of trust by doctors includes:

I mean patients have to trust the doctor that he or she is going to do the right thing by us, so why can't they trust us. I tell you, you can go in the doctor's, the first thing they say is, are you in Medibank or HBF? You say, yeah, here's my card. Or a private patient or a public patient or whatever, they just want to know they're going to; they're going to get their money. It is as though they keep saying to people, we don't trust you. We have to know if you can pay, if not we are not interested in you. It is the way they say it is the big problem; there is no trying to meet the person and care for them. You know there is no smile, it is the employee trying to meet the needs of the system and thought for the individual patient goes out the window. (character 13821 to 14423 GEOFF.TXT)

For two participants (Ann and Rosie) who had a belief and faith in God, their need of trust includes the name of their God.

I have trust in God and Jesus. I know that God loves me and wants the best for me, although at the times I can't actually see it, and that what he wants is right for me. (character 16059 to 16189 ANN.TXT)

Four of the participants (Tom, Sophie, Athika, and Scarlet) had learnt to trust their own spirituality and found that they can:

Trust my feelings, trust my inner thoughts too, and do certain things. (character 5578 to 5637 TOM.TXT)

In this way, mutual trust is very important to the participants as it recognises the equal balance of power between health care professional and participant, and the manner in which the power is manifested in communication and touch.

### Hope

The second spiritual need to be identified is that of hope. Within the participants' definitions of spirituality is the idea stated by Red: "what motivates me." I interpreted this motivation as the need for hope in their lives, for without hope, their spirituality would have no meaning to them. All eight participants said that they need to have hope in the future. Hope for the participants' means a desire of

something to occur. This future involves getting better physically so that they can again enjoy their family and friends.

Now that I am getting better and not so depressed, I don't have that dreadful feeling of hopelessness anymore. I actually have a sense of hope in the future. (character 23165 to 23293 ROSIE.TXT)

When Rosie is ill it is difficult for her to feel hope, as it is not until her medication has effect that her sense of hopelessness begins to fade.

I asked the participants at their second or third interview "if you were dying, would you have the same spiritual needs, especially that of hope?" They responded that if they were dying they would still want to have hope, not in getting well, but by doing the little things of importance to them. The things that they thought would give them hope when they were dying included talking with family and friends, sitting outside in the garden, getting financial affairs in order, tidying up the loose ends, saying good bye to people. One of the participants said:

You know I am quite looking forward to dying to see what it really is like...if there is a heaven or not. (character 32000 to 32081 SOPHIE.TXT)

Hope is connected to the participants' spirituality as it both infers and confers the inner need and spirit. Hope is also an ongoing process, with the participants expressing that they feel that during their life at various stages they would have different spiritual needs. For example, Ann, just after giving birth to her baby, needed to have an operation, and at the time she feared she would die and not be able to love her daughter. Whereas Sophie, who is older and with several chronic medical conditions, had thought about the possibilities of dying, to the extent that she is quite looking forward to the occasion.

Hope is a significant spiritual need inasmuch as the participants said that life would not be worth living if there is nothing to hope for. Sophie described how hopes can become realities, and give satisfaction to one's life.

I can remember the first music I heard playing was a violin concerto. Later, I wanted to play the violin and so I did. I have also hoped to go back to Norway, done hang gliding and all sorts of things. Made pottery and done painting. Now I ponder on the next goal in life that will give me hope, I think it might be publishing my stories and poetry or public speaking. I knew what ever it was that I needed to do in this phase of my life would present itself to me. Then reading the paper the other day, I noticed that public speaking groups looking for new members. So I knew then that is what I was meant to do next. For me, that is the working of the Spirit. I ask my Spirit questions and I get my answers, it never fails. It may not be the answer I was looking for, but it is still an answer. (character 15147 to 15811 SOPHIE.TXT)

In this excerpt, not only does Sophie describe the way in which hope had worked in her life, but she also explains a little about her communication with her spirit.

Red believes that the way in which people might find hope would be a cultural thing as well. He cited examples from his overseas travels of how various groups of people find hope in different aspects of their culture. Red thought that the aspect of Australian culture which gave people the concept of hope is "she'll be right attitude". That is, inherent in being Australian is the ethos:

The greatest export Australia can give the rest of the world is the 'she'll be right attitude' no matter what is happening all around them Aussies will try and find hope in that saying. (character 30473 to 30622 RED.TXT)

Family, friends and loved ones are important elements of hope too, as they provide the connection with the participants' meaning in life and purpose in life. Typical of the responses related to hope is this one by Geoff:

When I was ill with the cancer the love of my family gave me hope. For them, I wanted to get better and be able to do things together which we used to do. (character 14100 to 14221 GEOFF.TXT)

This connection with meaning in life and purpose in life is directly related, as Geoff found his meaning in life and purpose in life through his family and friends. The manner, in which a person can find new hope in life, after the death of a loved one, can also upset his or her loved ones. Sophie talked about the way in which

her mother pursued hope and new meaning in life and purpose in life after her father had died.

My mother had married young and had always done what my father had wanted. When he died, she started to live her own life, to find meaning in the things that she wanted to do. My sisters worried that they didn't know how she would cope after dad died.

One night my sister realised that Mum wasn't at home when she telephoned. In fact, she didn't get home until 2 in the morning; they worried about her. You see she seemed to find a life of her own. She found hope in doing all sorts of new things, making new friends, going out and staying out late. She had a ball. (character 15507 to 15961 SOPHIE.TXT)

Although family and friends can provide and facilitate hope, the eight participants also thought that they could also seek hope through helping themselves or asking others for help.

I was told I was a candidate for postnatal depression. I think that was a blessing that I didn't get it. I think I plugged into many things. I tried to get a lot of support to try to avoid it. I went to the Fremantle Women's Health Centre and there's a physio there and she really helped with my stitches, and she also explained how the uterus sometimes gets tired, hurts the muscle and with a long labour like that, that's why maybe the placenta didn't all come away, so that helped me understand a bit. My new mothers' group also was wonderful. The child health clinic nurse arranges the mothers groups. It's a group of mums who all gave birth at around the same time. The other thing I did was I went to see the counsellor at the hospital, and also the hospital patient advocate and complained about the things that had happened and also praised them for my midwife. And I got a letter back from them apologising, so I mean, all those things rather helped. (character 14974 to 16056 ANN.TXT)

Similarly, Sophie also got help for herself on the advice of a neighbour. Sophie's early-married life with four young children under the age of five had been plagued at times with anxiety and depression. Some years ago when she was terrified of leaving the house, she described her situation at the time.

When I had to leave the house, I'd hang on to the pickets of all the fences on the way down the street because I felt I was so; I'd be blown away, you know. One day I met a lady as I was clinging onto a fence

and she suggested that I join a support group called Grow. I joined Grow and found the steps to recovery very helpful. In fact I haven't looked back since. (character 16000 to 16287 SOPHIE.TXT)

Some participants (Athika, Rosie, and Scarlet) use artifacts as part of their spirituality. Some items help them to pray, although other items could procure hope through influence, such as Feng Shui. Scarlet makes artifacts for Romanies throughout Australia (by mail order) so that they might have hope in their future. Scarlet gave me one of these, which she called a "Magick Shell". This is a special type of shell, which she had filled with herbs and sealed with bees' wax. It has a lovely smell and it is said that it will protect me from evil spirits, and therefore give me good luck.

Tom explained the difference that nurses can make in giving spiritual care to patients by providing them with a sense of hope.

Nurses can't cure people the same way as a doctor can, but they can give the person hope so that they can find peace within themselves. If nurses can get a person to cure themselves through hope, or least come to some equilibrium where ah, they're at peace with themselves and, well, it might be happening, but that's the sort of thing. We can only stand with them and look at ways and means of supporting them. Getting them to talk about the past, the present and what they want to do in the future. But giving them an opportunity of talking is very important, particularly in a male prison. (character 9696 to 10171 TOM.TXT)

This strategy recommended by Tom would not be difficult for any health care professional to perform irrespective of their personal discipline, culture and/or spirituality.

Athika found that teaching cancer sufferers how to meditate gives them hope, as they find something that they can do that helps them feel better in themselves. She also finds that people are quite often surprised to find they can meditate regardless of whether or not they understood about their spirituality and connecting with their inner being.

I find that the first time they experience meditation it's a shock, the experience for some people I think is a shock, that's why they'll ask or make comments, did you hypnotize me (laughs), that sort of thing, because it's brought them into an understanding that there's something else existing in the world other than what they've experienced previously. Most of the people see it as being unusual. But it isn't, it's just there. Meditation definitely plays a part in mental wellbeing but it also depends on the level of spiritual awareness that the person has. I think that's what's significant and the amount of energy and concentration that the person's able to give to the meditation process. But the very fact that they find they can meditate and feel peace and comfort in the experience gives them hope. (character 8435 to 8807 ATHIKA.TXT)

#### Added by Athika at her last interview:

I have met some people who I would define as spiritually distressed, that is, they have no hope. But they don't say I have got something spirituality wrong with me, instead they describe their symptoms in physical and social terms. Then when I teach them meditation they say it helps them, empowers them. (character 28778 to 29029 ATHIKA.TXT)

The spiritual need for hope is important to the participants in that it represents a desire for something to occur which is usually associated with their own meaning in life, such as their loved ones and family. The participants feel that even if they were dying, hope would remain important to them as although they would not get well, hope could be found in choices and goals to achieve while waiting for death to occur. According to Athika, meditation can give cancer sufferers hope. Similarly, Scarlet believes that artifacts such as the lucky charms that she made for Romanies can give hope.

#### Love

The spiritual need of love is identified quite easily in that the participants stated that loving others gave their life spiritual meaning. The spiritual need of love in this study is not dependent upon the participant receiving love from another person; rather it depends on their ability to give love to another person. The

meaning of love to the participants is a feeling of great attachment and affection for another.

Other people are the most important things in life. (character 31327 to 31369 TOM.TXT)

My wife and children are very important to me to love. (character 14421 to14464 GEOFF.TXT)

I get a lot of positive satisfaction in my life, from activities that bring love and benefit to others. I get the satisfaction not from the activities themselves but from the outcome. (character 6812 to 6963 ATHIKA.TXT)

Each of the eight participants needs to give love to another person, but they also feel it could perhaps be given to an animal if they could not love another person. Such responses includes:

You know you can love animals the same as you can people. I have seen many elderly people who have lost their life companion that shower so much love on their pet. (character 29611 to 29742 RED.TXT)

In addition, demonstration of that love for another person can be shown in ways that incorporate respect for that other person and their spirit.

See those pictures there on my desk, they are of my children. They caused me so much pain as they grew up, as each of them was headstrong, and stubborn. Oh dear! They got into so many scrapes. But what kids don't? It was hard trying to bring them up to be good but at the same time not to break their spirit. I keep their photos there and things that they have given me close by so that I can remember my love for them, and theirs for me. (character 15507 to 15854 SOPHIE.TXT)

At her final interview, Sophie added.

The good thing about the photos around me as I write stories and poetry is that they give me company, but also they very are quiet- no bother at all!

All of the eight participants believe that health care professionals and family and friends can show love to their loved ones by allowing them to die naturally, and not keeping them alive to suffer.

When the time comes for people to die, it should be allowed to take place naturally. None of this keeping the person alive. (character 6993 to 7093 SCARLET.TXT)

Scarlet spoke of the Romany type of love for another at death.

If an elderly person is dying, they [the Romany] would be better off not in a hospital, but outside under a tree somewhere (especially if they have been a traveller all their life). My mother had her bed under a tree out in the back yard. The doctor used to come and see her out there. At death, the spirit must be allowed to leave the body freely. (character 8095 to 8394 SCARLET.TXT)

Rosie, with her history of mental illness, thought love for another could be expressed in making sure that the person receives appropriate health care. She remembered how ill she was before she was admitted to the psychiatric hospital, and thought that love could be shown in making sure the loved one receives treatment.

I think the greatest expression of love for a mentally ill person, would be for their loved one to encourage and if necessary force the person to get appropriate psychiatric care. You see when you are suffering deeply from a mental illness like depression your perception is not accurate. You don't realise how sick you are and you can't seem to get yourself to the psychiatrist yourself, as even though you might look well, your brain isn't functioning properly. (character 29860 to 30547 ROSIE.TXT)

When I sent the transcript of Rosie's interview back to her, she asked her husband if he wanted to read it. He did so, and found out many things that she herself had not been able to tell him, for example, about her father dying in a psychiatric hospital, and the importance of him taking her to see the psychiatrist when she doesn't realise that she needs to go.

I was also glad that Rosie told me this, as loved ones sometimes say to me that their husband or daughter should really go and see the psychiatrist again, but he or she thinks they are OK and doesn't want to go. Sometimes, the loved one is reluctant to call out the Emergency Psychiatric team although their schizophrenic son or daughter may be destroying furniture in their home. So, now that Rosie has told me about this type of love (in making sure people get the care they need), this assures me that it is advice that I can give to others when providing spiritual and/or pastoral care.

In this way, the spiritual need of love is related to the participants' meaning in life and purpose in life, in that they feel the need to love another. The spiritual need of love is also related to their spirituality, in that the giving of love to another gives them a good feeling in their inner being of spirituality.

#### Peace

The spiritual need of peace was identified when three of the participants (Rosie, Sophie, and Tom) were talking about their spirituality, stating that they need peace. On further perusal of the interview transcripts, I found that all eight participants spoke of this inner need of peace for themselves. This is not making peace with other people, but rather finding peace within oneself. All participants mentioned that inner peace is important.

Finding that peace within you is important. (character 14100 to14135 GEOFF.TXT)

To the participants, peace is a feeling of harmony or serenity within oneself. All eight participants mentioned that peace is easier to find in their own environment and in their own space. For seven of the participants (all except Ann), it is easier to find that peace in the creation out of doors in the garden, bush, or seaside. Red and Geoff both spoke about the feeling that gazing on a tree in nature gives them:

I just wanted to get out of the hospital and into my own environment and space again. I knew that if I could look outside the concrete walls of the hospital at the trees I would feel better. I went outside as soon

as I could after my operation into the hospital garden. My contemplation of the trees (lovely tall gums) helped in my healing, it helped me find that harmony inside to aid the healing. (character 14135 to 14457 GEOFF.TXT)

The manner in which all the eight participants receive this peace is through contemplation and reflection; when they use contemplation to think and plan what they are going to do, and consider possible outcomes. If the outcome is compatible with their own values and beliefs then they would undertake the particular behaviour that they had been contemplating. The eight participants also use reflection to think about things/behaviours that they had undertaken to ascertain if they are happy or satisfied with the result or outcome. Red gave an example of reflection in relation to his mother's death:

When my mother died, I wasn't there to say goodbye. I had seen her about two months before. She and I both knew she was dying. When I left to come back here [Perth], I said that I would see her at Christmas. But she didn't live that long. I still wish I had been able to thank her for everything and to say goodbye. (character 29800 to 30050 RED.TXT)

If, on reflection, the participants are satisfied with what has occurred, this gives them peace within themselves. If they are not satisfied, they then think about an additional way in which they can find peace. This is more important to some than to others. Those who had learnt to trust their spirituality need to have the prerequisite for peace before they can undertake that action. Includes in the data is this example from Tom:

I have to find the peace on the inner before I can do anything with the outer.... To do this I need time for reflection so that I can find that inner peace. (character 8136 to 8291 TOM.TXT)

The six participants who pray (to a god or higher power) said that they ask for peace. These participants include Sophie and Scarlet, whose prayer petition involves talking to their inner being and the stars or heavenly bodies. Ann and Rosie pray to their God for peace.

I find reflection and prayer gives me peace, peace within myself that is so important. (character 16789 to 16861 ANN.TXT)

Whereas, Athika uses meditation as well as reflection to achieve peace.

Meditation when I was seriously ill gave me hope but also peace, in that it helped me to stop worrying. The other times that I've used it to find peace have been (I mean it sounds silly) but I sometimes used it because I was stressed and bored. So you could say that meditation gives me peace for recreation and relaxation! (character 30864 to 31127 ATHIKA.TXT)

Three participants (Athika, Tom and Rosie) thought that health care professionals can teach people how to meditate so that they can have that peace in their lives. Athika who teaches meditation to small groups of people living with cancer said:

After we had finished the first session this man said, "I feel as though I've just woken up. Did you hypnotize me?" which I thought was really a very interesting comment, because I think that refers to the different state of consciousness that he experienced. Whenever the sessions are completed, and there are usually about six people involved, I notice that there's a quietness and a peacefulness and sometimes if I look at their faces, a sense of pride.... That they've achieved that sense of peace. (14502 to 15348 ATHIKA.TXT)

Athika also believes that it is important for people not to be hung up about doing activities to achieve peace. She stated that activities are not important as they can be replaced with other activities; what is important is the effect of peace and healing. She further elaborated:

I think one reason to use a meditation or focussing technique during the day at work would be to initiate a re-balance of the activities. For example, it could be that there are a lot of things happening and my focus has moved too much to the peripheries, so I feel I need to have a short time of meditation to re-focus. To make sure that I am experiencing what's happening at that time and to use the time as reflection, which could be anything from three minutes to fifteen minutes.

In the course of a usual day, my meditation is usually punctuated throughout. It would start in the morning, early, before the day has actually started, or before the plans of the day have been put into action. Then intermittently throughout the day. That is, I'll punctuate

the day with these times of meditation, to make sure that it can help me focus with the work that I'm doing to be able to concentrate on particular issues or situations, or take a different focus altogether, away from those, if I feel my mind needs to be cleared. (character 15448 to 16284 ATHIKA.TXT)

Peace for the participants in this study is the feeling of harmony within themselves. The manner in which this is achieved is through contemplation and reflection. Some participants also pray and meditate in order to achieve that sense of peace.

# Do the spiritual needs of the participants change according to their health problem?

The spiritual needs of trust, hope, peace, and love are experienced by all of the participants irrespective of their health problem, and they all require each spiritual need to be fulfilled. In this study, it did not appear that some spiritual needs would exist at some times and others under other conditions or health care problems. For example, Athika still has a spiritual need for peace even though she probably experienced the least difficult health problem suffered by the participants at the time of the interviews. So I could not say that the spiritual need of peace is only related to seriously ill people. Furthermore, many health care professionals assume that peace is a spiritual need only when patients are dying. Athika's case tells us otherwise.

Heiddegerr argued that people subjectively knows something because of their experience of their world. In this way it could be said that the participants' spiritual needs are only known and experienced within their worlds at the time. For example, Red discussed with me whether his spiritual needs might change if he is facing death:

I don't know if my spiritual needs might change if I am dying. I s'pose I'd start thinking to yourself, is there a God or isn't there? I watched my mother die from cancer over two years, Aunt Margaret now, she's just come out of a cancer scare and that's another thing.

But I'd be a bit cynical if somebody came to come and tell me that I'm going to the Promised Land. I'd tell them to go jump; I've been living in it. (character 18635 to 25969 RED.TXT)

### At the final interview, Red added these thoughts about death:

The old man down the road with the dicky heart said to me that he hoped that he would die watching television. I said to him, hang on a minute I would like to say goodbye before you cark it. He replied "Don't you worry about me, I've had a good innings, it's probably time to say hi to the old man up there". He then said, "I will be sitting watching the telly, and that won't go off, but I will." (character 19374 to 19689 RED.TXT)

#### Rosie did likewise:

I don't think my spiritual needs would change if I thought I was dying. The first time I went into the psychiatric hospital I was suicidal, and I had rules to obey so that I wouldn't kill myself. So in reality I was dying then, I was facing death, and you know what my spiritual needs at that time as I told you at the first interview. So, I don't really think my spiritual needs would change if I was facing death. That time was the closest I have ever been to death, I wanted to die, and I felt such hopelessness. Whether or not my spiritual needs would change if I was dying of cancer I don't really know, but I don't think so. (character 30547 to 31052 ROSIE)

## Participants' Affirmation of the Spiritual Needs

Although I had taken what the participants said is their spirituality and identified those behaviours and situations that are necessary to maintain their spirituality, I still had some doubt in my mind that I may have confused them with psychosocial needs. So I discussed this with them. They responded quite adamantly that I had identified their spiritual needs.

I really think you are trying to split hairs here. I am thinking that a person could quite easily have the same spiritual and psychosocial needs together, in which case meeting the spiritual needs will also meet the psychosocial needs. Don't forget when you have a health problem everything is mixed up together, as our physical, mental and

spiritual natures are all intermingled. (character 31999 to 32316 ANN.TXT)

Of course sometimes my spiritual needs might also be my psychosocial needs, if they happen at the same time. For example, if my spiritual needs being met, then if I had psychosocial needs they might also meet them. (character 29529 to 29705 ROSIE.TXT)

#### And

If the needs I described are related to my spirituality, then they must be my spiritual needs. (character 30822 to 30899 ATHIKA.TXT)

To me, if they can help my spirituality, then they are my spiritual needs. I know what my spirit needs are, and I can tell whether or not the nurse or doctor is treating my spirit properly. (character 27417 to 27569 SCARLET.TXT).

With those responses, I decided I had to accept what the participants (as coresearchers) told me, and to accept that trust, hope, love and peace constitute the participants' spiritual needs.

#### CHAPTER SUMMARY

For the participants in this study, their spiritual needs are those of mutual trust, hope, peace and love. Mutual trust is very important to them as it recognises the equal balance of power between health care professional and participant, and the manner in which the power is manifested in communication and touch. The spiritual need for hope is also important in that it represents a desire for something to occur that is associated with one's own meaning in life such as loved ones and family. In addition, participants feel that even if they were dying, hope would remain important to them as although they would not get well, hope can be found in choices and goals to achieve while waiting for death to occur. According to Athika, meditation can give cancer sufferers hope. Similarly, Scarlet believes that artifacts such as the lucky charms that she makes for Romanies can give hope.

The spiritual need of love is related to the participants' meaning in life, in that they feel the need to love another. The spiritual need of love is also related to their spirituality in that the giving of love to another person gives them a good feeling in their inner being of spirituality. Peace for the participants in this study is the feeling of harmony within themselves. The manner in which this is achieved is through contemplation and reflection. Some participants pray and meditate as well in order to achieve a sense of peace.

#### CHAPTER EIGHT

## DESIRED SPIRITUAL HEALTH CARE

She is a small elderly lady and fighting for her breath. I look at the medical notes, which state. "Mabel Jones, asthmatic and congestive cardiac failure". I recognise the address, and remember the house she lived in - with the roses out the front and the fruit trees and chickens in the backyard. With the lane giving access to the back yard, where as a child I could sneak in and eat baby carrots and peas from the vegetable patch. Now Mabel is very ill and she seems to be dying slowly before my very eyes.

As the nursing sister in charge of the ward, I telephone the pastoral care department and ask someone to come and provide spiritual care to Mrs. Mabel Jones. The phone is answered by Sr. Carmel, an Australian nun who knows about the "Mabel Jones's" and the other people of the surrounding neighbourhood in which the hospital is situated. However, her answer takes me by surprise. She says, "Sr. Georgina, I think you are just as capable as I am in providing spiritual care to Mrs. Jones." "But Sr. Carmel," I reply, "How do I do that?" There is a chuckle at the other end of the telephone as Sr. Carmel laughs and breaks the tension of the situation. "Oh dear," she says, " do what you do best, sit and hold her hand and give her comfort. Ask her what she would like, if she wants you to pray for her, or read a Psalm or get her priest, whatever it is, you just do it for her". I mumble a thank you to Sr. Carmel and put the telephone down. I am astonished that a nun in a Roman Catholic hospital would suggest that I provide the spiritual care! Me, a mere secular nurse.

I provided spiritual care to Mabel Jones. I gave her the comfort that she needed, by acknowledging her situation, empathising with her fear in struggling to breathe, and praying for her that God would ease her breathing and give her peace and comfort. I also arranged for her priest to come and see her.

Later that day, Sr. Carmel came to the ward and asked me how Mabel Jones was progressing and how I felt about providing the spiritual care. We talked for a while and then she said she felt that spiritual care should be fully integrated into health care, and that it would be good for nurses and doctors to provide that care to their own patients. The conversation finished with Sr. Carmel saying, "But perhaps I am dreaming again, perhaps that can't occur." I replied, "But there is no harm in dreaming and wishing, we never know what might happen."

I remembered the story when I was trying to work out the participants' ideals of spiritual care for this study. The conversations between Mabel Jones, Sr. Carmel and myself had occurred some twenty years ago. Since that time I had worked in other hospitals, and teaching institutions. In one government hospital, the Chaplaincy department admonished me for trying to provide that same ideal of spiritual care. I was firmly told, "it is not a nurse's duty, but a chaplain's role!". The Australian Council of Health Services has started to change such a negative view, with their standards quite clearly stating that all health care professionals will work together to provide spiritual care to patients and clients.

#### INTRODUCTION

The purpose of this chapter is to discuss the desired spiritual health care the participants spoke about during their interviews. Not only are the participants' own experiences of spiritual health care included, but also their perceptions of the care their loved ones experienced. In their interviews, the participants told me not

only of the care they were receiving currently from health care professionals, but also about incidents and situations that occurred many years ago. Sometimes, the stories of the past were relevant, but at other times it was not necessary for me to know. However, the participants thought it important to tell me, and so I respected their decision and listened. The reason why some things were not important for me is that I felt the topic had no bearing on health care and spirituality.

Indications of the standard of desired spiritual health care came from two sources. First, participants sometimes mentioned the spiritual care they would have liked when receiving health care. Second, two of the participants - Athika and Tom - gave spiritual health care to others. I did not discover this until the first interviews were underway. Both said that, although they thought they gave spiritual health care, they wanted some feedback from me as to whether or not they were doing this correctly. At the time, I reassured them that I did not think there was only one correct way of providing spiritual care, and that I would discuss the findings with them at the third interview, so that they could implement any of the them in their own practices.

The name of the theme, 'Desired Spiritual Health Care', represents participants' desires (based on their largely bad health care experiences), and also those of a small group of patients'/clients' visions of ideal health care professionals. Thus, epistemologically, it is essential that I do not (a) overly privilege these participants' perceptions/views or (b) make general recommendations for all health care professionals based on a limited case study (because a study of actual health care professionals might find very different perspectives about the nature and quality of care provided).

The first section discusses how the theme of Desired Spiritual Health Care was identified in the data, and the names of the codes that form the subgroups of the theme. The attributes of desired spiritual care are also described. The second

section presents an analysis of data that identifies various levels of spiritual care associated with participants' past and present experiences of health care. This commences with an account of the participants' experiences of lack of spiritual care. This is followed by participants' views of three levels of ideal spiritual health care: (i) a basic level of desired spiritual care, namely, Acknowledgment; (ii) an intermediate level of desired spiritual care, namely, Empathy, and (iii) the highest level of desired care, namely, Valuing. The third section discusses ways in which health care professionals can incorporate spiritual care into their practice. Finally, the participants' views of health care professionals providing such care is described.

## IDENTIFYING THE THEME OF DESIRED SPIRITUAL HEALTH CARE

In the transcripts of the interviews, I found clear incidents and situations where health care professionals seemingly dismissed participants' spiritual needs. Likewise, I found that the participants had told me about times when they were given spiritual care and how they perceived that care. I found also that they had expressed preferences for particular qualities of spiritual health care. Originally, I stored all this data together and gave the title, "Spiritual Care", to the code. Only later, when trying to find deeper meaning in the data, did I realise that there were three discrete subgroups, each illustrating a distinct level of desired spiritual care. I named the three subgroups Acknowledgment, Empathy, and Valuing. Together, they constitute the theme of Spiritual Care. Later, however, I realised that other codes needed to be incorporated, including "Patterns of Prayer or Meditation", and the themes of "Fears or Anxieties". Subsequently, these were incorporated into the main theme.

The theme of Desired Spiritual Care is not identical to the spiritual needs that the participants spoke of (see Chapter Seven). Instead it indicates the type of care they believe could be utilised by health care professionals when trying to provide and meet the participants' spiritual needs. It is important to note that this excluded possible evangelising or proselytising by the health care professional in order to win converts to a particular religious view. Rather, desired spiritual care was conceptualized as a process in which the health care professional responds appropriately to what the patient/client is telling them about their felt spiritual needs.

The data related to Desired Spiritual Care appeared to demonstrate that the health care professionals went though a process of (1) getting to know the spiritual elements of the participant (2) involvement in understanding the participant as a person who is different from them and (3) who had spiritual needs to be respected and facilitated. That is, giving Acknowledgment is the minimal level, and then the health care professionals need to be able to show Empathy to fully understand the patient so that their needs, anxieties and fears could be expressed. In Valuing, the health care professional needs to share that Acknowledgment and Empathy with the participant to be able to value and respect the participants' point of view and perhaps different mode of spirituality.

Contained within the levels of desired spiritual care were, what I believed to be, two distinct attributes. The first is that spiritual care is not something that is given in isolation or separate from the normal psychophysiological care provided by the health care professional. Second, spiritual care is a dimension that should be incorporated into the care of the whole person. That is, the spiritual aspects of care can be incorporated with those of psychophysiological care, to become part of the health care professional role of caring for the whole person.

This spiritual dimension of whole caring is needed to protect and nourish the spiritual nature of the person (that is, their inner being). For example, during Acknowledgment, the health care professional provides health care information so that the patient is capable of making his or her own health care decisions in regard to treatment. During Empathy, the health care professional listens to the patient and offers them the opportunity to talk about their suffering/distress/problem. During Valuing, the health care professional facilitates the expression of the person's spiritual needs even when they are in dissonance with the health care professional's own personal beliefs. This level incorporates not only acknowledgement and the giving of empathy, but also values and respects the participant's choice of treatment and the practicing of idiosyncratic spiritual rituals.

#### LEVELS OF DESIRED SPIRITUAL HEALTH CARE

I found within the data examples of when health care professionals seemed to have provided no spiritual care to the participants. When examining the data that I had coded as "no spiritual care," I also noticed that these were times when the participants had expressed to me how very vulnerable they felt. The following excerpt from Ann describes both the lack of spiritual care and her vulnerability:

I was treated as though I wasn't really a person but more of a problem to be fixed. The placenta had not come away, so I needed to be fixed by having an operation....The nurses and doctors were more interested in the physical side, than the spiritual side of me.(character 4026 to 4287 of ANN.TXT)

Although this data is from only one of Ann's interviews, it is not isolated in that all eight participants mentioned incidents at some time in which health care professionals did not, in any way, provide needed spiritual care.

Sophie remembers how her husband's (Alf's) doctor directed his anger towards her about her husband's condition when he was ill:

Alf had a sudden stroke at work, and they took him by ambulance to this private hospital because it was workers' compensation. A medical specialist was assigned to him to be looked after. But because Alf needed to withdraw from his addiction to alcohol and nicotine when he was first admitted with his stroke, it was rather awful...[pause]

Alf didn't know what he was saying and he would wet the bed and not make it to the toilet, etc, and needed to be fed... all those things. But also he wasn't getting better quickly enough for the doctor, as he would come and complain to me and get angry with me because Alf wasn't making the progress he thought he should be. It really was dreadful I didn't know what to do...The nurses too did not like Alf, I would hear them saying things like,"Oh No! Not him again", in a tone of voice which clearly expressed their disapproval of having to care for him. I didn't know what to do. Alf couldn't tell me what he wanted and the doctor and nurses did not want him. So I prayed to my spirit.

My spirit helped me to be nice to the nurses and bring them little things. I am a good cook, so I would make something and take it to the hospital for their morning tea, etc. You know it made all the difference... Yes it made all the difference. Alf wasn't too much trouble anymore. They would say nice things to Alf, and me they would say to me... "your husband is a lovely man, he is trying so hard to get better." Thankfully, he did gradually get better so that I could bring him home.

Looking back, it seems incredible that I needed to be "nice" to them so that they would take good care of Alf. Once they started speaking differently to him, he started to get better. Before that, I think he could sense that they did not care about him. It was dreadful. What must have been going on in his mind and spirit when he thought he was "nothing"? (character 1416 to 2937 of SOPHIE.TXT)

I met Alf on each occasion that I interviewed Sophie. I found in talking to him that he still suffered brain damage from chemical poisoning in his old job and also from the effects of a stroke. He would answer the doorbell when I arrived at his home, and welcome me inside without being able to remember my name. Each time, I asked him how he was and what gardening he had been doing lately. I noticed that his short-term memory, gait and eyesight were the most affected. However, he had genuine warmth of personality about him, which endeared him to people. For example, the road he and Sophie lived on was a busy one, and the

owner of the petrol station opposite would bring the daily newspaper over to Alf at about 7.00am each morning, so that he didn't need to cross the road. These aspects made me wonder and question why the nurses had been seemingly judgmental and offered poor care to him.

I asked Ann (who is an ex-teacher) how, from an educational point of view, she thought health care professionals could overcome lack of spiritual care. She replied:

This could have been remedied if the nurse/doctor had put themselves in my shoes and tried to think about what they would have liked in the circumstances. If perhaps the health care professional had experienced what it is like to be a patient that would help, also if they had tried to get in touch with their own spirituality. (character 17162-17430 of ANN.TXT)

I know that placing themselves in their patients' shoes is supposedly already being taught to health care professionals, but perhaps it needs to be re-stated in the curricula of all health care courses, and for organisations and hospitals to offer incentives for this to occur (perhaps, through Quality Assurance Programs), along with education about spirituality.

It was within this context of largely bad experiences of health care that, during interviews, each participant commented on his/her view of how health care could or should fulfil his/her spiritual needs.

## Basic Level of Acknowledgement

Acknowledgement was the minimal level of spiritual care desired by participants. At this level, the ideal health care professional acknowledges that patients/clients have a spiritual nature and may have spiritual needs. Whether or not the health care professional facilitates spiritual care is immaterial at this level. For example, Rosie had this to say:

I would have liked my spiritual needs to at least be acknowledged. (character 1745 to 1799 of ROSIE.TXT)

In acknowledging the person's spirit, the ideal health care professional is being receptive to the idea or concept of spiritual care. An example, of acknowledgement in the data includes the following:

My doctor was trying to understand what I have been going through. Before that, he didn't seem to be interested or even acknowledge that I was ill and had needs. I went to see him after I came out of hospital and told him I hadn't liked the care he had given me before I saw the psychiatrist and was admitted. I told him that he should have picked up the early warning signs that I was suicidal long before I started to burn myself. He apologised, but I still couldn't say he was a pastoral person, but since I spoke to him about what I thought of his care to me, at least he is trying, he has a greater awareness now of my needs. (character 1770-2274 of ROSIE. TXT)

The characteristics of Acknowledgement found in the data include:

Everyone has a spirit, it is innate. (character 1986 to 2186 of ATHIKA.TXT; character 1720 to 1750 of SCARLET.TXT)

It doesn't matter what a person has done (be they a prisoner, street person, or whatever), they still deserve that we treat them as a human being with a spirit. (character 2688 to 2818 of TOM.TXT)

I need the time and space for reflection. Health care professionals need to acknowledge this. Whether they do anything about it to facilitate the person doing it is up to the health care professional. However, the first step is to acknowledge to a person that many people do reflect and that they find it beneficial to their health to give them inner peace. All participants in some similar way (character 5674 to 5968 of TOM.TXT)

It would really be nice if the health care professionals could just stop and touch you. I don't mean putting in a drip or giving you tablets or that sort of thing. However, to place a hand on you and genuinely say "how are you now?" It is not asking for much but I would know then that they recognised that I have a spirit and I am unique. I may be a funny middle-aged dear looking after my husband, but there is something there that needs to respect my spirit, which is important to me. (character 16789 to 17181 of SOPHIE.TXT)

The difference between the levels of Acknowledgment and Empathy is illustrated in this excerpt from Ann.

The midwife who delivered Mary was aware of my needs, as she had got to know and understand me. During my labour, she was very understanding and supportive. Whereas, the operating room staff did not have the time to get to know me, and this made a big difference. On the ward that I went to after the operation, the staff did have the time span to get to know me, but they didn't. I was just the one with the physical problem that needed to be fixed up and discharged, so the person next in line could have my bed! (character 11138 to 11552 of ANN.TXT)

### Intermediate Level of Empathy

The next level of spiritual care desired by participants was Empathy. At this intermediate level, the ideal health care professional initially acknowledges the spiritual nature of the person, and then seeks to understand their vulnerability, concerns, fears, and anxieties. It is through the interchange of verbal and nonverbal messages that the ideal health care professional provides empathy to the patient/client. Thus, it is an active phase of spiritual care. An example of the type of empathy that the participants desired is:

There is a tremendous need for the health care professional to show empathy. When I was having the epidural I kept saying that it was hurting and the midwife came and held my hand... and that really helped. It showed that they understood your situation, and it helped to ease my pain. Also, I think if someone had been able to be with Jack while he was waiting (while I is in the operating room) or even if he had been told of what is going on would have helped him too. The little things like consideration for that other person make all the difference. (character 16493 to 16940 of ANN.TXT)

The characteristics of empathy, found in the data, that the participants felt were needed when health care professionals cared for them include:

Staff should realise/recognise patient anxieties and situations. All participants (or example, character 11138 to 11206 of GEOFF.TXT)

She has had a stroke, she is rather angry over the whole thing and she needs the nurse/doctor to understand that. Tom, talking about his sister (character 11429 to 11521 of TOM.TXT)

I don't like hospitals; I think nurses and doctors need to understand that. (character 16064 to 16127 of ANN.TXT)

At birth, the spirit of an ancestor comes and resides in the newborn baby. It might take a few days. However, the family will know if the child will grow up to be an elder of the tribe, by he or she starting to display "the gifts" of Romany. (character 2962 to 3154 of SCARLETT.TXT)

Pain gets easier if you can talk about it and that's one thing, I would like to see a lot more of... of doctors acknowledging your pain and allowing you to express it, being empathetic towards you. (character 13821 to 13982 of GEOFF.TXT)

When I tried to commit suicide, I was at my lowest ebb. "The darkest hours of my life." I needed someone to hold my hand and be with me. This would have shown me that they understood my pain and wanted to help ease the pain. (character 20265 to 20443 of ROSIE.TXT)

I find that I can touch a patient to show that I understand and care about them.... I find I can do this in a way that they don't interpret the touch as sexual. (character 12587 to 12713 of ATHIKA.TXT; character 20494 to 20620 of TOM.TXT)

Included in the level of Empathy is allaying the fears and anxieties participants experienced, such as fear of abandonment and/or death. Examples of types of fears, found in the data, include:

My brother is very anxious about his life and death so he has gone back to his Roman Catholic religion as he is after some sort of stability, some sort of spiritual belief to hang onto. Tom, talking about his brother. (character 23199 to 23348 of TOM.TXT)

The people of my church though they knew I was ill, did not try to help. I felt that they stood apart from me. They did not try to be there with me when I felt so much inner pain. (character 13133 to 13372 of ROSIE.TXT)

As a child I was terrified of nuns when they were near me, as I thought that if I got too close to their big black habits, that they would whip

me under their skirts and I would never be seen again! I still carry this fear of religious people. (character 16789 to 16979 of SOPHIE.TXT)

I needed to know that God is not abandoning me and that I would get better...My Mum left when we were quite young and then dad died so I have a fear of abandonment .I was just so scared that God would abandon me and I would die. (character 16059 to 16187 of ANN.TXT)

Fear of death is a common anxiety amongst patients/clients receiving health care, and I believe one that can be reduced through education provided by health care professionals. Fear of death could have been explored by health care professionals with some of the participants in this study. However, when talking to the participants about their fears and anxieties, I found that not all had a fear of death.

When I had the vision I saw what death was like and now it holds no fear for me. (character 2447 to 2508 of SOPHIE .TXT)

I would like to think that when I die it is nice and peaceful. (character 10954 to 11002 of TOM .TXT)

I am quite looking forward to what death is all about. I mean, I know I have to go and I am going. I'm quite looking forward to discovering what it is all about. (character 8807 to 8935 of ATHIKA.TXT; character 22666 to 22894 of TOM.TXT; character 2510 to 2637of SOPHIE.TXT)

I don't know if my spiritual needs might change if I knew I was dying. It is hard to say. I do know that if someone came to me and told me that I am going to the Promised Land. I'd tell them to go jump, as I've already been living in it, as Australia is so good. (character 30822 to30947 of RED.TXT)

When the ideal nurse/doctor shows empathy it enables the patient/client to express their spiritual needs and desires. That is, by showing empathy the health care professional gives the patient/client permission to tell more about themselves, including their spiritual beliefs. Thus, by recognising the spirituality of the patient/client, the ideal health care professional anticipates possible spiritual

distress that might arise if the person cannot practise or express their normal spiritual manifestation.

When providing empathy, the ideal health care professional is aware that the patient's/client's beliefs and truths may not be the same as the spiritual groups to which they seem to belong. In this way, to make sure the empathy is helpful to the person, the ideal health care professional recognizes the variations and personal truths the person may be holding at the time. For example, Muslim parents might say that they do not believe in organ transplantation. However, if their son or daughter is dying of kidney failure they may want to be offered the choice between their child living or dying. In this study, Athika, Tom, Rosie, and Sophie had rejected some beliefs of the organisations to which they belonged. Examples of the participants' personal types of spirituality include:

Although I might have rejected Roman Catholicism, I have not divorced myself from Christian beliefs. (character 16789 to 16875 of SOPHIE.TXT)

I don't have a true Christian belief, as I have never fully understood it. (character 22888 22948 of TOM.TXT)

By recognising such variations in spirituality, the ideal health care professional anticipates possible spiritual distress, which might arise if the patient/client is feeling anxious or concerned about health treatment which may not be acceptable to their particular spiritual organization (Keegan, 1993; Reed, 1991).

## **Highest Level of Valuing**

At the highest level of desired care, that of Valuing, the participants not only wanted their spiritual needs to be acknowledged and to be treated empathically, but they wanted also to feel valued by the nurse/doctor as a unique person. They wanted the health care professional to regard them as being important. In providing this level of spiritual care, the ideal health care professional values and

respects their patient's/client's choice of treatment and their practising of spiritual rituals. Valuing is therefore an active phase of spiritual care.

The ideal of valuing can be enacted by the health care professional facilitating the expression of the participant's spiritual needs (even when they are in dissonance with the health care professional's own personal beliefs). Examples of the Valuing level of spiritual care, in the data, include:

It would be nice for the doctors to treat you as an equal. (character 4241 to 4286 of RED .TXT)

Respecting the patient or client. (character 20680 to 20828 of TOM.TXT)

To value a person is to respect the integrity of the other person. (character 20789 to 20842 of SCARLET .TXT)

I think that people go about accessing their spirituality in different ways. One way could be through their usual religious practices, whatever those practices happen to be. And they may include things like prayer, contemplation, or they may include meditation, which is slightly different, so I think it's really up to the individual. I think that they have the ability to access those experiences in their everyday lifestyle, particularly if they're cognisant of what's happening around them and if they're aware of the detail of what's around them, so that they're actually...I think, I believe that if they're living in the present and experiencing each minute, or hour, and it's progressing, then they have the ability to access that spirituality in the things that are around them, the situations, the people, whatever, etc. (character 21349 to 22355 of ATHIKA.TXT)

The characteristics of valuing another person include:

The way the nurse or doctor do things is important, they need to show the person that they are important, that is, that they value that other person. (character 17475 to 17596 of ANN.TXT; character 13187 to 13308 of ROSIE .TXT; character 14067 to 14188 of SOPHIE .TXT)

The nurse/doctor need to respect the person so that person can find peace within himself or herself. (character 14100 to 14183 of GEOFF.TXT)

You know the Ten Commandments are similar in all religions and philosophies, and that is not a bad starting point for people in respecting themselves and each other. (character 6678 to 6815 of ATHIKA.TXT)

Respecting a person is to treat the person in the same way you would want to be treated. You want to be valued as another person who has unique qualities. It is important that people are respected, whether there are Buddhist, Communists or Humanists it doesn't really matter, you just need to let them get on with it. If it's not affecting you, you just need to let them bloody well get on with it. (character 25801 to 26124 of RED.TXT)

No matter what a person has done or what they have wrong with them they still deserve our respect as a human being with spiritual needs. (character 14244 to 14354 of TOM.TXT)

When I went to our antenatal class reunion, all the women had had a different birthing experience, we are all different...I don't think patients can be treated the same. (character 16789 to 16928 of .TXT)

The manner in which the participants suggested the health care professional give valuing care includes:

Respect the people that you are caring for. (character 11633 to 11668 of GEOFF .TXT)

All sorts of people can be ill, from all walks of life; it doesn't matter who they are. The health care professional needs to have the time and be able to have a meaningful conversation with the person.... To be able to talk with someone and for them to really take the time to properly listen. (Character 8957 to 9293of SOPHIE.TXT)

Storytelling, I've done it with some forensic patients, and I've seen other people do it with people dying. Getting them to tell a story and, and listening to people talking about it. Tom, talking about the importance of story telling. (character 11828 to 11819 of TOM .TXT)

The doctor used to come and see my mother in her bed under the tree out the back.... He would sit and talk with her out there...he understood and respected her. He realised that being a Romany she is more comfortable outside than feeling trapped indoors ...he also respected her own ideas about medication and let her use old gypsy things, he knew she was smoking pot for her nausea, etc.... He really is a marvellous doctor, he takes so much time and is gentle in touching and handling me ... my spirit would never be hurt by him. Scarlet speaking about her GP. (character 21805 to 22231 of SCARLET.TXT)

In valuing the patient, the ideal health care professional is aware of any manifestation of spirituality that the patient/client would like to undertake when receiving treatment. For example, all participants in this study meditated and/or prayed. Therefore, in order to value their spiritual needs, the health care professional needs to make sure that time is provided for the person to undertake this action. It may also require privacy, and so the health care professional should ensure this is available. The manner in which the participants meditated or prayed was found in the data theme named, "Reflection and Prayer". I included this theme in Valuing as I believed that if a health care professional values patients' spiritual needs they would want to assist or facilitate their fulfilment.

## INCORPORATING PARTICIPANTS' DESIRES INTO PRACTICE

In this study, reflection, meditation, and prayer reportedly were the methods participants used to access the focus of their spirituality (see Chapters Two and Six). The purpose in describing these ways is to offer insight into how this aspect of desired spiritual care could be readily incorporated into patient care. As previously mentioned, the participants desired to be informed about the proposed treatment and to also be involved with the decision making process. They also desired empathy so that they could tell the health care professional about their spirituality and desired needs. Finally, they wanted to be able to practice their own spiritual behaviours.

Each participant had a particular personal way in which they meditated or prayed when accessing the focus of their spirituality. Each reportedly found their method very satisfactory and strongly believed that it improved their quality of life (see Chapter Six). Their methods of meditation and/or prayer are directed either inwards to the inner self, or outwards to others, such as ancestors, God, gods, Buddha. Examples of meditative practices by Athika and Scarlet are:

I use meditation to access my spirituality, it's portable and doesn't require any equipment, and the situation usually doesn't affect whether I can access it or not. Then I use natural things to focus on, as visual focus can be important, I then limit the amount of stimuli, change my pattern of breathing, and use positive thoughts, such as I am relaxing, I am relaxed, etc. (character 25809 to 26118 of ATHIKA.TXT)

I talk to my inner self, my will for things to happen. The will is very strong and controls so many things we do and so I use my will to bring about things. I also talk to my ancestors and ask for things to occur. As a witch/healer, I can facilitate good or bad things to occur. I don't use the "evil" but I do have the power to cause bad things to happen if I wished. (character 31128 to 31418 of SCARLET .TXT)

The frequency with which the participants needed or wanted to meditate or pray varied. Some meditated/prayed once per day (Ann, Athika, Tom, Geoff, Red,

Rosie, Scarlet and Sophie). Four meditated/prayed twice per day (Tom, Rosie, Scarlet and Sophie). Athika meditated several times a day. On some days Scarlet needed to pray more than twice, especially if she was called to do a house cleansing or blessing, or to pray on behalf of another person. Descriptions of the participants' meditation/prayer patterns include (they are included here so the reader is aware of the various styles):

Prayer or meditation for me is a time for relaxing the body and getting in touch with the inner. I don't pray directly to a god. But rather I go into my jungle, sit there and talk to my inner self about a problem or whatever, and then when I am not expecting it the thought comes into my head on how to work through the problem. Sometimes I have to make an effort to interpret what it is. (character 30312 to 30621 of TOM .TXT)

Spend time reflecting on things. I also talk to myself, which is the same as praying. (character 27790 to 27859 of RED .TXT)

I like to walk each day and relax my thoughts and meditate as I do so. (character 13712 to 13766 of GEOFF .TXT)

I do Morning Prayer each morning from the Anglican Prayer Book, and I like to reflect on what I am going to do and what I have done. I also meditate. It is through prayer and meditation that I get inner peace. My prayer is just talking to God, as one would with a friend or confidante. But I also use the Buddhist way of meditating, and I usually burn incense when I do that. (character 27790 to 28090 of ROSIE.TXT)

I have a corner in my study where I sit, reflect and pray. I might do some Bible reading, pray, and write in my journal. (character 11887 to 11982 of ANN.TXT)

I listen to some classical music, perhaps have a cigarette, and then talk to my inner self, and talk over the day with, and if I need guidance in any area well then I will ask for that. I have some tapes that I meditate with. I have my favourites (some sounds of birds and one of the sea, they are all nature ones). I have a little communion with my inner spirit. (character 14067 to 14357 of SOPHIE.TXT)

Every morning I get up at six o'clock or ten to six and by about ten past six, quarter past six, I've done all the making cups of tea and all of that stuff, then I'll ah, do it, for probably only twenty minutes, half an hour depending on how much time I've got, and ah, then after that I just progress on through the day, through the normal daily activities, but again, during the course of the day, when I have opportunities, I'll take these; a minute here, three minutes there, to focus on what's happening and if I'm feeling stressed during the day, I might take a whole five minutes off (laughter) and do a mini meditation....If I want to clarify my thoughts during the day, I might meditate for a couple of minutes to get rid of non-productive thoughts and those, that are not essential. It helps me to refocus. (character 27497 to 28160 of ATHIKA.TXT)

This diversity of meditation/prayer patterns amongst the eight participants illustrates the uniqueness of their spirituality and highlights the need for the ideal health care professional to understand the individuality of each patient's/client's spirituality.

#### PARTICIPANTS' VIEWS ON FINDINGS

When I discussed the findings of desired spiritual care to the participants at their third interview, Red expressed the following opinion:

I think the doctors and nurses have been too much into protecting people. That is, they want to protect them from doing something wrong or what they think is foolish, like expressing or manifesting spiritual practices. Therefore, they don't allow them to practise their spirituality in hospital. It's all part of the system; the patient must do what the doctor and nurse want.

I remember I was about 15 years at the time. I had gone into hospital to have an undescended testicle taken from inside the groin area and sewn down into the scrotum. As you know they sew an elastic band from the scrotum to the inside of the thigh to stop the testicle from ascending again into the groin. I was so embarrassed by the operation. Jeez I was 15 years! Vulnerable as they come. Anyway, the

first operation was not too bad. Then I had to go back in again for the final operation to free the scrotal sac from the inside of my thigh. Anyway the surgeon came around and was not pleased with the way it was healing, and he told the Sister off in front of me that she hadn't been cleaning the site well enough. They both departed very angry.

But then each morning this Sister would come into my room, throw back the covers and proceed to clean and dress the site on my scrotum and inner thigh. Each time she displayed her anger at the surgeon when she did my dressings. She showed no feeling for my embarrassment and me. Gawd it is dreadful, She used to make me feel dreadful. Here she is completely ignoring me, except my bloody penis, scrotum and inner thigh.

Shit! We are taught these things at school and in Church, that isn't shown or displayed! It is "hallowed ground". Nobody ever saw it except me. We are taught that this taboo area is sacrosanct and not used until marriage. That surgeon and nursing sister had no idea what they were doing to me.

I hope things have now changed. When I think about all the Muslim women we must have in Australia now, who cannot be seen undressed by a male except by their husband! The mind boggles. I just hope that they care for those women better than they cared for me. (character 32000 to 33709 of RED.TXT)

Athika pointed out the importance of the health care professional trying not to 'pigeon hole' a patient or client into one particular type of spirituality, but to explore with them their spiritual beliefs and behaviours.

I have looked at a few different types of spiritualities. I looked at Judaism, and not just the religion, but the cultural aspects associated with that, I looked at Islam, I looked at ah, and tried to find out about Sikhs, and there would have been Buddhism. They'd be the main ones; I have also looked at African religions, animistic religions and amalgamated religions. I lived in Africa years ago and I thought that was very interesting, the way that cultural beliefs had been integrated into a sort of pseudo Christianity. I thought that was interesting, not because I agreed with what had happened. You see I view all these from an anthropologist's point of view. I see some things, I sift though the new information or examine, and I then sort out what is of interest to me and reject the rest. While spiritually it could be said that I am

Hindu, there are some aspects that I reject. (character 30822 to 31553 of ATHIKA .TXT)

Perhaps the participants are saying to the health care professional:

"I am me, I am not anyone else, or anybody similar that you have looked after before, I have had my own life experiences that have given me my own subjective knowledge of health care and spirituality. Some of these experiences have been positive and some of them have been negative, so talk to me about these things. Do not be judgmental in your care for me. Do not be dismissive of my fears, vulnerability, and anxieties, listen to them and help me to understand. Give me information so that I can make my own decisions; respect and value the choice that I make, although it may not be your choice. I am unique and an individual just like you, please respect me and show me that you can respect my spirit by being gentle and not hurried".

#### **CHAPTER SUMMARY**

The theme of Desired Spiritual Health Care represents the eight participants' expressed desires for (based on their largely bad health care experiences) and visions of ideal health care professionals. However, for methodological reasons, it is important that I do not (a) overly privilege these participants' perceptions/views or (b) make general recommendations for all health care professionals based on a limited case study examination of these data.

This theme incorporates the characteristics of spiritual care in that it is not mutually exclusive of psychophysiological care; rather it is intermingled, so that whole care is given to the patient. The minimal level of care is named as Acknowledgment, and is seen as acknowledgement by the ideal health care professional of participants' spiritual nature and possible spiritual needs. That of Empathy, which involves listening to the patient and offering understanding of

their suffering/distress/problem at the time, follows this level. The highest level of care is that of Valuing, which involves the ideal health care professional demonstrating respect of the participant's spiritual needs and facilitating those even when they might be different from the health care professional's own spiritual beliefs. To provide the spiritual care of Valuing, the health care professional needs to incorporate acknowledgement and the giving of empathy, and also value and respect the participant's choice of treatment and his/her practising of (perhaps idiosyncratic) spiritual rituals.

#### **CHAPTER NINE**

#### RITE OF PASSAGE

Jack was a lovely old gentleman. A veteran of more than one war, who carried the agonies of these experiences deep inside himself and never spoke about them. Not only was his mental health affected by these life experiences, but also his physical health. When I came to know Jack his frame was pathetically thin at 50 kilograms and he was no more than 153cm. in height. He always looked so small in the hospital bed, I often thought that if you piled several blankets on top of him you wouldn't be able to see him. Everyday the ward orderlies would shower him, change his pyjamas and then place him back on his bed in time for breakfast. The male charge nurse and the orderlies knew Jack's past from the little bits he had said over the years when he had been in and out of hospital, and had grown very protective of him.

One day I was sitting talking to him with one of the students. The student had asked Jack if he could talk and discuss a few issues with him. The charge nurse and the orderlies rather liked this student, and had given permission for him to sit with Jack and undertake a life review.

It was a lovely sight, Jack lying on his side facing the student and quietly telling him about some of his life and the head of the young student intently poised and listening to every word Jack said. However, they were rudely interrupted when the ECG technician came to take a recording of Jack's heart. There was no "excuse me", or "pardon me", from the technician. She just

walked up to the bed with the ECG machine and leaning over Jack started to undo the buttons of his pyjamas and apply the ECG leads. Jack rolled over onto his back to try to accommodate this new demand on his time. The student displayed shock at the rude interruption. I kindly asked the technician if she would come back later, but I was not given a reply as she methodically proceeded to take the ECG.

Over several weeks of talking between Jack and the student the life review was complete. Jack's story was rich and colourful, and portrayed a life that encapsulated the high spirits of young adulthood, marriage, war service and war injuries and illness, children and grandchildren, the dignity and purpose that he found in his meaning of life. His life was a journey or passage in time interwoven with the threads of mental anguish, physical illness, love of family, and a deep sense of awareness of a power greater than himself, which he termed as "my god".

#### INTRODUCTION

The purpose of this chapter is to explore further the experiences of the eight participants of this study during their time of health care. In Chapter Five, the participants gave examples of their negative experiences of health care. Chapter Six discusses the meaning of spirituality for the participants, and gives examples of the lack of spiritual care provided by health care professionals. Chapter Seven examines the participants' health-care related spiritual needs. Chapter Eight contains examples of spiritual care being absent and of good standards and levels of care received by some participants.

This chapter reveals the rite of passage undertaken by the participants while receiving health care treatment. I have chosen the term 'rite of passage' for the following reasons. The term 'rite' means an act or practice of something that occurs (Sinclair, 1993, p. 998). It is a term used at times to describe a ceremony or

observance, whereas 'passage' means an 'opening or journey'. Placing both of these terms together implies that the participants were 'entering into a journey, which has significant acts (or stages) or occurrences'. Although the term 'rite of passage' is sometimes used to describe a wedding service or initiation ceremony into adolescence (both of which are one-way journeys), in this study I use it to describe the one-way involuntary journey involved in having a severe health problem and being in need of related spiritual care.

#### RITE OF PASSAGE

Discovery of the rite of passage undertaken by the participants came about when I was asking myself the question:

What is the process that the participants engage in while being ill and having either their spiritual needs met or ignored?

On sorting through the data, I noticed a process that begins when a person realises that they are ill and finishes when they evaluate the extent to which their health care and related spiritual needs have been met. Although the eight participants undertook this passage, not all underwent it in the same way or in the same order.

The eight participants underwent the rite of passage when trying to look after their spiritual needs while experiencing a severe health care problem. The concept of rite of passage arose from studying the transcripts on the interrelationship between the themes of spirituality, spiritual needs, and those of health. The rite of passage involves the following five stages.

- 1. Realising health care problem.
- 2. Recognising dissonance between normal routines/daily rituals and/or feelings of anxiety or fear due to present condition.
- 3. Asking for spiritual care.
- 4. Receiving or not receiving that care.

#### 5. Reflection.

Each of these stages is described, commencing with the first stage of the participants realising they have a health problem, and continuing to the last stage when they reflect on the extent to which their spiritual need has been resolved. All participants talked about more than one episode of illness, including previous hospitalisations and past and present health problems. The rite of passage was difficult to discern, as the participants frequently moved from telling about their present experience to talking about their past experience and their loved one's experience. For the sake of clarity and because of the richness of detail available, I have given Athika's passage as an exemplar of each of the five stages of the rite of passage. For each stage, I first describe Athika's experience and then provide supporting evidence from other participants.

#### 1. Realising Health Care Problem

This stage of the passage occurs when the patient realises that s/he has a health problem. In this study all participants were aware that they had a health problem. Although at the time of her interviews, Athika was experiencing hypertension and stress, she related her previous experiences of health care problems and spiritual needs. One such problem she did not specifically name but referred to as "hospitalisation". Athika readily recalled that:

I went into hospital for a minor operation. Nothing big deal. I was in my 20s at the time. Fortunately I had told my parents that I was going to have the op., and they came to the hospital to see why I hadn't gone home when I said I would. You know what it is like, you go in for something minor — told my parents not to come and visit, as I was only going in and out. What had happened is the simple operation went terribly wrong. After the operation I had extreme abdominal pain and vomiting, but the staff kept telling me there was nothing wrong. I knew there was. (character 20265 to 21317 ATHIKA.TXT)

When Athika continued to be ill and complained of severe pain, she was told by the nurse that she probably had a psychological problem, which she needed to talk about. With that the nurse sat down on the bed and told me to tell her what my problem was, and there I was clutching hold of the curtain screen and ringing it in agony while she tells me to talk! (character 27838 to 28447 ATHIKA.TXT)

Here, it can be seen that Athika realised that she had a problem, and sought the help of the health care professional by telling the nurse that something was wrong. However, the nurse seemed not to realise that severe pain can arise from a complication and is not necessarily a psychological problem of a person wanting the administration of a potentially addictive drug.

The other participants also were able to realise that they had a health problem. At the time of the interviews, Sophie suffered from heart failure and osteoporosis, and was the primary carer for her husband (who was suffering from the effect of a stroke). In the past, she had what she termed "a nervous condition".

I'd go to bed for a week and take these pills, so I'd go to bed and the kids would come in and say "Mum, he's fighting me"; and Alf'd come in and say "Um, what do I do for tea?" or something, so I'd get up and start again. (character 14690 to 15050 SOPHIE.TXT)

Tom was suffering from 'burn out' from his job as a mental health nurse. His symptoms resembled depression, but at the same time, he was trying to develop reflective practice on the unit where he worked. This development was not working and he was anxiously trying:

To think of a way, there must be a different way. (character 11429 to 11584 TOM.TXT)

He was also trying to introduce spirituality into patient care for the mentally ill patients in his care. So, although Tom had a health problem, he was also trying to alleviate the health problems of his patients. This means Tom's journey included not only his own health problem but also those of the patient group he was caring for.

# 2. Recognising Dissonance

This stage involves awareness that there is a difference between what the patient normally feels, as far as their spiritual feelings are concerned, and how they feel at the time of their illness. This was not easy for Athika to realise because of the severity of her illness at the time. Thus, the patient might not be able to express her (or his) concerns and/or articulate them as spiritual needs. So, if the health care professional is not able to realise the person's health problem, then it is possible that s/he may not be able to recognise the patient's spiritual needs.

I knew I was going to die, if the staff did not do something. At that stage of my life I was already a spiritual person who meditated etc. And here I was stuck in a hospital dying because the staff wouldn't listen to me. (character 20265 to 21317 ATHIKA.TXT)

I inferred from this excerpt that, because the nursing staff did not realise Athika was possibly dying, they would not necessarily recognise the need to meet the spiritual needs of a dying patient.

This stage of recognising dissonance between normal and new feelings involves the awareness that there is an alteration between what the person normally feels, as far as their spiritual feelings are concerned, and how they feel at the time. This was not easy for some of the participants to realise, as they were very ill, however, they all had an awareness "of things not being right". This meant that the person might not have been able to express their concerns and/or articulate them as spiritual needs. The participants realised that there was some inconsistency between normal spiritual routines/daily rituals and/or feelings of anxiety or fear due to their present condition. Rosie's experience includes:

I knew there was something wrong with me, as I couldn't sleep. I tried taking sleeping tablets that the doctor had given me, but they didn't help. So I took more and more and still they didn't help. I felt so weak and tired. I felt that I couldn't do anything any more. I went to the doctor and told him I was overdosing on the sleeping tablets but he didn't do anything. I was desperate; I didn't feel as though I had control of my life anymore. I can remember praying "Oh God please help me, I feel so dreadful. (character 27923 to 29143 ROSIE.TXT)

All participants were able to identify when they thought their spiritual needs were apparent, even though for some their health at the time may have excluded them from realising that what they were missing was spiritual care. Ann realised this difficulty:

It was not easy to do as the spiritual needs are all mixed up with the physical and mental needs. However, if there had been someone there at the time that could have helped me work out what my spiritual needs was, this would have helped. This was particularly so when I was waiting to go into the operating room and I was sad, angry, hurt, scared, and fearful. Looking back, I can work out with you what were my spiritual needs and what were physical needs but at the time, I couldn't. (character 16064 to 16457 ANN.TXT)

Ann's experiences are the behavioural manifestations of her spiritual needs and her physical and mental needs. The nurse or doctor could have helped alleviate her feelings by showing empathy for her fears and perhaps separating the spiritual from the physical disorder, that is, delineating or describing to the patient what is spiritual and what is physical.

# 3. Asking for Spiritual Care

At this stage the patient tries to have their spiritual needs met. Requesting spiritual help can be either passive (in that someone else recognises the patient's poor psychophysiological status and asks the person if they have a spiritual need) or active (when the patient states that they want a spiritual need to be met) (Hawley, 1996). In the passive mode the patient talks with another person (such as the health care professional), who may or may not ask if s/he would like spiritual care

sought on their behalf. Sometimes requests for spiritual care involve a visit from a person in Chaplaincy or Pastoral Care, a spiritual leader outside of the hospital environment or a local person.

In Athika's journey, although she recognised that she was possibly dying and would have liked spiritual care, the nursing staff did not:

I was very ill, and the care was very bad. Nothing positive was happening; it was horrendous. Because they did not realize how very ill I was it didn't occur to the nurse that I was dying and ask if I had some spiritual needs to be met before I died. (character 23514 to 23713 ATHIKA.TXT)

Rosie believed that health care professionals did not listen to patients and therefore were not aware that there may be an implied request for care. She said:

I think sometimes the nurses and doctors don't listen properly so they don't hear what the patient is telling them. I know myself, I had to phone you to ask you to come and see me. The staff didn't seem to realise my spiritual need. They were very good but they were more interested in my physical and mental needs. (character 21869 to 22124 ROSIE.TXT)

However, some patients with certain philosophical or cultural beliefs may not ask for their spiritual needs to be met. Rather, they might accept that their spiritual needs are not acknowledged or catered for. When talking about this issue with Sophie at her final interview, she said:

Because Alf and I are now on the invalid pension we go into the public hospital system. I couldn't ask those nurses and doctors to try to look after my spiritual needs, as they are too busy doing other things. I just wait until I get home again. (character 31572 to 31770 SOPHIE.TXT)

# 4. Receiving or Not Receiving Care

The next stage is receiving or not receiving spiritual care. A finding in this study of spiritual care was sought but was not always forthcoming: this is disappointing for example, one participant (Ann) had wanted to see the Chaplain while in

hospital, but was told by the nurse "that he is a very busy man and he only sees the very ill patients". Although Athika did not request spiritual care, as the nursing staff did not recognise her deteriorating physical state, neither did she receive care. Instead, she attended to her own spiritual needs:

I just closed my eyes and talked to myself and I used repetitive selfhelp talk to survive. (character 23714 to 23788 ATHIKA.TXT)

It may be that if the nurse/doctor recognised the spiritual component of health care then they would facilitate the request.

The Clinic did not have a regular chaplain, someone that wanders around and talks to the patients. I thought this is frightening. I told them so when I was leaving when you fill out one of those forms asking about your stay. If I had not been able to contact you to come to see me, I don't know what I would have done. Even then, it was a few days before I realised that I needed someone to help me spiritually. (character 27167 to 27480 ROSIE.TXT)

Another possibility is that some hospitals are very busy and staff are overworked. I know from my own chaplaincy experience that I was shocked to learn that some chaplains may not be able to answer a request for spiritual care for 2-3 days. At times, the circumstances may not allow much time, for example, I was asked to give spiritual care to a 90-year-old lady whose husband had died within the previous 12 months. She was ill and requested spiritual care. I did a life review with her and enjoyed our chats together. One day she said to me that she wanted to have confession and absolution for her sins. I asked if she wanted me to do it with her, or to get someone else. She replied, "You will do, I need to ask forgiveness for loathing Rev'd X." We talked a while and it transpired that, when her husband was ill and dying in the same hospital, she requested Rev'd X to give her husband "The Last Rites and Holy Communion", however she said he "fobbed me off" and said he would come when he had time, "but the trouble was my lovely died that night, without The Last Rites."

Sophie sought spiritual help from me at her first interview. In fact, her opening words include a covert request for spiritual help:

Sophie: If I sit here will it be all right with you in that chair there? Georgie: Yeah that'd be fine. I'll just put that [microphone] here and we can forget about it now it is on.

Sophie: Well I have an ambiguous things going on in my mind in the last few days.

Georgie: Right.

Sophie: The carers' group that I go to was asking things to put in the newsletter. I wrote some poetry that was personal and asked that my name not be mentioned. But she [the organiser] printed the poems with my name. I felt dreadful; I was so embarrassed that people would know that I wrote them as they had personal things in them, like how hard it is to be a carer. What happens if my husband reads it? I really don't know what I am going to do about it. (character 100 to 689 SOPHIE.TXT)

Although Athika experienced a health problem and was a participant in the study (and her experience of this journey is described in the first part of the chapter), she also provided spiritual care to others. This care involved teaching meditation to people with cancer (something which she had been doing for several years). She described several responses of cancer patients who did meditation with her:

There's about six people involved in a session, and when that session is completed, there's a quietness and a peacefulness about the people, and sometimes if I look at their faces, I see a sense of pride in that they had achieved a feeling of peace.

An elderly man who had just finished a meditation session with me said 'Aah, ah, I feel as though I've just woken up. Did you hypnotize me?' (Laughs) Which I thought was very interesting comment because I think that refers to the different state of consciousness that he experienced. (character 30822 to 31260 ATHIKA.TXT)

When Athika was commenting on these passages (during her final interview), she added:

I find some people who have come to the meditation groups that I run in very sad circumstances. For example, an Oncologist telling the person "that nothing more can be done for them so they might like to try some meditation or pray etc." It is this notion that doctors and

nurses can only recommend prayer and meditation as a last resort I find very worrying. (character 31270 to 31563 ATHIKA.TXT)

Athika also spoke of the way she meditated to help heal someone:

I believe that that image of light has the ability to improve the condition of the person. It's usually an image of the whole person that I meditate on, and I'll see them in the centre of this large beam of light and I'll be repeating or concentrating that as the light filters through the body from the head through, and it's a situation being through and around the person at the same time, the person is experiencing a positive and peaceful feeling that activates their own healing. I don't know if they activate their own healing, but the healing is activated through a process that goes on. (character 31564 to 31951 ATHIKA.TXT)

Tom spoke of his difficulty not only as a participant with a health care problem but also as a nurse in trying to implement spiritual care in his clinical practice.

I wonder if we can really change what seems like a standard practice, to implement spirituality so that we might be able to help those who at the moment we can't do a great deal for. I had a patient who we couldn't help, and I keep wondering if what he said was part of his spirituality, and that we might have been able to help him that way. You see this patient was seen as mad, but I think he was just talking to his ancestors.

I'm not sure how to address it [spirituality], but it's something that does need to be done. I've taken it on in my own way, and tried to look at the spiritual aspects of mental health, and look at how it can be implemented. However, the others here [staff] can be pretty entrenched and not convinced. (character 31327 to 31636 TOM.TXT)

Asking for and receiving spiritual care appears to be an ongoing occurrence for some people. In Ann's first interview, she became distressed and asked for the tape to be turned off so that she could pray in order to settle herself; and she asked me to help her. I interpreted from that incident that although Ann had thought she had completed the journey, in fact, the asking for spiritual help from me provided me with the insight to understand the ongoing perspective or cyclical nature of the rite of passage. Furthermore, when Rosie was in hospital the first time she

telephoned and asked that I come and see her. Later on in the study, when she needed to be re-admitted, she also phoned me and asked for spiritual help. For Rosie and me, this now appears to be an on-going relationship, in that she will need hospitalisation from time to time and will probably ask me to provide her with spiritual care when this occurs.

# 5. Reflecting to Discern Whether the Needs Have Been Met, and Whether or Not to Ask Again

The period of reflection involves patients asking themselves if their spiritual needs have been met. In Athika's situation of being ill in hospital, her mother came to see her:

Mum came to see me and was shocked at how ill I was. She was working as a secretary for a surgeon at that time, so she went and phoned him up and he came and saw me. He diagnosed peritonitis and told the staff that I was to be transferred to the hospital where he operated....So although I'd already had the original operation; another operation needed to be organised, to drain and clear the peritonitis. I was very ill, and the care was appalling from the nursing staff and it took a while for things to be re-organised and for me to be moved into the different hospital. Nothing positive was happening it was horrendous but I think that the technique of self-talk helped me greatly. I survived that situation. I know more about the technique now than I did then because that was years ago, but it almost seemed instinctive. It was almost like a survival technique because there were so many things going on around me and ah, nothing was happening with relation to my health care. (character 20546 to 21348 ATHIKA.TXT)

The timing of the reflection may depend on the patient's psychophysiological condition at the time, that is, their need to be sufficiently well in order to have the ability to reflect (Hawley, 1996; Hawley & Irurita, 1998). So, it was weeks later before Athika was able to reflect on her experience as to whether or not her spiritual needs were met. As an aside, spiritual care was given to her after she transferred to the next hospital.

On the other hand Tom was able to reflect daily on his condition, as was Sophie:

I like to sit outside each night after I put Alf to bed, and talk to my favourite star. (character 26988 to 27057 SOPHIE.TXT)

Although mentally distressed at times, Rosie felt that she could decide as to whether her needs were met or not. This, she pointed out, is "gut reaction" to how she feels. In her third interview (and after her second hospitalisation during the interviews), Rosie felt her perception at times was not always the same as others, and she wondered if this coloured her ability to say whether or not her spiritual needs were facilitated and met.

Red not only reflected on whether or nor his spiritual needs were met during his illness episode but also on his greatest spiritual need of hope of life after death.

You can't tell me there's the Roman Catholic God or this God or that God. We will all go through the same gate together and you'll probably all be put out to pasture together. And if you don't believe you'll have peace in your time (laughter). (character 21804 to 22002 RED.TXT)

Ann was not able to reflect properly until a couple of months after the birth of her baby (possibly due to her psychophysiological status as mentioned above in relation to Athika).

Sometimes it just takes time and also because I didn't have the time when Mary was first born. For those first few incredibly chaotic weeks I couldn't think about anything else. Usually I'm used to being able to just go along somewhere and sit by the water or go for a walk and think these things through and come to a resolution, but not now. I also took time for reflections well. And having someone listen. Many people when I tried to talk to them would tell me that you have depression. Not many people actually listen and draw someone out. I think I still have spiritual needs arising from Mary's birth. (character 16407 to 16816 ANN.TXT)

To me, Ann is saying that although she is now able to reflect on the situation her spiritual needs have not been resolved and in fact she still has those needs.

#### SUMMARY

This chapter describes the characteristics of a rite of passage undertaken by all participants in this study. In doing so, evidence has been provided that illustrates how individual people's spirituality and spiritual needs can be intertwined with their health problems. The rite of passage was not a pleasant experience for the participants in this study, and was one in which they had no option but to proceed through its five stages: (1) identification of health care problem; (2) realisation of dissonance between normal routines/daily rituals and/or feelings of anxiety or fears; (3) asking for spiritual help/care; (4) receiving or not receiving the care; and (5) reflection. If a spiritual need continued to exist, stages 3, 4, and 5 were undertaken again. The priority placed by the participants on their spiritual needs depended on how many times the rite of passage, or part thereof, had been undertaken, and how strongly they had wanted their needs met.

This rite of passage was not necessarily limited to the period of hospitalisation but, for some participants, was ongoing several months after the event (for example, six months after the birth of Mary, Ann was still processing the reflection stage). I argue that knowing about and understanding the process could help health care professionals appreciate the difficulties involved for the patient in obtaining spiritual help, and the complexity of that passage when the patients are too ill to ask for care. If further research finds this rite of passage to be widespread then, in order to discern the nature of patients'/clients' spiritual needs, health care professionals would need to be mindful of their patient's/client's experiences of this rite of passage.

What is the meaning of this story? These men [and women] have none of our education and yet they stand up and storm the gates of heaven

(Augustine of Hippo, Confessions, 8, viii)

#### SECTION THREE

# WHAT IS NEEDED IN EDUCATION FOR HEALTH CARE PROFESSIONALS TO PROVIDE SPIRITUAL CARE FOR THESE PARTICIPANTS?

Section Three comprises Chapters Ten and Eleven which address the findings of spirituality presented in Chapters Five to Nine. Chapter Ten acknowledges that the findings reflect a postmodern perspective on spirituality. Chapter Eleven discusses appropriate spiritual care for the participants. However, before discussing the final chapters of the thesis, it is worthwhile to evaluate what this research set out to achieve and the outcome to date. In Chapter One, I explained that the purpose of this study was to (1) explore the phenomenon of spirituality for multicultural Western Australians who experienced a health care problem, and (2) propose a set of recommendations for education, in order that nurses and other health care professionals can be made aware of these needs.

After surveying spiritual groups in Western Australia, I conducted a case study of the spiritual needs of eight people with multicultural backgrounds. The study addressed a set of research questions listed in Chapter One.

1. Who and what are the various spiritual groups in Western Australia? What are their histories, beliefs and truths in relation to health care? The data illuminated the diverse nature of these groups and their distinctive concepts of spirituality, from which I formulated subsequently a philosophical framework and research design. This question is addressed in Chapter Two.

Section three 249

What might be an appropriate research methodology for identifying the spiritual needs of culturally diverse Australians? This question is addressed in Chapters Three and Four.

- 3. When a person from a non Judeo-Christian background has a health problem what might be the essence of their spirituality? This question is explored in Chapter Six.
- 4. When considering the essence of spirituality from a diverse multicultural perspective, what might be people's health care related 'spiritual needs'? The answer to this question is addressed in Chapter Seven.
- 5. What are the implications for the education of health care professionals? The answer to this question can be answered only in respect to the eight participants of this study.
- 6. To what extent does the literature on postmodernism reflect and/or support the findings of the research? This question is addressed in the Chapters Ten.
- 7. What recommendations may be made for the education of health care professionals within Western Australia in order to improve their knowledge and understanding of spirituality, and thus improve the spiritual care of the participants of this study? This question is addressed in Chapter Eleven.

Although this study commenced in 1998 from an epistemological viewpoint representative of blurred genres of the Fifth and Sixth Moment of qualitative research, the data generated has seen the emergent research become one of the Seventh Moment (Denzin & Lincoln, 2000). The sacred existential epistemology of the Seventh Moment recognises "nonhierarchical and noncompetitive relationship to the earth, to nature, and to the larger world (p. 1052). Moreover, the flavour "is political" and presumes the acceptance of the concepts of "feminist, communitarian moral ethics stressing the values of empowerment, shared governance, care, solidarity, love, community, and civic transformation (p. 1052)". When I commenced the data analysis in Section Two of the thesis I had not realised the extent to which patients can feel disempowered in the health

care system. Nor had I knowledge and understanding of the use of power by some health care professionals to control many aspects of patients' lives to an extent that their spiritual needs can be denied.

The value of the Seventh Moment epistemology is that it supports those "interactional moments when humans come together in their struggles over love, loss, pain, shame, betrayal and dignity, when self and other are constituted in mutuality (p. 1052)". The participants in this study did talk with me of these interactional moments, especially the betrayal of trust and dignity from health care professionals, their cultural shame, their loss of body image and self esteem, and their need for mutual trust, hope, love and peace. This epistemology avoids "jargon and incomprehensive discourse... and celebrates the local, sacred, the act of constructing meaning". In doing so, I have tried to understand the conditions of spiritual oppression placed upon patients by health care professionals. It is discussion of the findings in relation to postmodern spirituality and health care to bring about change in health care practice that are addressed in this section. The constructed meanings from the participants now (as presented in the findings) become the starting point for recommending ways in which the participants' spiritual needs could be met by health care professionals.

In the Preface of this thesis, I mention that I use the voice of the first person to reflect the sensitivity of the subject of spirituality. Then, in Section Two, I utilise my voice more fully to raise questions, to state my beliefs, and convey my feelings in relation to the care the participants received or did not receive. In Section Three, I remain using my own voice as a co-researcher with the participants, with the epistemology coming more deeply into the Seventh Moment.

In Chapter Three, I explained my use of a modified interpretative phenomenological methodology for Chapters Four to Nine. In Chapters Ten and Eleven, although I still use the same hallmarks of this approach, it isn't as obvious to the reader. Although I have previously discussed the findings, some 'loose ends' remained that I felt needed to be discussed. Because we (the participants and I) live in the postmodern era, questions arise such as:

How much of the findings are representative of postmodernism? Could it be that since some religions are not postmodern in practice and thought, that postmodernism is also not present in the spirituality of the participants?

Thus, in Chapter Ten, I explore the postmodern notions of spirituality arising from the readings of Cupitt and Wilber, and relate these to the findings. It is from this postmodernist perspective that the recommendations for spiritual care for the participants are introduced in Chapter Eleven.

Chapter Eleven recognises the benchmarks of the Australian Council of Health Service standards, which stipulate that individual patient's spiritual needs should be met. These recommendations bring to the reader's attention how, from a health care perspective, the spiritual needs of the participants could be met. This is not the perspective of an ordained minister or priest, or a spiritual elders' perspective, but rather relates directly to the health care professional who is trying to protect the patient's spiritual integrity and meet their spiritual needs while providing treatment or therapy.

#### CHAPTER TEN

# POSTMODERNIST SPIRITUALITY

The Heart of Australia: Uluru (previously named Ayers Rock by white Australians).

Australia is blessed with a symbolic heart, the great red monolith in the center, Uluru. It stands in a motionless, timeless landscape, imagining eternity. Perhaps thrust across the planes by a genesis cataclysm, it stands with majestic strength, a centring place for all to come to: Aborigines traditionally journeyed to this rock refuge and sanctuary in times past. Now it belongs to them again. But now, too, pilgrims, be they reverent travelers or rushing tourists, from all over Australia are able to travel to the Rock.

Peter Malone, The heart of Australia (1988)

#### INTRODUCTION

The aim of this thesis is to identify the spiritual needs of a group of multicultural Australians who experienced a health problem and subsequent treatment by health care professionals. In this chapter, a postmodernist perspective of spirituality is developed and used to interpret the findings of Chapters 2, 5-9.

I became excited and anxious about the findings that had emerged from the research. Excited because I felt that if health care professionals could remember to provide care based on these findings then, although they may appear simplistic, patients' spiritual needs might be met. Anxious because I may have been guilty of what some critics claim as having, "reduced spirituality to basic factors". In addition, I started to have conversations with people about my findings. My supervisor was delighted, and urged me forward.

Others who were affiliated with Christian churches were critical of my findings, in that they thought I had taken a reductionist approach and "diluted their faith" to common factors.

Some of these church people thought that theirs was the only proper and correct religion. They felt threatened and angry that I should say that their spiritual needs might be in common with other people from various religions.

One day when teaching a group of second year nursing students about spirituality, two males became very angry with me and I was told; "but Christianity is the only correct religion, I cannot respect people of those others...I certainly will not try and meet their spiritual needs when they are in hospital".

I realised then the enormous role a spiritual curriculum would need to have to shatter this cultural elitism and religious bigotry.

I also began to wonder what sort of discussion chapter the thesis would have. Would I be able to convince readers that spirituality is as important as religious ideology, and that people's spiritual needs of love, peace, hope and trust need to be facilitated in health care?

As I re-read some of the writings of Peter Malone I gained a sense of hope for postmodernist Australian spirituality (see epigraph at beginning of chapter). Malone catches the spirit of this new symbolic appreciation of the land as it is occurring in the often inarticulate heart.

Searching for the centre, knowing it is there, finding it, journeying back and forth are all aspects of any pilgrimage through a spiritual landscape. Hence the spiritual quest, in its integrity, is both belief and a compassion (for others), and an endless setting out, an awareness of the eternal and a renewed return to the everyday' (Kelly, 1990, p. 123).

It was while reading for this discussion chapter at St Deiniol's Library in Wales (United Kingdom) that the Librarian and Warden (The Rev'd Dr. Peter Francis) recommended I read the writings of Don Cupitt. Cupitt has written many books and articles from a postmodernist perspective on philosophy of religion and spirituality. Later, when I returned to Curtin University, a visiting science education specialist, Dr Nancy Davis, asked me, "Have you read what Wilber has to say about spirituality?". I replied in the negative, as I had not come across his writings. Wilber has written many books from a postmodernist perspective within the range of physics, metaphysical philosophy and transpersonal psychology that relate to spirituality. It was Wilber's (1998) book "The Eye of the Spirit: An Integral Vision for a World Gone Slightly Mad" that resonated with the findings of this study.

Heidegger and Bakhtin, whose writings underpin the methodology of the thesis, are said to be philosophical writers at the beginning of the postmodernist era (Edwards, 1998). As a consequence, it could be assumed the findings will reflect these postmodern philosophies. The research methodology of this study was strongly managed in the style of Van Manen (1990) and Benner (1994), both of whom are acknowledged writers in postmodernist interpretative phenomenology (Madjar & Walton, 1999). Therefore, in this chapter I want to answer the question to what extent does the literature on postmodernism reflect and/or support the findings of the research. When undertaking this study and writing Sections One and Two of the thesis I had not thought of the findings as being either 'modern' or 'postmodern'. So, to give the findings the explanatory power that I am seeking I focus on this issue in this chapter.

The first section of this chapter discusses the methodology I utilise for the remainder of the chapter and the next. The second section discusses Watson's postmodern perspective of 'caring' in health care, followed by Cupitt's argument that postmodern deconstruction has occurred to spirituality. The

third section, discusses the findings of the study in relation to some of the common themes of postmodernist spirituality in order to validate the emergent models and concepts of this thesis. The three main findings that are discussed are: (a) the emergent model of spirituality (see Chapter Two); (b) spiritual needs of mutual trust, hope, love and peace (see Chapter Six); and (c) the desired levels of spiritual care, named and described as 'acknowledgement', 'empathy', and 'valuing' (see Chapter Seven). Finally, the downside of postmodernism, or deconstruction, is briefly discussed in order to demonstrate that postmodernism is not without its critics and problems.

### CATCHING APPLES

I am playing the game of being blindfolded and bending over a bucket of water, I need to grasp an apple in my mouth, and deposit it on the ground beside the bucket, without using my hands or arms. The winner of the game is the person that has retrieved the most apples from the bucket in a set period of time. How do I grapple with the wet slippery apples (of postmodernist spirituality) in a bucket of phenomenological water?

Being phenomenological I need to state that my interpretation of these written works will reflect my own perception. That is, there is no such thing as a value free interpretation, and at the same time I want to find the essence of postmodernist spirituality in relation to the findings of Chapters Five to Nine.

The way that I will 'catch the apples' from the bucket of water is probably quite different (due to my previous skill in playing this game) to the way another player might play the game. Therefore, this part of the chapter is primarily concerned with raising the methodology I utilise when exploring the participants' stories in relation to what could be termed 'postmodernist spirituality'. My intention is not to develop a theory of postmodernist spirituality, but instead to use some of the available literature on the subject to illuminate the findings.

The major difference you will notice in the writing of this chapter and the next is that I start to use my authorial voice more strongly than in Chapters Five to Nine. My views are now more powerful as I realise that the findings of this study will be strongly represented in my own future teaching of law, ethics and spirituality. I will own my beliefs when lecturing and talking to students about the health care of minority groups and will be working constructively towards improving the spiritual health care of multicultural Australians.

My authorial voice is that of a 'vertically challenged', middle-aged woman who has extensive nursing experience both in Australia and overseas (37 years), coupled with university lecturer (15 years), spiritual director (8 years), hospital chaplain (6 years) and the life experiences of lover, wife, mother, grandmother, friend, and foe! When I speak of "my experience" I will state where that experience has originated from but, at the same time, I realise that life is not a series of compartmental boxes. At my age and maturity there are no separate boxes, instead, my views are rather like an integrated 'whole' container.

In Chapter Three, I explained my use of a modified interpretative phenomenological methodology for Chapters Five to Nine. In Chapters Ten and Eleven, although I still use the same hallmarks of this approach, it isn't as obvious. Although, the values of Heiddegger and Bakhtin continue to influence my interpretations, I explore the additional values of the Seventh Moment of qualitative research (Denzin & Lincoln, 2000). Thus, the epistemology supports and validates the shared meanings that have arisen between the participants and myself when they shared with me their stories (of betrayal of trust and dignity by health care professionals and others). My writing is without esoteric flowery phases and incomprehensive discourse sometimes seen in spiritual literature (Cupitt, 1999).

My personal voice is emphasised in my way of 'catching apples'. That is, it is peculiar to me and is possibly different from the voice of another researcher. In this way, I blend reflections on my own lived experience with a reconsideration of the findings of the study from a postmodernist perspective. Thus, my epistemology is 'postmodern' in that it allows me to raise questions of the literature at the same time as raising questions from the data (Lincoln & Denzin, 2001).

#### POSTMODERN CARE

Since we live in the postmodernist age surely the participants' responses have incorporated some notions of postmodernist life?

The term 'postmodernism' is difficult to define because, in many ways, it is a misnomer (Edwards, 1998). However, according to Watson (1997), the term is often employed to cover a major transformation that has taken place in Western societies. That is, postmodernism is a consequence of the failure of modernism, which assumed a logical and ordered universe, whose laws could be uncovered by science. Acceptance of the modernism ideology disappeared with the wars (World War 1 and 2), and global environmental, social changes, poverty, and health issues. This loss of belief in the modernist enterprise has brought about the postmodern response. This response includes a radical rejection of the possibility of rational and constant knowledge and a celebration of the diverse and ephemeral; on the one hand, a critical recognition of the limits and excesses of modernism, yet a willingness to continue to seek understanding without the certainties of modernist assumptions. Watson (1997) characterised the postmodernist position for caring in health care as "not on knowledge for its own sake, but rather, emphasise context, paradox, process and the mysteries of 'being in the world" (p.16). That is, the provision of an all-encompassing approach to care (Watson, 1985; 1988). In literature this type of care is commonly termed "holistic", that is, patient or client care is not segmented but regarded as a whole. In this perspective, spiritual care is regarded as part of integral care and is not separate or divorced from physical and mental treatment.

If health care has postmodern aspects can the same be said for spirituality?

# POSTMODERNIST PERSPECTIVE OF SPIRITUALITY

In order to answer this question and explore a postmodernist perspective on spirituality, it would be wise at this point to re-address the definitions used for spirituality in this thesis; to think again, and modify the perspective if necessary. In order to do this, a recap of the historical nature of spirituality is given, followed by the notions of spiritual postmodernism. Then, I will discuss these in relation to the main findings of Chapters 2,5-8.

For most of the Judeo-Christian era, spirituality has been an esoteric concept viewed with suspicion or anxiety (Smart, 1971). In the West, in the post-Renaissance environment of the university, spirituality became a subject of philosophical debate and logical argumentation, a rather heady academic analysis of the human desire for God. In the seventeenth century, the term 'spirituality' referred exclusively to the interior life of Christians, and often was expressed in bizarre ascetic devotional practices. By the eighteenth century, it referred largely to the perfection associated with mystical states, unattainable by the majority of people. Then, in the eighteenth and nineteenth centuries, spirituality assumed a certain academic status under the rubrics of ethics or moral theology. Finally, in today's postmodernist period, spirituality is viewed as global in orientation, reflecting contemporary life, and yet personal and branded with each person's own understanding (Cupitt, 1998).

According to Cupitt (1989;1998), a postmodernist approach to spirituality has occurred. He argues that this is demonstrated by the transition from the realist to a non-realist approach to spirituality and religion, the impulse to get rid of

the old two-level account of reality (i.e., of the ruling god above and inferior humans below), the desire to let go of the traditional infinite divine (i.e., the white Anglo-Celtic Christian God who controls and rules the world with fear and punishment), and a greater equality in sharing the new notions of spirituality so that no single human community has a privileged relationship. Cupitt's perspective helps to explain the anger I had encountered from various quarters (Lucida font second page of this chapter) which disapproved of the findings of this study. This feeling may have arisen from an inability to find personal agreement with any aspect of the findings, especially amongst those who have not grown into a postmodernist perspective of spirituality and who may not be open to sharing new notions which recognise that there is no single privileged position, either in culture or religion.

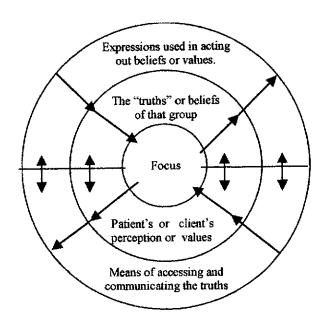
It is perhaps for this reason that I believe (as a nurse, chaplain, and university lecturer in nursing ethics) that the teaching of a postmodernist perspective of spirituality to health care professionals is important, so that cultural elitism and religious bigotry is shattered; and to go beyond 'the whiteness'.

According to Cupitt (1998), postmodern spirituality is affected by globalisation (of the world) that has occurred, and at the same time reflected in peoples' personal perspective of spirituality. Cupitt argues, that in this way postmodern spirituality is part of peoples' daily lives, and it is not something that is institutionalised within the churches. In my own way of catching apples, I have chosen to adopt the four common themes of postmodern spirituality (as mentioned earlier in this chapter with the three main findings of this study. That is, the themes of 1) the transition from realist to non-realist religious accounts, 2) the impulse to get rid of the old two-level account of reality, 3) the desire to let go of traditional infinite divine attributes, and 4) a greater equality in sharing the new notions of spirituality so that no single community has a privileged relationship, with the emergent model of spirituality, spiritual needs, and desired level of spiritual care.

# **Emergent Model of Spirituality**

A model of spirituality was developed from the data supplied by the various spiritual groups in Western Australia (see Chapter Two and Fig 4). I argued that it could be used to understand patients' and clients' spirituality, and also to enable students and health care professionals to understand better their own spirituality. Now we can see that the model is supported by Cupitt's argument that postmodern spirituality reflects contemporary life, and is personal, with people having their own spiritual understandings. That is, since the data were derived from the various spiritual groups in Western Australia and generated the themes and questions incorporated into the model, the model represents a contemporary perspective of spirituality amongst the multicultural population across the state. Likewise, the model allows for personal expressions of belief (patients' or clients' perspective of values), which again is consistent with Cupitt's criterion of postmodern spirituality that people will have their own spiritual understandings.

Figure 4: Emergent Model of Patient/Client Spirituality



# Spiritual Needs of Mutual Trust, Hope, Love and Peace

In Chapters 5 and 6, we accepted the assumption that the participants had knowledge of health care and spirituality arising from their subjective experiences. According to Wilber (1998, p. 4), people know something only in an 'interior', or subjective and immediate, way. That is, although a person might attempt to think of consciousness as nothing but information travelling through the nervous system, nonetheless that idea itself is only known to the person as something that occurs; that is, he or she does not experience the transition of the thoughts through the nervous system. When a person introspects, they are not aware of the physiological or psychological processes that are occurring, but are aware instead of a world of images and desires, hungers, pains, thoughts and ideas, wishes, and needs, etc. We know these interior data in an immediate and direct fashion: they are simply given to us, as they are there.

These interior data might indeed be part of extensive chains of mediated events, but at the moment of introspection that does not matter; for they are simply interior states given for awareness, immediately the person takes the time to look (Wilber, 1998). When the participants in this study reflected on their experiences, and communicated their information as data for this study, they constituted behaviours that Wilber (1998) describes as "from the interior of an individual, at the site of consciousness itself (p. 30)". This way of knowing correlates to the postmodern concept of 'non-rationalist traditional knowledge', which is personal, nonstatic and transitory (Watson, 1997). That is, there is no single way of knowledge development, nor a single idea of truth or meaning of reality. In this way, we can say that the participants' expressions of their spiritual needs were postmodern.

For the participants in this study, their spiritual needs were identified as mutual trust, hope, peace and love. These spiritual needs demonstrate a transition from the realist to a non-realist expression of spirituality, in that

were expressed as intangible and inseparable from their physical and mental needs at the time. They also recognise Cupitt's postmodern theme of getting rid of the old two-level account of reality (a world below and ruling and controlling god/s above) That is, the spirituality of each of the eight participants was not of two levels, but rather it was a personal knowing within themselves. Likewise, not all the participants (e.g., Athika, Geoff, Red, Scarlet, Sophie, and Tom) recognised the 'traditional infinite divine image', instead it was a welcoming mystery of our birth and death, and as Kelly (1990) argues "the silence in which we belong, the silence in which every voice is heard" (p. 132).

The spiritual need of mutual trust was very important to the participants because it recognised the equal balance of power between health care professional and participant, and the manner in which the power is manifested in communication and touch. Wilber (1998) was 'at pain' to emphasise equality of all people, with no single section of the community having greater claim to true knowledge than others. Cupitt (1984; 1991; 1998) also argued that no single group of people or religion had greater knowledge than another, that each is striving to come to know their spirit in their own way. In this way, the spiritual need of mutual trust experienced by the participants reflects postmodern spirituality.

The spiritual need for hope was important to the participants because it represented a desire for something to occur that was associated with their own meaning in life, such as their loved ones and family. In addition, the participants felt that even if they were dying, hope would remain important to them because although they would not get well again, hope could be found in choices and goals to achieve while waiting for death to occur. According to Wilber (1998), modernity flattened the entire 'Great Nest of Being' into nothing but systems of material bodies. That is, gone was the mind, the soul and the spirit, and in their place scientific materialism came into force and prevailed. But the participants in this study wanted the spirit and hope

returned to their lives, which demonstrates the shift from modernity to postmodernity. According to the participant Athika, meditation can give hope to cancer sufferers. Similarly, Scarlet believed that artifacts, such as the lucky charms she made for Romanies, can give hope.

The spiritual need of love was related to the participants' meaning in life, in that they felt the need to love another. The spiritual need of love was related also to their spirituality in that the giving of love to another person gave them a good feeling in their inner being of spirituality. This spiritual need encompasses the core values of the world's great wisdom traditions, from Taoism to Buddhism, from Hinduism to Neoplatonism, from Sufism to Christian mysticism, in that to be truly human is to love another, the same as one loves oneself (Cupitt, 1982; Watson, 1988; Wilber, 1998).

Peace, for the participants in this study, was the feeling of harmony within themselves. The manner in which this can be achieved is through contemplation and reflection. Some participants prayed and meditated as well in order to achieve a sense of peace. The participants' knowledge of spirituality, and in particular that of peace, reflects O'Murchu's (1996) concept of postmodernist spirituality. That is, spirituality is a mode of thought and feeling that can be found in any human experience, and which upon reflection may prompt encounter with the person's perception of his or her basis of existence. All the participants in this study reflected upon their own lives in order to give them their own perspective of peace. Although Ann, Rosie, and Tom did make mention of their church's doctrine through prayer, their own personal perception and experience of life seemed to drive or assist their perspective of spirituality.

# Desired Levels of Spiritual Care

Cupitt's postmodern characteristics of spirituality (the transition from realist to non-realist accounts, the impulse to get rid of the two-level account of reality, the desire to let go of traditional infinitive divine attributes, and greater equality in sharing new notions of spirituality so that no single particular human community has a privileged relationship) can also be illustrated in the desired levels of spiritual care (i.e., Acknowledgement, Empathy, Valuing; see Chapter 8) which were derived uniquely from the attributes or characteristics reflected in the participants' data. This data portrayed their difficulty in trying to describe their spirituality, their god/s or divine being (if they believed in one), and indicated their desire for spiritual care that was no more or no less than what others would receive.

According to Wilber (1998), postmodernist people can engage in various forms of spirituality through a range of cultural activities. In doing so, these activities enable people to transform themselves in ways that enhance their participation in their source of ultimacy. It is essential, therefore, that they be understood as important vehicles of spiritual life in today's society. That is, health care professionals should respect and value the various forms of spirituality that patients may have and endeavour to incorporate these into health care (this is further discussed in Chapter 11).

Western society expects people to be autonomous beings who make choices and decisions (Hawley, 1997). However, orthodox spirituality (as represented by some religious churches and spiritual groups) still expects people to be unquestioning of man-made beliefs in respect of the religious doctrine of that particular group (Cupitt, 1989). This is discordant with this study, which found participants to be critical and questioning of health care and spirituality. Also, irrespective of their belief and religious doctrines, all participants, whether they were Anglican, Buddhist, Roman Catholic, Humanist, Quaker, or Socialist, wanted the same spiritual needs of love, trust, peace and hope to be met, and the same desired levels of spiritual care.

#### The Down Side to Postmodern Health Care

According to Watson (1997), the downside to a postmodern perspective on health care is the deconstruction that has occurred. While postmodern life has

been liberating and given birth to new notions of reality and new quests for meaning of the human condition, socially it has led to human and environmental confusion and even moral void. Yet, it has been within the framework of deconstruction that reconstruction has emerged. For many writers, such as Cupitt, Watson, and Wilber, this reconstruction has involved a new quest for meaning in the cosmos. In nursing, it has led to a new transformative paradigm of caring in the human health experience. Watson (1997) argues that this new paradigm of caring emerged out of postmodern thought identified as 'moral foundation nursing' and an imperative of human caring with respect to the human health experience. I believe (as a chaplain and nurse), that it is within this new concept of caring that human encounter of engaging with the indelible stories of people, caring moments of connecting though eyes, touch, sound, and space, that caring for a person's spirit can occur. To Watson (1997), these engaging moments of caring touch the human spirit and provide a reflection into human existence - the personal and the profound, serving as mirror and image into humanity.

#### CODA

'Catching apples' is the term I have used to describe my interpretation of the findings in relation to Cupitt's postmodern themes of spirituality. Another researcher could follow different lines of questioning and write other points of view in this discussion. To me, spirituality is not a subject that can be pigeonholed into one box or an academic department of a university. In fact, the findings of this research have formed my fundamental conviction that spirituality is a universal phenomenon, across time and culture, predating the formal religions we know today by many thousands of years. In this way, the postmodernist perspective of spirituality is an innate human disposition to the mystery and ultimate understanding/meaning in life, and is therefore different for each person. Although I have used the postmodernist writings of Cupitt, Watson, and Wilber to discuss the findings, I do not intend that this interpretation should constitute a new theory of spirituality. Instead, these

findings suggest the need for those who teach health care professionals to update their conception of spirituality so that it more accurately speaks to contemporary society and allows a range of largely unrecognised spiritual needs, particularly amongst multicultural Australians, to be met in ways that are discussed in Chapter Eleven.

#### CHAPTER ELEVEN

# EDUCATING IN THE UNTAUGHT SUBJECT OF SPIRITUALITY

At first people refuse to believe that a strange new thing can be done, then they begin to hope it can't be done, then they see it done - then it is done and all the world wonders why it was not done centuries before.

The Secret Garden by Frances Hodgson Burnett, 1986

#### INTRODUCTION

The purpose of this chapter is to develop recommendations arising from the key empirical and theoretical findings of the study, namely, the identification of the participants' postmodernist perspective on spirituality and of their health care related needs. The title of the chapter, "Educating in the Untaught Subject of Spirituality", brings to mind the need for the health care professionals who cared for the participants to be educated in the subject. Evidence obtained from the eight participants with experience as patients in Western Australian hospitals suggests that health care professionals might not understand (a) the importance of spirituality for some of their patients, especially those with a non-Judeo Christian background, and (b) how spiritual needs may have greater value than patients' physical health. These findings form the conceptual framework for developing the recommendations of the study.

In Chapter One it was argued that:

- (1) very little research has been conducted into the subject of health care related spirituality;
- (2) because immigration to Australia between 1902-1975 was restricted by the 'White Australia Policy' certain cultural and spiritual groups were excluded;
- (3) since the abolition of this policy various racial and cultural groups have taken up residence in Australia (e.g., Indian, Chinese, Burmese, African, Indonesian, Laotians, Vietnamese, and those from Middle and Eastern Europe);
- (4) however, the long period of Anglo-Celtic Judeo-Christian traditions has created a climate of cultural elitism favouring the spiritual needs of this dominant cultural group; and
- (5) the introduction of the ACHS standards that require nurses and other health care professionals to meet individual patient's spiritual needs has raised the urgency of identifying the extant spiritual needs of the multicultural Australian population.

In Chapter Ten, I discussed the perspective of postmodernist spirituality in relation to the model of spirituality, spiritual needs, and the desired levels of spiritual care derived from the analyses in Chapters 2-9. In this chapter, these key findings will be used to formulate an emergent postmodern perspective on spirituality and related recommendations for health care. The first section defines the emergent postmodern perspective of spirituality. The second discusses how the health care professionals treating the participants in this study could have fulfilled their spiritual needs (given some of the idiosyncratic circumstances). The third section raises the possibility that participants' spiritual needs may be incompatible with their proposed health care treatment. The fourth section outlines a suggested approach for spiritual care education of future health care professionals (with patients of similar cultural backgrounds and spiritual needs). The final section describes what I have learnt from the research undertaken, especially the journey and the changing nature of the study.

#### NEW PERSPECTIVE ON SPIRITUALITY

Emerging from the empirical findings of the study and from a theoretical consideration of postmodernist perspectives of spirituality, a new definition of the phenomenon of spirituality has developed for me. My proposed definition of spirituality from a postmodernist perspective is thus:

Spirituality is an innate human disposition to mystery and meaning of life in which there is "otherness". When considering the phenomenon, health care professionals need to recognise the core components of spirituality, that is, the focus, beliefs and truths, manifestations, and means by which people will access their focus. This ultimate concern sensitises people to the possibility that authentic spirituality is not necessarily confined to the life of theological institutions or churches, or to a single perspective Instead, it is that which is contained in the responses of the participants, that is, their personal way of knowing about their inner being, creation and understanding of its deepest mystery that incorporates each person's creative reality and their ultimate significance.

Spirituality in this way becomes a type or mode of human thought and feeling that reflects each person's understanding of their world and can be found in many different human experiences. Awareness of their spirit could prompt an encounter with the ultimate ground of existence or "otherness". (i.e., their spirit), with each person having his or her own perspective. Each participant needed specific spiritual care by the health care professionals treating them to meet their needs of mutual trust, hope, love and peace.

The emergent phenomenon of spirituality, from this postmodernist perspective, will now be used to formulate recommendations for health care professionals in order to provide spiritual care to the participants of this study.

# PROVIDING SPIRITUAL CARE FOR THE PARTICIPANTS IN THIS STUDY

There are two broad recommendations arising from (1) the apparent deficit knowledge base of health care professionals, which they seem to bring to their practice, and (2) how the education of health care professionals can be improved to include a more comprehensive knowledge base. These two issues are not mutually exclusive and could be met by implementing an education program.

It was apparent in this study that the participants' spiritual needs were not taken seriously by health care professionals or the organisations for which they worked. This finding gives rise to the need for these health care professionals to be educated about spirituality, the need to provide such care, and how to do so. In considering the characteristics of spirituality and the various spiritual needs identified in this study, it appears that the health care professional may need to understand a postmodernist view of spirituality, desired levels of spiritual care, and how to meet specific spiritual needs.

# Health Care Professionals Needing to Understand the Phenomenon of Spirituality

In discussing the Model of Spirituality in Chapter Ten, I argued that it could be used by health care professionals to understand their patients'/clients' spirituality and also to understand their own spirituality. Such dual qualities may allow the model to be used to help the health care professional understand the concept of postmodern spirituality, not only for the benefit of the patient/client but also for their own knowledge of health.

In trying to understand the patient's/client's idea of spirituality, it would be necessary to be aware of issues that may affect the context of that care (such as personal circumstances, socio-economic status, availability of health care and access to their choice of spiritual group). For example, in respect to personal circumstance, the participants in this study were literate, educated, spoke English

fluently, and had the ability to be both critical of spiritual organisations and hospitals and reflect on situations and life experiences (see Appendix 17 for the participants' social and contextual information). None of the participants was "penniless" or living on the streets. However, socio-economic status can have an effect on peoples' health-care. This was illustrated to me when I sent a poster to the Men's Meeting Place in Kwinana (a low socio-economic area) seeking participants for this study. There was no response. On phoning the coordinator of the centre, I was told that that the attending clientele were more interested in having their basic needs (of shelter and food) met before other needs, such as emotional and spiritual. This situation correlates well with Maslow's hierarchy of needs which states that people want their basic needs of food, water and shelter met first before higher needs of love and self-esteem (Black & Matassarin-Jacobs, 1993).

Hospitals have an obligation to supply spiritual care to all patients/clients, not only to those within the Judeo-Christian tradition. Although the participants in this study were literate and educated, at times they had problems with not having sufficient information, or with trying to get health care professionals to listen to them and give them choices.

Communication skills and the use of touch may need to be incorporated into the practice of these health care professionals; with an emphasis on how these two behaviours can help meet the spiritual needs of their patient/client. When I was talking with the participants about how their spiritual needs might have been met, they mentioned both communication and touch. I was taken aback to learn that they did not realise that communication and touch were already being taught to health care professionals! For example, when I asked Ann at her third interview how she felt her care could have been improved, she replied:

I believe it would be important in the education of health care professionals that they are taught about communication and touch, the different dimensions and perspectives. When I was going into the operating room, if there had been someone that could have listened to my fears, and talked with me, that would have really helped. (Character 31221 to 31500 ANN.TXT)

Scarlet also mentioned the importance of communication and touch.

Taking time to listen and reaching out to touch are very important. These are the ways in which a person knows that you respect and care for their spirit. Character 6986 to 7111 SCARLET.TXT)

Athika and Tom mentioned the role of someone in the health care team being able to say, "let's stop, think what is happening", and perhaps re-plan the care to suit the patient's spirituality.

There is a need for someone to say, hang on a minute, there is someone here with a need that is more than physical.... There is a need to look at the bigger picture. (character 31505 to 31636 TOM.TXT)

#### Sophie with her wisdom said:

The ability of them [health care professionals] to be able to reach out and show the patients that they care and understand their predicament. Then, if they could assist the patient to use their spirituality. Like to value the patient's spirituality. (character 23252 to 23462 SOPHIE.TXT)

Communication is not unique to health care; it exists in any field that shares concern with the humanistic problems of choice, value and understanding. For me, as both a nurse and chaplain, if I was the health care professional looking after one of this study's participants in hospital and was trying to communicate in postmodernist language, I would use the word "life" in places where I may have previously used "god" (Cupitt, 1998). If I wanted to find out a person's spirituality, I would be inclined to ask them, "What is important in your life for you?" This question would be satisfactory for the very religious person, as they could reply, "My relationship with God or Allah" (or whatever god is for that person). On the other hand, the same question would be satisfactory for a person like Red, who would probably answer with something like, "My wife and family, and the environment....You know we are bloody lucky for the country we live in." Again, I would know what he meant by his spirituality and also his needs, in that his family and the outside world are very important to him. In this way, I could help facilitate his spiritual needs by knowing what was important to him in life.

Listening is a crucial skill in communication and, importantly, represents the most effective way to demonstrate an empathic attitude in health care. Active listening means trying to hear the significance of a person's remarks. The health care professional needs to be able to take in a lot of discourse in real time, mentally tag items of interest, and compare and contrast them with what is said later. In order to communicate well with participants of this study, the health care professional would need to listen for possible deep meaning in what is being said, what may have been meant and what a remark might mean outside the immediate context. For example, asking a person about their garden, allows that person's subconscious mind to communicate what he/she may be having difficulties with in their life and which may have a spiritual implication (Savage, 1987). This is not an easy task and requires highly developed skill, one that needs practice and educational assessment. As a nurse or chaplain, I do not ask a patient directly if they are scared of dying. Rather, I may ask them a general question about their garden. In their response there may be a metaphor related to life or death, which will alert me to their true feelings.

In providing spiritual care for these eight participants, understanding of the phenomenon of spirituality and the development of communication skills may assist the health care professional. It is in asking questions and listening to the answers that the health care professional can interpret hidden meanings of what patients/clients might want in relation to their spiritual needs.

## Meeting Spiritual Needs

The needs of mutual trust, hope, love and peace were important to the participants of this study. The health care professional could communicate that s/he trusts the patient/client by demonstrating respect in all aspects of care. This would include:

- respecting the patient's/client's opinion,
- giving the patient/client choice,
- allowing sufficient time for decision making,
- asking the patient/client whether s/he has any questions they wish to ask, and helping him/her to express them.

In meeting the need for hope, the health care professional could incorporate the patient's/client's wishes. Question prompts, such as, 'Does the patient/client have some urgent want that needs to be attended to, so that anxiety, fear, or worry can be decreased?', can be used to guide the health care professional's practice. Then, after anxiety and fears have been largely allayed, the patient/client could be encouraged to make choices about how to obtain hope in relation to their particular meaning and purpose in life. This could be something quite simple, such as in the case of Geoff who wished to go outside the hospital building into the grounds so that he could hug a tree.

In meeting the need for love, the health care professional could encourage patients/clients to maintain their relationships with others by providing quality time for visitation. The health care professional would need also to allow for the expression of emotion between the patient/client and visitor. In my experience, many health care professionals intervene unnecessarily (between patient and visitors) to make the situation 'right' by ensuring that there is no crying, no anger, no regret expressed. However, allowing patients/clients to express their true feelings with either the visitor or the health care professional could enable expression of their spiritual needs.

In meeting the need for peace, the health care professional could remember that peace can be obtained though the expression of feelings (either to the inner self or to someone else), contemplation, reflection, and meditation. The health care professional could allow sufficient time when planning care and could encourage expression of feelings, and also contemplation, reflection or meditation. Reflection can be facilitated by asking patients/clients what they think and feel about their diagnosis and treatment or, alternatively, how they feel about not being able to do things that they could do before (if their physical movements and actions are now restricted). Expressing their feelings and reflecting on them may allow patients/clients to resolve inner feelings about their meaning of life and, thus, to find peace. The health care professional could also encourage meditation,

or teach this if the patient/client wishes. If the health care professional can't do this teaching, they could refer the patient/client to someone who can, so that they can relax their body and mind and gain an inner peace.

However, the health care professional would need to remember that, at times, patients/clients may be too ill to know their own spiritual needs. For example, Ann and Athika were both too ill at one stage to have awareness of their own spiritual needs. In this situation the patient/client may have limited ability to gain peace. In cases such as that of Ann and Athika, the health care professional could teach the patient/client how to meditate by saying a mantra or prayer that was personal to them (this practice would constitute their particular way of finding peace).

Also of benefit to the health care professional would be the knowledge and understanding of the different levels of spiritual care, and how these could be incorporated into his/her practice.

### Desired Levels of Spiritual Care

The eight participants in this study spoke of desired levels of spiritual care that they would have liked to have received during their treatment. Providing these levels of spiritual care would involve the health care professional in (i) acknowledging the spiritual nature of the patient/client (Acknowledgement); (ii) spending time with the patient/client, listening and talking things through with him/her (Empathy); and allowing the patient/client to engage in spiritual behaviours if they so wished (Valuing). In providing any aspect of spiritual care trying to understand the patients'/clients' spirituality, fulfilling their spiritual needs, or providing desired levels of care - the health care professional will come to know that some aspects overlap and intertwine with others. The extent to which the health care professional provides these aspects of spiritual care may be a matter of personal choice, or it may depend on the philosophy of the organisation in which they are employed, or on the condition and/or diagnosis of the particular patient/client at the time.

### Acknowledgement

This aspect of spiritual care would involve the health care professional in demonstrating his/her awareness of the patient's/client's spiritual nature, either through verbal or nonverbal communication. Providing acknowledgment would depend on the type of treatment the patient/client was to receive at the time. As the participants in this study gained meaning of life and purpose in life from family and friends, the health care professional would need to encourage patients/clients to maintain their relationships with others. In this way, the close contact and communication through discussion of their illness with loved ones who have similar values and beliefs may enable the patient/client to construct a meaning of their situation and receive necessary support.

### **Empathy**

When providing this level of spiritual care, the health care professional would need to include those interventions described in Acknowledgment, as well as listening carefully to the patient/client and replying with empathy. This would allow the patient/client to verbalise any factors/issues/problems that could possibly contribute to his/her spiritual distress. While assisting the patient/client to express his/her spirituality and related needs, the health care professional may need to facilitate accompanying expressions of anger, fear, anxiety, and tales of abuse or self-destructive behaviours. Thus, the health care professional would need to have counselling skills and, perhaps also, to have access to debriefing sessions. In this study, not all of the participants had the need to express heart-rending emotions and stories. However, it is important that the health care professional is mindful not only of the possibility of this occurring, but that it is important to allow empathically such expressions.

#### Valuing

Practising the spiritual care of Valuing would involve the health care professional in not only providing the interventions of Acknowledgment and Empathy, but also facilitating the patient's/client's spiritual behaviour (e.g., reflection, meditation), manifestations and rituals (e.g., prayer times, services - sometimes

named 'Offices'), and display of artefacts. In valuing the patient's/client's spirituality, health care professionals may find that they holds beliefs and truths on spirituality that differ markedly from those of the patient/client. In this situation, the health care professional would need to respect the context in which the patient's/client's need or manifestation occurs. For example, from my experience as a chaplain, I have noticed that when I have given a person the Last Rites, they then can experience a level of peace and comfort, which cannot be attained in any other way. Quite often, there can be an improvement in the person's physical condition thereby enabling s/he to say their final good byes prior to slipping into unconsciousness and then death. In these circumstances, although the health care professional may not believe in such truths, they would need to facilitate the patient's/client's desires in order to demonstrate respect and valuing in caring.

By asking, "what is it that you would like to do?" the health care professional would allow the patient/client to request particular spiritual behaviours. If the patient/client is Buddhist the patient/client may ask if they could set up a small shrine (an icon/ornament of Buddha, candle, and flowers) on the bedside table. If the patient/client says that s/he normally prays or meditates at a specific time each day at home, the health care professional could ensure that the patient/client is able to continue this practice while in hospital. If however, the patient/client needed to attend clinics on a daily basis, then the health care professional could negotiate a suitable time for treatment. For example, when Rosie was discharged from hospital as an in-patient, she needed to return daily for the following week so that her mental state could be accurately monitored. In these ways, not only would the health care professional be valuing the patient's/client's expression of their own spirituality but, at the same, s/he would be facilitating the realisation of desires which offer trust, hope, peace and love.

Another way in which the health care professional can be involved in valuing the patient/client is to 'be with the person' (that is, share nonverbal spiritual moments/time together) and read or pray with or for him/her. For example, Ann wanted prayer and/or reassurance prior to having her operation – in this scenario

the health care professional could have prayed with Ann, or asked the chaplain to come and pray with her. Such a positive response would have valued her spiritual nature and fulfilled the highest level of care she desired. As a health care professional, Athika was able to offer such behaviours by 'being with a person' and meditating on his behalf:

I was working in a rehabilitation and extended care unit of a private hospital. One day a man was transferred from another hospital, suffering from a type of cancer, semi conscious and not able to do anything for himself. He was being nursed in a private room and I used to sit with him and at other times I would use some forms of meditation techniques for a couple of periods every day; not really expecting anything to happen to him, but to just make the situation more peaceful for him.

He had a wife who had already organised his funeral (even though he had not died) and would talk to him about how much the funeral was going to cost, the repayments and these sorts of things and what the coffin was like! I felt so sorry for this man. He also had a daughter with a severe psychiatric disturbance who, when she came to see him, spent most of the time outside, being very noisy and running up and down the verandahs outside his room having little manic episodes. So there he was, a still presence in the middle of all this chaos going around him. When the wife and daughter were not around I would go into his room and meditate with him, so that he could feel some peace and comfort in the chaos of his death.

After two weeks, he suddenly started opening his eyes and talking to me. So I asked him, did he want to sit on the side of the bed. The end of this story was that every day I increased his activities, started him off on an exercise program, and gradually introduced new dietary components into his life. Eventually he was up and walking around the unit. These activities were in total defiance of all the x-rays and tests that we had sitting in front of us. You see when you care for a patient's spirit you offer them peace and hope. (ATHIKA.TXT peace, char 30864 to 32000)

In the above, I have recommended various ways, through enhanced knowledge and understanding of the phenomenon of spirituality, that health care professionals could provide better care for the participants of this study. Perhaps these approaches could be considered for other patients/clients undergoing health care, especially those with cultural backgrounds similar to the participants of this study and who experience similar social contexts?

Nevertheless, in attempting to provide care, the health care professional could be asked to allow a spiritual behaviour which they believe would not be in the best interest of the patient/client. For example, some years ago I was working as a nurse in an intensive care unit looking after a man who had undergone extensive surgery. He was a Seventh Day Adventist, and therefore did not drink the hospital tea and coffee (as it is stimulant and sinful). His wife asked permission to bring a thermos of herbal tea for him and permission was granted. The patient started drinking the herbal tea, which caused him to produce copious amounts of urine, which in turn resulted in the sudden deterioration of his already precarious physiological status. Clearly, then, the allowing of spiritual behaviours needs to be tempered with good health care practice.

When should a health care professional allow or not allow spiritual behaviours to be practiced?

What happens when spiritual beliefs are incompatible with proposed treatment?

# Incompatibility of Proposed Health Treatment and Patients' Spiritual Beliefs

At some time during his/her career, the health care professional may have patients/clients who face incompatibility between proposed health treatment and their spiritual beliefs. This was illustrated to me when I requested documentation from the various spiritual groups in Western Australia (see Chapter Two), and various incidents came to my notice that could cause major incompatibility between a patient's/client's spiritual beliefs and the treatment proposed by a health care professional. Examples include:

 No health care treatment should be given unless it is absolutely needed (such as repairing a fractured leg) for Christian Science members, but no treatment for those diseases, which they believe can be healed spiritually.

- No extraordinary care should be given (such as resuscitation), for Orthodox Jew, Buddhist, Hindu, Muslim, Pagan Romany, some Roman Catholic orders, and some Aborigine.
- 3. No blood transfusion and/or haemopoetic stem cell transplantation should be given for Jehovah Witnesses, and some people listed in 2.
- 4. No organ transplantations for Orthodox Jew, Buddhist, Hindu, Muslim, Jehovah Witnesses, Christian Science, and some Aborigine.
- 5. No contraception or aids to enhance human reproduction (such as artificial insemination and various invitro fertilization (IVF) and other techniques) for Orthodox Jew, Dutch Free Reform, Exclusive Brethren, some Roman Catholic.
- 6. Dietary restrictions for Jew, Buddhist, Hindu, Muslim, Jehovah Witnesses, Church of Latter Day Saints, Christian Science, Exclusive Brethren, and some Protestant religions ban alcohol and spices.
- Clothing and wearing of important artifacts for Jew, Buddhist, Hindu,
   Muslim, Sikh, Exclusive Brethren, and some Aborigine.
- 8. Non urgent treatment not to be given or done on the Sabbath/or equivalent for Jew, Buddhist, Hindu, Muslim, Jehovah Witnesses, Church of Latter Day Saints, Christian Science, Exclusive Brethren.
- 9. Care of the body at the time of death for Jew, Muslim, Pagan Romany, and some Aborigine
- 10. Post mortem allowed only if ordered by the Court for Orthodox Jew, Buddhist, Hindu, Muslim, Jehovah Witnesses, Christian Science, and some Aborigine.

Because of the diversity and complexity of health care related spiritual beliefs, this list is incomplete. To answer questions such as "What happens when spiritual beliefs are incompatible to proposed treatment?" and "When should a health care professional allow or not allow spiritual behaviours to be practiced?", the health care professional needs extensive knowledge of legal and ethical principles related to health care. On the one hand, a patient's spiritual beliefs may allow them to assume responsibility for refusing potentially life-preserving treatment. In Western Australia, patients/clients are legally allowed to refuse treatment if they

are mentally competent and understand the implications of refusing certain treatments (Wallace, 1995). Therefore, it is not unusual for a Jehovah Witness patient to die because s/he has refused a blood transfusion. On the other hand, a health care professional could refuse to allow spiritual behaviours to be performed if they were deemed to be detrimental to the patient's/client's health or to endanger the lives of other people. For example, the lighting of a fire in a hospital room to create sufficient dense smoke to rid evil spirits could be refused, whereas, the provision of a prayer mat facing north and water in which to wash prior to prayer could be provided for a Muslim patient.

The health care professional providing treatment to a patient/client needs to be aware also that the truths and beliefs listed in an authoritative religious text might not accurately reflect the patient's/client's own beliefs. For example, Athika, whose spirituality exceeded the boundaries of usual beliefs and truths of Hinduism, would probably accept some exceptions to these rules. Likewise, Scarlet, as an elder of the Pagan Romanies, may decide for herself which beliefs and truths she wanted to adopt at the time. For Ann, with her Aboriginal heritage and Anglican beliefs, it would be difficult to preempt what she may want. Someone like Rosie, with her mixture of Anglicanism, Buddhism practices and Brethren background, and her unstable psychiatric condition, might not know what she wants and also might change her mind about the nature of spiritual care she desires, what needs she wants fulfilled, and what health care treatment is incompatible with her beliefs at the time.

Is it possible to think of some way to inform health care professionals about the spirituality of prospective patients/clients?

# SPIRITUAL CARE EDUCATION OF FUTURE HEALTH CARE PROFESSIONALS

For the participants in this study, who shared common characteristics of spiritual needs, desired levels of spiritual care, and a rite of passage, specific spiritual

related health care strategies have been recommended. The question then arises as to how future health care professionals may be better prepared during their initial education and training in order to comply with the Australian Council of Health Standards (ACHS) which require spiritual care to be provided to every patient/client regardless of their spirituality.

In reflecting on the apparent care deficits of the health care professionals who looked after the participants in this study, appropriate education would entail (i) increasing knowledge and understanding about spirituality, (ii) developing communication and relationship skills, and (iii) facilitating the health care professional getting in touch with their own spirituality. In relation to the third point, according to Harrington (1996), health care professionals need to be aware of their own spirituality in order to facilitate spiritual care for others.

# Improving Health Care Professionals' Understanding of Spirituality

In order to improve health care professionals' understanding of the diverse spiritual needs amongst the Western Australian community, knowledge of spiritual, ethical and religious matters may be needed. This could be achieved through:

- dialogue with people of different faiths;
- communication of reliable information about different traditions; and
- recognition of variations in patients'/clients' pastoral needs, which reflect particular ethical, cultural and religious backgrounds.

The spiritual model described in Chapter Two could be used to identify the distinctive beliefs, doctrines and practices of the major spiritual or ethnic groups in the community. By identifying the various groups within a health care professional's local practice or, more broadly, within a hospital's catchment area, and recording the information as per the components of the model, detailed knowledge may be generated of the foci of the various groups, their beliefs, how a

member would access the foci, and how the beliefs and truths would be manifested.

This detailed knowledge may help to forewarn the health care professional about proposed treatments that are likely to be regarded as incompatible with the beliefs of patients/clients from particular cultural groups. Of course, this knowledge should not prevent the health care professional from offering incompatible treatment to a patient/client. However, it would help to make the health care professional aware that the patient/client might refuse the suggested treatment, and perhaps provide an opportunity for the health care professional to think of possible alternative treatments that are more in harmony with a patient's/client's beliefs. See Appendix 4 for examples of how the model (from Chapter Two) has been used in this way with different spiritualities, including Buddhist, Humanist, and Orthodox Jewish perspectives.

To enable the health care professional to be able to hold a particular personal faith and, at the same time, promote the religious freedom and pluralism that is an important component of a harmonious and peaceful community, discussion could be implemented during training in order to:

- assist the health care professionals to understand the four underlying features
  of belief systems (see Chapters Two, Ten, and Appendix 17), which are
  shared human experiences and individual patterns of belief, such as personal
  life, family life, community life and public life; and
- share human experiences that affect individual patterns of belief through participating, valuing and adopting (see Chapters Two, Ten, and Appendix 17).

From my experience as a university lecturer, raising questions about values and beliefs will possibly cause the students to express anxiety (and even anger and fear). Consequently, there is the need to adequately prepare the students prior to any such discussion. This preparation needs to inform students of the aim and rules of the session/s. That is, the aim of the session is for them to gain an understanding of others' spiritual beliefs. Moreover, it is important that they treat

each other's views with respect and not be judgmental or denigrating in any way to another viewpoints (Hawley, 1997a & b).

# Education to Improve Interpersonal Relationships Between Health Care Professionals and Patients/Clients

Caring for patients/clients takes place within ethical and cultural contexts (Benner, 1994; Watson, 1997). Earlier in this chapter, it was argued that, in order to meet the spiritual needs of the participants in this study, health care professionals should acknowledge their spirituality. This action would demonstrate respect for the person's rights and needs, and therefore would reflect the ethical context of care. This raises the question of how health care professionals can care for patients/clients within diverse cultural contexts without offending spiritual beliefs. According to Rasool (2001), nursing models and frameworks of care practiced within the Judeo-Christian tradition, may be devoid of the core of spirituality, and thus may be inappropriate for meeting the holistic needs of Muslim patients in Islamic and non-Islamic countries. This assertion is of concern because Islam is the fastest growing spiritual group in Western Australia (Church Life Survey, 1999). Rasool recommends the development of culturally appropriate spiritual assessment tools to assess patients' needs in order to reduce the ethnocentrism or bias towards the Judeo-Christian tradition. According to Kasule (cited by Rasool), caring within a cultural context from an Islamic perspective emphasises the dignity of the person and places high value on direct patient/client contact and interaction.

# How then can health care professionals be educated to improve their interpersonal relationships with patients/clients in order to improve spiritual care?

Although many health care professionals are taught about interpersonal relationships and communication skills at some time in their initial education and training, some evidently still have difficulty putting this knowledge/skill into practice and, in my experience, many tend to shy away from talking about things spiritual. Perhaps part of this problem may be related to the issue of "presumption of knowledge" in spiritual care. Some health care professionals

(including Judeo-Christian chaplains) assume the superiority of their personal knowledge of religion or spirituality, and hold the corresponding view that others have inferior knowledge and beliefs (Rasool, 2000). I am concerned that this concept of assumed superior knowledge and/or beliefs may be contributing to an ongoing lack of understanding of multicultural spirituality by health care professionals.

In Chapter Two, I wrote about my own religion being one of 'missionology' which promoted an expectation that, being of the Christian faith, I should endeavour to convert others to Christianity. That situation was a time of crisis for me until I was able to explore theologically how I might enact my Christian values and beliefs and, at the same time, respect other people's values and beliefs, particularly those that are very different to my own. I realised that I needed to go beyond the teachings of my church and work out what was right for me. The issue of assumption of superior knowledge raises the question as to how educational strategies may be implemented to help the health care professional when communicating about spirituality with other health care professionals and with patients/clients.

This problem might be overcome if the health care professional learns how to alter his/her pattern of speech during patient/client assessment, care, and/or treatment, in order to allow the other person to be able to express freely their own beliefs. If the health care professional can employ a way of questioning and talking that leaves others free to state clearly what they value and believe in a spiritual sense (i.e., what their tradition believes and does, or what their sacred scriptures say), the other may be encouraged and enabled to respond from an empowered perspective (compared to a situation of alienation).

One way in which interpersonal relationships may be improved in order for spiritual care to be performed sensitively within a multicultural context could be by educating the health care professional in use of the behaviours of "owning" and "grounding" of belief statements when communicating with others. (Fuller &

Schuller-Ayers, 1990). The practices of "owning" (in relation to a belief) and "grounding" (in relation to linking knowledge to its source of authority) are ways in which people may indicate their commitment to particular spiritual beliefs. For example, a patient/client may be indicating their ownership of a specific belief while talking with the health care professional by using phrases such as "I believe...", "It seems to me that...", "I feel...", "I think..." and "In my experience",. During assessment or treatment, the health care professional could ascertain the degree of ownership of a patient's/client's inferred belief by referring it to an external source from which the patient/client may be presumed to have gained their knowledge. For example, the health care professional might find it helpful to pursue an inquiry in the following manner: "In my experience with other Muslims patients, they have told me that they believe..."

If the health care professional wants to verify the "owning" and "grounding" of patients'/clients' belief statements they could ask, "Could you explain to me why you think that.....?", "Is this what your spiritual group teaches you?", "When you say... [quote patient/client]... who is it that said that?" or "Do you believe that is true?". By keeping their tone of voice light and non-judgmental, the health care professional may find that such questions assist patients to communicate clearly their spiritual beliefs.

Some patients/clients might ask the health care professional about the nature of his/her own spiritual beliefs. If the health care professional believes that it is appropriate to disclose these, then it may be wise to do so in such a way that the beliefs appear to be grounded (thereby making clear their traditional context). Thus, they are likely to seem less dogmatic. For example, a patient/client may request a type of treatment that conflicts with the health care professional's own spiritual beliefs. In refusing the treatment the I would suggest that the health care professional could explain to the patient/client, - by utilising ownership and grounding the source, that the treatment would be contrary to his/her spirituality. Such disclosure by the health care professional may enhance their interpersonal relationship with the patient/client. Incorporating the suggested interpersonal

education into curricular for health care professionals is that it could acknowledge the existence of multicultural differences of both the patient/client and health care professional and reflect the fact that, for many, their uniqueness or individuality is as important to them as those features that they share with others. However, future research is needed to assess the viability of these interpersonal strategies for providing spiritual care that recognises the ethical and cultural contexts of patients'/clients' lives.

### PERSONAL LEARNING FROM THE RESEARCH

Looking back to the start of this research I am amazed at the various ways in which I have grown. Not only has my own knowledge of the subject of spirituality increased, but also my spiritual life has developed. This has been coupled with gaining skills in undertaking phenomenology research, and thinking of the pedagogic issues of incorporating spirituality into education for health care professionals.

These topics, although disparate in some respects, are also intertwined for me, for example, the more I learnt about the subject of spirituality, the more I questioned my own spiritual nature and personal faith and sought answers about my own beliefs. This, in turn, facilitated my own spiritual development, which resulted in a new maturity that enabled me to become more accepting of other's concepts of spirituality.

At the outset of the research, my understanding of phenomenology had been only theoretical. Like other postgraduate research students, I had learnt about phenomenology and when it would be appropriate to use it in studies. However, to be able to use the method accurately and efficiently I needed to gain understanding of the practical nature of the subject. I was fortunate to be able to utilise peers and colleagues who had already undertaken phenomenological research and who offered guidance and clarification of the process.

Pedagogy is intertwined with all of the topics I have mentioned, mainly because of the location and situation of where I served as a Doctoral student. This was in a university centre for science and mathematics education; my supervisor being a senior lecturer for science teachers was involved therefore in the art and process of pedagogy.

### Spirituality

As a lecturer in health care ethics and a strong advocate for patients' rights, my interest in spirituality was aroused initially when I noticed that if a patient was not of Anglo-Celtic origin and from a Judeo-Christian tradition then they were unlikely to have their spiritual needs met while being hospitalised. So the research began, and as my knowledge and understanding of the subject increased, my spirituality was increasingly deconstructed, in true postmodern fashion. Gaining maturity in spirituality is not an easy exercise and I found that I needed to question the religious beliefs that gave expression to my own spirituality. This gave rise to anxiety and irritability to an extent that I questioned my own grasp of reality. It was a time of suffering that I needed to experience so that new knowledge and further understanding of the self in the 'I-thou' relationship could be processed. This experience commenced when writing Chapter One and is described in Chapter Two. In postmodern terminology, deconstruction and reconstruction commenced at around that time. However, it did not stop at the end of Chapter Two; instead, the experience continues with cycles of deconstruction and reconstruction. Many times I wondered whether I should abandon the study just to ease the constant questioning concerning my own spirituality. [It takes a brave Bishop to listen to the outpourings of a feminist mind in agony about her personal spirituality and the controlling patriarchal mechanisms of the church.] In some respects, it would have been easier to give up and find another subject to explore for my PhD research - but then I would not have gained my spiritual maturity which now enables me to be increasingly humble towards others' beliefs and to maintain a desire to see patients' beliefs incorporated into spiritual care by health care professionals.

I also found that when I became 'one with the participants', and tried to interpret their understandings of their suffering and experiences, I came to realise the inwardness journey and connectedness to others. This understanding has resulted in a personal challenge that involves me in continuing spiritually and theologically to face, and come to terms with, holding a particular personal faith while promoting religious freedom and pluralism in ways that also promote harmonious and peaceful community. This journey, I believe, will continue for some time and I have no idea how or when it may end. What I have found to be important in this rite of passage is the acquaintance of others with whom I can raise my thoughts and discuss issues without offending their beliefs (and their emotional feelings attached to these beliefs).

### Phenomenology

We called ourselves the 'Pythagorean Mothers Group', a term supposedly depicting a meeting of early Greek feminist philosophers discussing phenomenology. We were neither Greek nor true philosophers, but rather we came together fortnightly as a group of women to discuss phenomenology and our research. The focal point of our discussions was the way that we all, in turn, were interpreting the various philosophical approaches and how this affected the data collection and analysis we were undertaking. The value of this group was that it served to facilitate the trustworthiness of the methodologies we were undertaking, as we were not afraid to criticise and make suggestions about each other's work. Such openness and honesty is not always possible within academic circles, and the true advantage for me was in being one of the students.

# Pedagogic Research

Curtin University's Centre for Science and Mathematics Education (SMEC) is, by its nature, involved in pedagogic research. Some of my fellow doctoral students were investigating curriculum issues and other topics of pedagogy. We met each week for a colloquium and, not surprisingly, towards the end of my time at the Center I found myself applying for pedagogic research funding (to study student

and staff perspectives of being part of a satellite university campus). This event has little relevance for the ethical rights of multicultural patients having their spiritual needs met, but rather it stemmed from my position of university lecturer (in nursing education) and having been stimulated by my fellow doctoral students who were engaged in pedagogic research.

At about this time, I realised that I needed to improve the pedagogic nature of my teaching of ethics so that my own inner spirituality was better reflected in my teaching practice. This challenge became important when I accepted a new university appointment (in the UK) which involved not only teaching multidisciplinary health care ethics, but at the same time leading the teaching of research methodology and supervising Honours and postgraduate students. In meeting this challenge, especially in demonstrating respect for the spiritual nature of my own students, I have begun to adopt into my own teaching, recommendations of this research. By incorporating in seminars sufficient time for students to discuss their values and beliefs on subjects, I am striving to enable students to own their own perspectives whilst also hearing the values of other students which may be quite different from their own.

Furthermore, I employ a passion for teaching, so that students can witness the existential and spiritual significance in me as a teacher (Glazer, 1999). In the wider university sphere, I encourage junior colleagues whom I mentor to do the same, so that their teaching and research becomes 'alive' both for themselves and their students (Apple, 1993; Vandenburg, 1990). I also make suggestions for university policy and planning about incorporating the recognition of the whole person. I believe that when we recognise the whole person in another human being we engage in spiritual caring (in some small way) for that person.

#### CODA

The potential impact of the findings of this research excites me when I imagine that others' spiritual needs might be met when the recommendations of this

research are incorporated into educational policy and practice, and that revised clinical standards for health care might be based on results of this study. To date, one of the consequences of this research is the adoption of the emergent model of spirituality that is being trialled by a professor of nursing at a Jesuit university in the USA (Kunes-Connell, 2001). Papers for refereed journals are being written, and conference presentations given and posters discussed (Hawley & Taylor, 2001a, 2001b; Hawley, 1999, 2000)

According to Packer and Addison (1989), there is no such thing as an interpretation-free, objective "truth" account of "things" in themselves, and there is no technical procedure for validating that an account corresponds to the timeless, objective "truth". This is because criteria such as plausibility, coherence, and consistency do not help to determine the degree of correspondence between an account and the way things "really are". Rather, they help to determine how well an account served to answer the original concern that initiated the line of inquiry leading to the research in the first place. Interpretive inquiry always begins from practical concernful engagement, and never seeks to simply describe a phenomenon, but is always concerned with some issue of human behaviour. In this case, it was the perceived lack of knowledge and understanding amongst health care professionals of the spiritual needs of multicultural patients or clients.

Therefore, the ultimate criterion for evaluating the adequacy of an interpretive account is the degree to which it resolves the issue and opens new possibilities for engaging the research problem. Disputes in interpretation based on the plausibility of alternative interpretations cannot be reduced to a-priori-derived, cut-and-dried criteria. In an interpretive approach there can always be another, perhaps deeper and more persuasive, interpretation of a phenomenon. According to van Manen (1993), the findings may be disparate from one study to another and will therefore produce quite dissimilar accounts of the same phenomenon. Moreover, competing accounts do not negate each other; rather, they create a conversation. This decreased emphasis on one true account of a phenomenon has effect beyond the scope of the individual research project, in that it encourages the creative

exchange of perspectives and ideas in professional journals to fully explore new phenomena and issues. This interpretive phenomenological study, consisting of a survey of the spiritual groups in Western Australia, then a case study of selected participants from different multicultural backgrounds will add to developing knowledge and understanding of the phenomenon of spirituality. The findings of the research can not be generalised and regarded as the truth of spiritual care, but what it does do is to offer health care professionals the insight into the participants' concept of being a person, their spirituality, what they believed their spiritual needs to be (mutual trust, hope, love, and peace), their desired spiritual care (Acknowledgment, Empathy, and Valuing), and the rite of passage.

Caring, or providing care to patients, has been termed an existential skill, or what Socrates would have called "a knack!" However, using a term like 'knack' to describe caring in this postmodern world would be inappropriate (given the knowledge and skills of health care professionals). Perhaps Aristotle's term for care - "practical wisdom"- is more appropriate (Benner, 1994). In a postmodernist sense, spiritual caring by health care professionals is the art of connecting an individual spirit with the universal (Watson, 1997). To do this well, health care professionals would need to openly respect patients' spirituality and facilitate their spiritual needs and desires.

This respect would include showing patients our presence in being with them, and listening and refraining from being judgmental or proselytizing. Although some patients/clients might believe that their spiritual beliefs are based on absolute truth, and want to practice their manifestations of spirituality while in hospital or receiving care from us, health care professionals need to be mindful of their legal and ethical obligations. That is, the patient's/client's request for his/her spiritual needs must not override the health care professional's autonomy (bearing in mind that while patients or clients may request to have specific spiritual needs met, beneficence for the patient or client needs to take precedence). In these instances, it may be appropriate for the health care professional to refuse the request for a spiritual need to be facilitated.

Although I discovered many things when undertaking this research, there is still much more that needs to be researched. While I was finding answers to the questions I raised at the beginning of the study, the answers resulted in further questions that will need to be answered in future research. The obvious questions are related to the recommendations and suggestions I made earlier in this chapter. For example, "Will the implementation of the teaching recommendations improve the health care professionals' knowledge and understanding of spirituality, and improve the quality of spiritual care?" and "Can the teaching of the communication styles of owning beliefs and grounding sources of knowledge improve the cultural and spiritual interpersonal relationship between patient/client and health care professional?'

I am being driven forward Into an unknown land The pass grows steeper, The air colder and sharper,

A wind from my unknown goal
Stirs the strings
Of expectation
Still the question
Shall I ever get there?
There where life resounds,
A clear pure note
In the silence.

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#### APPENDIX

# (Page numbers refer to citation page in the report).

- 1. CENSUS LIST OF SPIRITUAL GROUPS (p.28)
- 2. NORMAN AISBETT (p.35)
- 3. LETTER TO SPIRITUAL GROUPS FOR INFORMATION (p.35)
- 4. DIAGRAMS OF RELATIONSHIPS BETWEEN THEMES (p.45,46,47)
- 5. JOURNAL (p.79)
- 6. INFORMATION AND CONSENT FORM (p.77,81,92)
- 7. CORONERS CASE (p.79)
- 8. LETTER FROM HOSPITAL (p.88)
- 9. LETTER REQUESTING PARTICIPANTS (p.89)
- 10. TELEPHONE INFORMATION (p.89)
- 11. QUESTIONS (p.90,92)
- 12. LETTER TO PARTICIPANTS WITH TRANSCRIPT OF INTERVIEW (p.93)
- 13. FIELD NOTES (p.107)
- 14. EXAMPLE OF CODING BY HYPERESEARCH (p.108)
- 15. PEER REVIEW OF CODING THEMES AND CASES (p.70, )
- 16. LETTER TO PARTICIPANTS WITH OVERALL FINDINGS (p.116)
- 17. PARTICIPANTS' SOCIAL CONSTRUCT (p. 73

# **APPENDIX 1**

# **CENSUS LIST**

### **APPENDIX 1: Census list**

Note: For copyright reasons Appendix 1 has not been reproduced.

1996 Census of Population and Housing Selected Social and Housing Characteristics for Statistical Local Areas

(Co-ordinator, ADT Project (Bibliographic Services), Curtin University of Technology, 21/08/03)

## **APPENDIX 2**

# ARTICLE BY NORMAN AISBETT

## **APPENDIX 2: Article by Norman Aisbett**

Note: For copyright reasons Appendix 2 has not been reproduced.

Aisbett, N. (2000) No vacancies. West Australian, October 7th.

(Co-ordinator, ADT Project (Retrospective), Curtin University of Technology, 21/08/03)

## **APPENDIX 3**

# LETTER TO SPIRITUAL GROUPS FOR INFORMATION

Dewachen Buddhist Sanctuary

Dear Sir or Madam

#### TO WHOM IT MAY CONCERN

I teach a component on spirituality in the undergraduate degree which focuses on patients' spiritual needs. With the many different religions and spiritual beliefs present in today's multicultural society, I having difficulty in being accurate with the information I supply to students. For this reason, I am writing to ask if would be so kind as to answer the following questions so that I can pass this information onto the students. The questions are:

- 1. The origin of the religion, spiritual group, philosophy or sect to which you belong
- 2. The beliefs of this group
- 3. Activities and/or rituals performed and practiced
- 4. Beliefs and rituals when needing health care including, diet, fasting, prayer/worship, washing, clothing, contraception, childbirth, abortion, blood transfusion, autopsy, organ donation and transplantation, care of the dying person and deceased body.

If you have any other information which you think may be of interest and/or assistance in this matter I will be most grateful.

Sincerely,

The Rev'd Georgina Hawley Lecturer School of Nursing GH/DL

#### Dear Sir or Madam:

Earlier this year I wrote seeking information on the beliefs and practices of your religion and/or spiritual group in relation to health care. The information that I received has been overwhelming and I sincerely thank you. I now have pamphlets, booklets, reference books, and religious texts in my office to use as a resource when lecturing students and for other staff members to use as the need arises. Again, thank you for replying to my previous request.

I hope in the future that perhaps more links can be made between your community and me. Perhaps, some of your members may like to volunteer in a study about their spiritual needs when they were ill. Such a study would lend support to the interrelationship between body, mind, and spirit. In addition, such findings would show nurses and other health care professionals the importance of patients' spiritual desires and needs. For it is only when studies are done and the research published that health care professionals pay attention to various aspects of health care.

Yours truly,

Georgina Hawley Lecturer

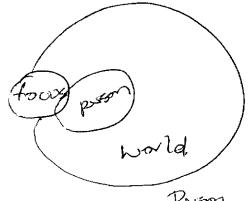
# **APPENDIX 4**

## **DIAGRAMS**

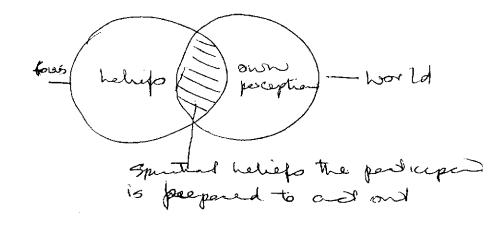
# Sphermed 98

Possible Matronthip hetver

Belonging to group Belief Doctrines present Janaring etc



Bearland Spirotrally



prays Hogran
Betroto Hogran

aiet Castin

# **Model of spirituality**

manifestations used to act out truths beliefs or values

Beliefs or truths of the organisation

Name power ultimate

Person's perspective
Of truths

Means of accessing the truths
And/or communicating with the power or deity



Undertaking charitable acts
Respecting and tolerating differences

Belief in humanity resolve individual or universal problems

Universal human family

Person's perspective
Of truths

Reading, talking, discussion with other members



Vegetarian diet
Modesty, time for prayer, meditation,
use of shrine, chanting (near deatn).
Analgesia not to diminish mindfulness.

8<sup>th</sup> fold path to Enlightenment 5precepts 10 virtues

> Buddha god

Many groups in WA. cultural tie to country of origin.

Virtuous living, prayer, purification, meditation, retreats.

# Jew/ish/

Fasting, Kashrut(kosher food), observing Sabbath. No extraordinary treatment, no abortion, no mechanical means of contraception

Torah or Pentateuch (1-5 books of Old testametra:
JewishBible),including God created the earth and life
after death.

God

Different types (orthodox, conservative, liberal).

Prayer, fasting, diet, reading of Scriptures
Teaching by Rabbi

APPENDIX 306

## **APPENDIX 5**

## **EXTRACT FROM JOURNAL**

#### Interviews

- 1. Ann gave detailed spiritual needs within Judeo-Christian tradition.
- 2. It would appear that spiritual needs are changed according to persons faith development. That is, the persons understanding or perception of their personal faith. Fowler stages 1-6. Questions therefore need to change for each person and how the research findings are developed.
- 3. Red, talked about Australian culture and personal links with spirituality
- 4. Both hinted that spirituality was the reason for living, it gave purpose to life.
- 5. Spiritual needs that are very apparent to date:
  - Trust. The patient/person needs to be able to trust the HCP to do right thing by them

Ann needed to be able to trust the operating room staff to treat her skillfully and with dignity – which they were not able to do.

Red. Needed to know that the locum doctor would perform adequate treatment to relieve his pain after he had paid.

Likewise, the person needs to feel trusted by the HCP.

Red had to write a cheque for the locum before he would examine and treat him. Ann needed to feel trusted by the operating room staff that her concern for her baby was real and legitimate.

• Respect. The patient/person needs to know that the HCP respects them sufficiently and allow the patient autonomy to make their own decisions. This notion of respect would involve the person be given sufficient information to make the autonomous decision and to respect the decision the patient/person made. Trying to get the person/patient to change their mind, or making the decision on behalf of the patient are not demonstrations of respect. Ann was told to wake her baby up and to give the baby a bath because it was 10am in the morning and that was when the midwife said that Ann should bath the baby. Ann wanted to wait until the baby woke then she would feed and bath the baby.

Red was not given sufficient information about his condition. He doubted the doctor's diagnosis, as the Dr had not told him sufficient information about how it can occur, the pain involved and the effect of treatment.

#### February

In response to meeting with Peter: Where do World View come in? Read Williams thesis of doing research negatively.

... 15<sup>th</sup> February. Interview with A/Prof Liz Lindsay.-.about research project to date. Gave me 3 articles of hers which may be helpful on interpretive phenomonly. Discoused the differences between Hurseel and Heidegarrian and Benner and Van Manen.

Hursell believed that the researcher when interviewing people could bracket their own personal perceptions and ideaologies, that is, state what they are for the subject being researched and then believe that what the person is saying is not predujeced by ones

own thoughts. Heideggar, on the other hand did not believe that was possible, and that the researchers perceptions will colour the interpretation and to be aware of thaat. Another difference between Husell and Heidegger, was the Huseell believed that the "essence" of a problem was the "truth" as far as the person was concerned. Heiddegar on the other hand said it was only possible to perceive what the person was telling the researcher, and that they may be various layers or depths in finding the essence. Benner's book on interpretative phenomenology takes Hussels and Heideggars research philosophies and uses these within the nursing context. The premise of Benner's method of interpretative phenomenology it to make meaning of clients and patients experiences to further the knowledge of nursing.

Max Van Manen. Researching the lived experience. Although he doesn't name the methods that he uses as interpretative phenomenology, the writing is about interpretative phenomenology. The only difference is that he has not named the research method. Van Manen also believes it is possible to bracket prior knowledge and perceptions.

This researcher does not think this is at all possible and that it would be better for the researcher to state these at the beginning of the writing so it is completely honest to the reader the perspective that researcher had and was dealing with at the time.

#### Look at

- 1. Merleau-Ponty's work about perception.
- 2. Coombs ad Avilla perception and meaning making
- 3. Packer hermeneutic
- 4. Gaddamer co-creation. The fusion of horizons of the researcher and participants. So that together they make meaning of the phenomena.

The Ph.D. student should develop own recipe, so that methodology ties to together and becomes unique.

Discussed development of model. Why did I do this? As researcher, I could not get a handle on the components and parts of spirituality.

#### NB"s

- 1. Write down own values/ beliefs about spirituality.
- 2. When interviewing and analysing data check own values and ask "Am I interpreting my own values here, what are my values in this situation. Are my perceptions influencing my interpretation of the research.
- 3. Need to explore own spirituality in relation to model and to document this?
- 4. Then when interviewing and analysing data ask myself the question "whose needs are being met?
- 5. Aim of research. To identify and develop new definition of spiritual needs for the Australian health care recipient.

16/2/99

Analysed Ann data:

Themes identified as:

- Anger towards the hospital staff in not demonstrating care and compassion.
   Participant very fatalistic while hospitalised used words such as God's will and very impassive. However, on discharge from hospital sought and asked for help (mothers groups, child health nurse, psychologist)
- 2. Unresolved grief concerning fathers death (anger still towards mother from not being there and helping; still has questions about the death which are unanswered 12 years later).

The anger towards the staff involved participant feelings of anger, anxiety, fear, fear of death, hurt, pain, vulnerability, abandonment.

<u>Descriptive terms</u> used by participant included (words which are bracketed are opposites and which did not appear in the transcript:

- 1. God's will (empowered)
- 2. Lack of support (ask)
- 3. Hurt/pain (help, comfort, pleasant)
- 4. Fear of death (unafraid)
- 5. Anger (inner peace)
- 6. Anxiety (calm, assurance)
- 7. Denial (acceptance)

### Spiritual needs identified as

- 1. Respect (for the individual by those close at hand esp HCP's)
- 2. Empathy (asking the participant about their worries, listening to what the participant says; showing care either verbally or non verbally use of appropriate touch;
- 3. Acknowledgement (of the pt feelings, explanation of procedures, reassurance as to why certain things are necessary).

#### Passage (this was the type of journey which the participant underwent).

- 1. Identification of health care problem and/or hospitalisation
- 2. Realisation of dissonance between "normal routines/daily rituals and/or feelings of anxiety or fear due to present condition (at this stage the participant may not be able to express their concerns and/or articulate them as spiritual needs.
- 3. Asking for support or spiritual help/care, this could be passive or active
- 4. Receiving or not receiving spiritual care (this would depend on whether or pt and HCP recognised the spiritual component of the health care and how to give that).
- 5. Reflection, if continued spiritual need still exists, stages 1-5 are processed again. Perception colouring whether the person feels as to whether their need has been fulfilled. Also, the participants ability to reflect will deptend on whether they are in concrete or formal/abstaract thought at the time. Therefore, it may only be that once a person is well they are able to reflect. See Hawley (1998).

### Spiritual care provided by the HCP needs to be:

- 1. Making time to sit and listen
- 2. Offer empathy
- 3. Acknowledge pt concern difficulty/problem

- 4. Provide information so that the pt has full facts regarding the health problem, the possible treatments
- 5. Encourage and allow pt to make decisions. Discourage fatalistic attitudes and behaviours if appropriate esp with mental health problems and/or negativity regarding illness, for example "God is punishing me for doing something wrong". Many people will express negativity under the religious cop out of "God's will" this may need to be challanged. For example, a person may think they are being punished or given the illness beceasue they do not know of the eitology of the condition. This then is where information for knowledge deficiet is very important. Questions such as "why do you think it is God's will?"
- 6. Encourage patient participation in care and treatment
- 7. Offer spiritual support (whatever is appropriate to their spiritual focus). This support may be offerring to contact officer or elder or leader of group; ensuring support groups of client or pt is fully aware of the situation if the pt is not able to do this for themselves:
- 8. Be truthfull and honest at all time

### Sunday

Is there are heirarchy of spiritual needs?:

What would be lowest form of spiritual need to be met, through to the ultimate spiritual need:

Low to High

- 1. Acknowledge
- 2. Empathy
- 3. Respect

That is,

- 4. Acknowledge. Acknowledgment by the HCP that the person will have some spiritual needs to be met, even though the person themself may not be able to express the needs. Providing inforantion so that the person is capable of making own decisions rearding their health care treatment etc...
- 5. Empthy. Listening to the person and offering empathy both verbally and non verbally of their suffering/distress/problem at the time. NB making sure that the person understands that you realise their situation and that it may difficult time for them if they need to make a health care decision which will involve their spirituality. Especially if you are going to offer them treatment which my be contrary to their own beliefs. Provide reassurance is important.
- 6. Respecting, the person's wishes and desires. This stage, not only incorporates acknowledgement, and the giving of empathy, but also respecting the persons choice of treamtnet and the practing of spiritual rituals etc.

How do these Georgie definitions fit with the dictionary definiations? Examples

Expansion of Descriptors of participants behaviour when they have identified that they have a spiritual need/s.

- 8. Powerless, passivity, disempowered (empowered). Some people are very passive about their spiritual beliefs and their understanding of both the HCP and their beliefs/truths. For example, some pts are extremely passive and not seek any help for their health care problem, saying "it is god's will etc". This may be due to their lack of spiritual maturity or stage of faith, or be of intellect that they do not have the ability to reflect. The opposite of passivity, is the person who has bothered to gain as much understanding as possible about their health care problem and feels and acts empowered in their knowledge and understanding of the situation. The JW even though they may not accept the blood transfusion, is empowered by their religious conviction that they are doing the right thing for Jehovah in not receiving the blood transfusion. With JW there is nothing passive about their decision or refusal of treatment.
- 9. Lack of support (ask). The participant realsied their vulnerbaility or passovoty and at the same time realisied that the HCP was not openly supporting them. That is there were no words of assurance or acknowledgement of their situation by the HCP. The HCP did not verbally or non verbally offer support to the participant.

### 10. Hurt/ pain (help, comfort, pleasant)

The situation of the time was made worse by the HCP hurting or offending the participant to the extent that they felt pain as a result of the HCP behaviour.

### 11. Fear of death (unafraid)

The only person who does not fear death or dying is the person who wants to commit suicide. It is the suicidal participant who can not think of anything else but the pain inside of themselves and not being able to take any more pain, decides to die. Other participants/persons don't want to leave their loved ones etc. Therefore, all people have an anxiety and/or fear of death. Information about the death/dying process will decrease this anxiety. That is, the person becomes weaker, they will sleep more often and gradually laspe into unconsiousness. However, if a person is concerned about death when facing an operation they fear is only resolved when they are anethetised and then wake up. Giving the person the statistics of how few people die as a result of an anaethesite only partially helps.

### 12. Anger (inner peace)

Anger arises when the HCP does not explain, provide information, gives incompetent care or stuffs up. That is, when the participants expectations of the HCP and/system does not match the care they are being given.

#### 13. Anxiety (calm, assurance).

Facing uncertainty produces anxiety in any human being. While stress may provide the herbs or flight or fight, there is probably a percentage of anxiety involved.

### 14. Denial (acceptance)

### Extract of Part of the Journal

### Notes on Themes and Exemplars to date: November, 1999

The themes contained in the interview sessions are related to the participants' health problems and their spirituality and related needs. There was no real way of saying this is a particular spiritual theme without the text having reference to something of the health problem and vice versa.

Possible relationship between the themes.

The participants meaning and purpose in life, their personal reflection and prayer and/or meditation were affected by the nature of their health problem. The uncertainty they faced, their knowledge deficit, whether or not they had emergency treatment and the attitude of the HCP (health care professional) compounded the effects of their health problem.

The various spiritual needs arise from the themes of love, trust, hope, and peace. The nature of spiritual care arises from the themes of acknowledgement, understanding (I think this needs to be changed to empathy), and respect (as a unique individual/person, need to change to valuing or cherish).

Questions to check out in the data
Is there are hierarchy of spiritual needs?
Is there a hierarchy of spiritual care?
Are the spiritual needs correlated to the levels of care?

## **APPENDIX 6**

# INFORMATION AND CONSENT FORM

#### PARTICIPANT'S INFORMATION SHEET

Dear Participant,

I invite you to take part in a study seeking to find out patient's and client's spiritual needs. At present, those of us working in health care do not know what these needs may be. Written below is information about the study:

Each person has three important parts:

- 1. Physical
- 2. Mental
- 3. Spiritual

In recent years, health care has improved, as we now know so much more about the physical and mental aspects of a person's body. However, little is known about what a person would regard as their spirit or spirituality and what those needs may be.

What is known from overseas research is that a person's spirit or spiritual beliefs influence:

The person's ability to cope with illnesses

The decisions they make in regard to their health; and

Whether or not to accept various medical treatments.

Since none of the research was undertaken in Australia it is not known if Australian people have the same beliefs or needs. If you take part in this study, you will be asked to talk with me about what you regard as your spirit or spirituality and your health problem. There are no right or wrong answers, so any information you can give me will be very helpful.

It will help if the talk with me can be recorded with a small tape recorder (pocket sized, battery operated). I will check back with you after the interviews so that

you can check that the information you gave me is what you want. If you take part

in this study, you can be assured that no identifying information will be publicly

disclosed. The tape-recorded talk you have with me will not contain your name

and will be kept in a private and secure place. In addition, the results of the study

will be published in such way that your name will not be used and people will not

know that you have taken part in the study unless you tell them personally.

Thinking about your spirituality may be of benefit to you as you think about life

means to you, and what it is that gives you purpose in life. On the other hand, if

thinking about your spirituality raises some concerns, then please get in touch

with your own spirituality leader or myself so that you can discuss the concern.

By taking part in the study, you will be helping health care professionals (doctors.

nurses, physiotherapists etc), by providing the information that is need to protect

and nurture a persons' spirit.

Thank you for reading this information, if you would like to take part in this study

please contact me, so that arrangements can be made for an interview/talk to take

place.

Many thanks

Georgina Hawley

Telephone 93317267

Witness signature, name and date.

## **CONSENT FORM**

# TO BE USED IN CONJUNCTION WITH THE INFORMATION SHEET

PARTICIPANT'SNAME
DATE OF BIRTH
1. I agree entirely voluntarily to take part in this study of patients or clients
perspective of their spiritual needs.
2. I am over the age of 18 years
3. I have been given a full explanation of the purpose of this study and I understand
the possible personal benefits and/or risks of this research
4. I understand that if I have any concerns or queries about this study I can contact
the researcher, Georgina Hawley on 93317267 or Dr. Peter Taylor on 92667501.
5. I understand that the interview will be recorded, and that the researcher will need
to contact me at a later date to check the information I gave her during the interview.
6. I understand that I will not be referred to by name in any report concerning this
study. In turn, I cannot restrict in any way the use of the findings, which arise from
this study.
7. I have been given and have read a copy of this Consent Form and Patient
Information Sheet.
Signature of participant and date.

## **APPENDIX 7**

# **CORONERS CASE**

#### **APPENDIX 7: Coroners case**

Note: For copyright reasons Appendix 7 has not been reproduced.

Barton, Mairi. (2000) Open findings on Graylands hanging. West Australian, October 5<sup>th</sup>.

(Co-ordinator, ADT Project (Retrospective), Curtin University of Technology, 21/08/03)

# LETTER FROM HOSPITAL



Note: For privacy reasons Appendix 8 has not been reproduced.

(Co-ordinator, ADT Project (Bibliographic Services), Curtin University of Technology, 21/08/03)

# LETTER REQUESTING PARTICIPANTS

## **APPENDIX 9: Letter requesting participants**

Note: For privacy reasons Appendix 9 has not been reproduced.

(Co-ordinator, ADT Project (Bibliographic Services), Curtin University of Technology, 21/08/03)

# **TELEPHONE INFORMATION**

# Information from research volunteer

1. Date
2. Name
3. Address
4. Phone
5. Name of spiritual group if known
6. Place of birth
7. Place of birth of parents
8. Place of birth of grandparents
9. Medical problem as specified by patient
10.Length of current illness: years; months; days
11. Hospitalised. Yes/No: If yes, how many times?
Name of hospitals:
•
•
•
12. Practices some aspects of place of birth culture yes/no
13. If yes, what aspects
14. If volunteer born in Australia but parents or grandparents were not, does the volunteer practices some aspects of their culture yes/no
15.If yes, what aspects
***************************************
Researcher's notes
1. To be interviewed yes/no
2. Arrangements (date, time, place)
3. Pseudonym used by volunteer at interview
4. Interview typed(date)

- 5. Checked...(date)
- 6. Coded....(date)
- 7. Further contact with volunteer necessary yes/no (date)

  - (date)
- 8. Thank you letter sent (date)9. Volunteer notified of findings (date).

# **APPENDIX 11**

# **QUESTIONS**

The following are examples of the questions adapted from the Kleinman Model (1978). Some of these will be used to establish a relationship with the participants.

What brings you into hospital?

What do you understand is the matter with you? What do you understand about your illness?

What have you, family members and others (nurses, doctors, spiritual leaders, healers, or other caregivers) done so far?

How has the illness affected your life?

How has the illness affected the life of your family or relationships with others? What do you expect to happen in hospital this time?

What worries you most about the illness and treatment?

Open ended questions the researcher will ask the patients (adapted from Fish and Shelly, 1979, p. 64).

- 1. When you hear the word spiritual, what do you think of? (If context not raised: do you have a particular time or place with which you relate this idea of spirituality?)
- 2. What would you describe as your spiritual needs? (If context not raised: how would you see these fitting in with your life at present?)
- 3. How do you think nurses or other health care professionals could help you meet these needs? (If context not raised: Is there any particular way you would want this to happen?)

The following questions would be used as prompts if the above questions did not elicit sufficient information.

- 4. Are there practices of your culture or faith that are important to you?

  If so, could you please tell me about them?
- 5. Do you feel your beliefs and values are helpful to you? If positive: How are they helpful (prayers, religious reading from Koran, Torah, or Bible, or prayer book/s)?

If negative: In what way are they not helpful?

- 6. Has your current health problem made any difference?
- 7. In what ways are your spiritual beliefs important to you?
- 8. What helps you most when you are feeling alone and afraid?
- 9. What is it you are hoping for now?
- 10. What is helping you to cope now? Alternatively, your source of strength right now?
- 11. In recognising that all chronic illnesses have stages, which stage do you think you are at now?
- 12. Have any events or experiences changed your feelings?
- 13. Do you think your spiritual needs have changed during your illness? If so how?
- 14. Of all your hospitalisations, when was it easiest to keep your spiritual beliefs and practices? Why?
- 15. Similarly, when was it hardest to try to keep your spiritual beliefs and practices? Why?

Patient demographic questions, which the researcher will obtain from patient's notes/records, or if not recorded, will ask the participant for the information.

# LETTER TO PARTICIPANTS WITH TRANSCRIPT OF INTERVIEW

#### Science and Mathematics Education Centre (SMEC)

1.

Director: Professor Barry J Fraser FAAAS FIAE FASSA FACE



GPO Box U 1987 Perth 6845 Western Australia

Kent Street Bentley 6102 Western Australia

Attached is the transcript of the conversational interview we had together. Could you please read through the transcript and:

- 1. Add any further comments that you wish to make;
- 2. If there is something that you have said that doesn't appear clear to you, could you please change the word so it does; and
- 3. You will notice question marks as ?? typed in several places through the script. These have occurred when I could not quite understand what it was you said on the tape. If think you know what it might have been that you said could you please add the necessary words.

When you have done this could you please phone me (93317267) so that we can make arrangements for me to receive the new information from you.

Many thanks

Best wishes

Georgina Hawley

Home: 12 Homes Place Hilton WA 6163 phone 93317267

Fax +61 8 9266 2503 Tel +61 8 9266 7896

**APPENDIX 13** 

**FIELD NOTES** 

Listenies with drue Dec 18

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CODING BY HyperResearch (trade name)

# APPENDIX 14: Coding by HyperResearch

Note: For copyright reasons Appendix 14 has not been reproduced.

(Co-ordinator, ADT Project (Bibliographic Services), Curtin University of Technology, 21/08/03)

APPENDIX 15: Peer review of coding themes and paradigm cases
Note: For privacy reasons Appendix 15 has not been reproduced.
(Co-ordinator, ADT Project (Bibliographic Services), Curtin University of Technology, 21/08/03)

# LETTER TO PARTICIPANTS PRIOR TO INTERVIEW 3

322

If you want to talk to me please contact me at home on 93317267 or fax 93376879

#### Dear

# RE RESEARCH INTO THE SPIRITUAL NEEDS OF CULTURALLY DIVERSE AUSTRALIANS

I write to tell you about the findings that I have found in the interviews that you kindly gave me. All of you 'bared your soul' so to speak to tell me about past experiences with hospitals and doctors and nurses etc., and situations in which you felt that you had a spiritual need. In addition, you spoke about the journey or passage that you took when having a health care problem and how your spiritual needs were part of that journey. Finally, you gave me clues as to what type of spiritual care that you would like to have from doctors and nurses.

Below I have briefly listed the spiritual needs that I have identified in the data, followed by the journey, and the levels of care you would have liked. These findings are by no means finished, as I need you to tell me whether you agree with them or not. That is, if you do not agree with them you need to let me know so that I can correct any mistakes and/or make changes. I will let you mull over the findings for a couple of weeks and then I will contact you for a final interview at which you can tell me what you think of the findings and changes that you suggest.

#### Brief description of research findings

The spiritual needs that I was able to identify from the interviews irrespective of whether the person was Buddhist, Romany, Quaker, Hindu, or Anglican, or Humanist or Socialist was:

#### 1. <u>Spiritual need of trust – mutual trust.</u>

Not only did the people need to be able to trust in their own spiritual beliefs, and those around them such as family and friends, but they also had a need for trust in the nurse/doctor.

#### 2. Spiritual need of Hope

All the people said that they needed to have hope in the future. This future involved getting better physically so that could again enjoy their family and friends,. They felt that if they were dying they would still want to have hope, not in getting better, but by doing the little things that would be important to them. The manner in which people thought that hope could be available to them was varied

#### 3. Spiritual need of Love

The spiritual need of love in this study was not dependent upon the participant receiving love from another person, rather it was on their ability to give love to another person.

#### 4. Spiritual need of Peace

The spiritual need of peace was not making peace with other people, but rather finding peace within oneself. All the people mentioned that inner peace was important. Finding that peace within yourself is important (X). The manner in which they received peace was varied but primarily involved reflection, meditation and or prayer.

The journey or passage people undertook when they had a health care problem and the way this intertwined with their spiritual needs:

- 1. Person recognises that they have a health care problem and/or has hospitalisation.
- 2. They also realise that something is not quite right spiritually. That is, the person feels that there is some dissonance between normal routines/daily rituals and/or feelings of anxiety or fear due to present condition. For example, they may normally like to take a short while for reflection in the morning and they find they can not do that. Sometimes, the person may not be able to say that they have a spiritual need at this stage.
- 3. If the person is aware that they have of spiritual need, they asked for support or spiritual help/care.
- 4. The person then either received did not receive the spiritual care. This depended on whether or not the nurse/doctor acknowledged the spiritual part of people and how to give that care.

5. Reflection: the person reflected on both their health care problem and their spirituality together, and decided if they needed any further care or not. Reflection usually occurred when either the participant was experiencing the resolution of the health care problem or an increase in severity of their health problem. If a continued spiritual need still existed, stages 2-5 were processed again. If the health problem had resolved, but the participant still experienced some spiritual need they may or may not ask help to resolve the spiritual need. For example, Ann recovered from her traumatic birth experience, but she still had a need for peace related to her fear of dying (for which she had not sought help).

#### Types of spiritual care

Types of spiritual care described care that the people received or would have liked to have received from the nurse/doctor. In addition, two people (X and X) spoke of the spiritual care that they gave to people.

- 1. Acknowledgement, was the lowest level of care by the doctor/nurse. In this level the nurse/doctor acknowledged the spiritual nature of the person, and that they may have spiritual needs that would need to be facilitated (even though the person themselves may not be able to express the needs) while receiving health care. I would have liked my spiritual needs to have at least been acknowledged (X)
- 2. The next level was empathy, which was like an intermediate level of care where the nurse/doctor acknowledged the spiritual nature of the person, but also sought to understand their vulnerability, concerns, fears, and anxieties. Through the inter change of verbal and non-verbal messages the nurse/doctor provided empathy to the person.
- 3. The highest level was valuing or cherishing which occurred when the nurse/doctor acknowledged the spiritual nature of the person, sought to understand their situation, provided empathy, but also had sufficient respect for the person that enabled the nurse/doctor to facilitate the expression of the person's spiritual nature. This could be allowing them to die if they wished, or not having treatment on a special day or Sabbath. Whatever it was that the person needed at the time..

I hope you find these thoughts interesting. I shall phone you in a week or so time to come and see you again. I have attached a confidential draft of the findings for you to

peruse. Could you please examine these and make any corrections that you want and give it back when I come and see you. I ask that you do not photocopy the draft as it includes information about other people. In addition, there will be changes made and then I will be sending you your own final copy. If you want to contact me in the meantime please phone me at home 93317267.

Many thanks

Yours sincerely,

Georgina Hawley

# AN ESSAY EXPLORING SOCIAL CONSTRUCT OF PARTICIPANTS' LANGUAGE

#### **APPENDIX 17**

# AN ESSAY EXPLORING SOCIAL CONSTRUCT OF PARTICIPANTS' LANGUAGE

Dhammapada, chapter 15, verses 197-200

O let us live in joy, in love amongst those who hate!
Among people who harm, let us live in love.
O let us live in joy, in health amongst those who are ill!
Among people who are ill, let us live in health.
O let us love in joy, in peace amongst those who struggle!
Among people who struggle, let us live in peace.
O let us live in joy, although having nothing!

In joy, let us live like spirits of light!

The verses from Dhammapada in the epigraph remind me that although I visited the homes of the eight participants, I knew very little about their social circumstances, and that I needed to remedy this in order to understand more deeply their spiritual needs.

Bakhtin (1978) emphasised the need to identify the social construct of peoples' language if change is to take place (see Chapter Three). That is, he argued that change could not be brought about if the social construct is not known or not used in a way that recognises the starting point from which the change needs to be implemented. He advocated that attempts to bring about change would be ineffectual if the social language of the person/population is not known.

I used Bakhtin's method of textual analysis at two levels. At the first level was the rhetorical analysis of interviews with the participants that yielded the findings recorded as Chapters Five to Nine. At the second level, in this chapter, I undertook a 'material construction of the participants' conversations' within their social contexts (Bernard-Donals, 1994). To achieve this, I explored beyond what was said in interviews to gain a more "holistic" perspective of their experiences in relation to the social constructs (i.e., communal infrastructures or needs of society) comprising key aspects of the social environments in which they lived (Bernard-Donals, 1994).

#### LEVELS OF SOCIAL CONSTRUCT

The epigraph for this section comprises verses from the Buddhist Holy Scripture which are used here to refer to the range of human feelings and personal circumstance that a person seeking health care may be experiencing. Joy, hate (violence, war, conflict, abuse), love, illness (physical, mental, emotional and spiritual), struggle (lack of money, food, or shelter, poverty, fear, anxiety) and peace are mentioned. Although not every person seeking health care will be experiencing these feelings and circumstances, the verses serve to remind health care professionals of the rich diversity of lifestyles amongst the people in their care.

Being a visual person, how am I going to picture the social construct?

I remember feminist moral theory in early Greek culture as three levels (the individual, then the family, and then wider social parameters or society)(Hawley, 1997b).

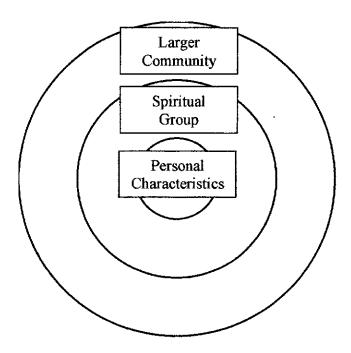
Perhaps I can conceptualise the participants' construct also as three levels, and because context is something that surrounds, the three levels could be concentric circles?

I conceptualised the participants' social construct as three concentric circles (see Fig 4) which represent three levels of social circumstances and interactions.

The first level, that is, the personal characteristics of the participants, includes their age, sex, language, education, and socioeconomic status. The second level is the participants' association with their spiritual community and the characteristics of that community. This includes the history and culture of the spiritual group, the beliefs or truths held by that group (including the members' expected spiritual manifestations and behaviours), the manner in which members are treated by the elders, officials, priests, ministers, and/or pastors, etc. The third level, the participants' connections and dealings with the wider community, includes the availability of spiritual and health care resources and the degree of social support for the participants.

The three layers of social construct have some effect on the spiritual needs and related care that the participants experienced; most importantly they highlighted reference points from which implications and recommendations could be developed. In this chapter, each of these circles, or differing levels of social construct, is explored.

Figure 4 Social construct of participants' language



#### The First Level or Inner Circle - Personal Characteristics

I now consider factors that contributed to the participants' personal characteristics.

#### Age

The eight participants were aged between 30 and 55 years, because I wanted the sample to include only young and middle-aged adults. Previous European and United States research had identified the spiritual needs of Judeo-Christian people who were dying. My purposive sample was chosen, therefore, to avoid people who were elderly and dying.

#### Sexuality and gender

There did not appear to be any data indicating that the gender of the participants had an affect on their social construct. All eight participants were co-habitating with another person, seven in heterosexual relationships and one in a homosexual relationship. Of the seven heterosexuals, five were legally married and two had long-term defacto relationships. Homosexuality is not condoned in many spiritual groups, in particular in fundamentalist Christian religions. A person's ability to cope with health care treatment and hospitalisation is closely tied to the level of social support they receive at the time (Mishell, 1989; Mishell & Powers, 1991). Therefore, if the person has a health problem that is morally unacceptable to their family or spiritual group they may not receive any support from these sources. In circumstances where the sexual relationship with a partner impacts on the degree of social support the participant receives, the health care professional could be the only source of support. This could have been the situation with Tom, for he stated he had experienced 'not fitting in' in various denominations, whereas, he was 'openly accepted with the Society of Friends for who I am' (character 20481 to 20533 TOM.TXT).

#### Language

All eight participants spoke English and were able to articulate reasonably clearly their health care problem and spirituality. Likewise, all participants were literate

and able to reflect on their life experiences, that is, none had an English language disability, which could have affected their ability in gaining health treatment and spiritual care.

#### Education

All of the participants had received primary level and some secondary level education. Six had undertaken further education (Ann, Athika, Tom, Red, Rosie, Sophie), and two had obtained university Masters Degrees (Ann, Athika). The ability to reflect and talk about their spirituality was a crucial factor in deciding whether or not they were to be interviewed for this study. However, being able to talk about their spirituality, which is a subject not openly discussed in society, was said by all the participants to be difficult.

The ability to be reflective affected the participants' potential to realise their spiritual needs when searching for their meaning and purpose in life, and in determining what they wanted of their spiritual group and community, especially when seeking health care. Amongst those who had experienced severe illness, ability to reflect on their health-care related spiritual needs had been restricted by their psychophysiological status (Landrum, Beck, & Williams, 1993). For, example, both Ann and Athika stated that when they were seriously ill they did not have the ability to reflect on their actual spiritual needs at that time.

The participants' levels of education did not correlate positively with their degrees of assertiveness or the extent of their knowledge of health care. For example, although Ann had received a high level of education and was able to communicate and read very well, she had not been aware of the depth of pain that she might experience in childbirth or the frequency of the various positions that a foetus may use to herald its entry into the world. In both of these processes she was overwhelmed and became a very passive participant in events during hospitalisation. Similarly, Red (with a university Bachelor's Degree) was able during interviews to state clearly the kind of health care he preferred, but he seemed to lack assertiveness when dealing with health care professionals. For

example, when he had intense pain and the locum doctor came to see him at home, he was taken aback when the doctor asked him for payment before treating him.

#### Socioeconomic status

All participants received an income that enabled them to live in a house with facilities such as power, electricity, gas, water, and telephone, and have sufficient food to eat. That is, none were "penniless" or living on the streets.

However, four of the eight did not have private health insurance, and it was these four people who had the most complaints about their health care. They (Ann, Tom, Sophie, Scarlet) stated that they could not afford private health insurance or pay the full cost of treatment in a private hospital (See Outer level – participants wider community).

#### Personal Life Experiences

The life experiences of the participants were explored in the previous chapters when their subjective knowledge was discussed (Chapter Five). At this time, the participants recalled their age and method of arrival in Australia (if they had immigrated). Those who were able to remember the experience (Athika, Rosie, Scarlet, Sophie, and Tom) spoke of how their life had changed after arrival. For example, Scarlet said that her family enjoyed greater cultural freedom in Australia (that is, they did not face the discrimination that is directed towards Romanies in Europe).

#### **Employment**

At the time of the interviews, Athika, Geoff, Red, Rosie, and Tom were employed, although Ann, Scarlet and Sophie were not, although Scarlet was recognised as an elder of her spiritual group and received remuneration for services she performed. The types of jobs performed by the participants did not appear to cause them any conflict with their spiritual beliefs, with membership of any groups or with acceptance by the wider community. Because none was engaged in a job or service that others might find distasteful, they did not

experience segregation from spiritual groups or the wider community. A spiritual group may not accept some people who gain their employment through illegal means. Likewise, people employed in risk-taking behaviours sometimes have difficulty obtaining private health insurance. Once, in my capacity as an ordained minister of a church, I met a lady in the community who decided to come to the church services because she claimed that "as a woman, would understand." I had no difficulty in ministering to this woman and giving her Holy Communion at the church services. However, after several weeks the elders (men and woman) of the church took me aside and told me of their difficulty in receiving communion at the same time as this woman, because they believed her to be a prostitute. Such means of employment can affect a person's membership or association with a spiritual group.

#### The Second Level or Middle Circle - Association with Spiritual Group

All eight participants had been associated with one or more spiritual groups during their lives. At the time of the interviews the degree of association varied: Ann, Rosie, Scarlet and Tom were members of various groups, while Athika, Geoff, Red, and Sophie were not. Ann worshipped regularly at a Christian church within walking distance of her home. She and her partner experienced a friendly relationship with the clergy of that church, in that she felt "free and easy to drop into" the Church Rectory and have a coffee with the priests when out walking. Rosie was a member of a Christian church in a different suburb to which she lived. This meant that she needed to drive by car, or make a telephone call to associate with the other members, clergy and elders of that spiritual group. Rosie also sought truths and comfort from outside the Anglican religion..

I have taken what I find to be true and helpful from Christianity, and Buddhism and have worked through my own philosophy of life. I can go into a Buddhist temple, or a Roman Catholic Church, or a Brethren Chapel, or an Anglican Cathedral, Presbyterian Church... it doesn't make any difference to me, it is the comfort of the building that I like. (character 7887 to 8167 ROSIE.TXT)

Scarlet's association with the Romanies meant that, as one of the elders, she used her skills of counsellor, witch, and/or healer within that community. Tom liked to regularly associate with his spiritual group, which is situated in a different suburb to which he lived. He tried to maintain a weekly or fortnightly contact with the group, however this depended on the shifts he worked.

Athika did not associate with a particular spiritual group in Australia, but she did associate with a spiritual group of Hindu's when she was in India each year. Geoff had received some religious instruction during his schooling, but did not associate with a spiritual group at the time of the interviews. However, his job as a green keeper at a Roman Catholic school meant that when he was ill, the staff were supportive and told him that they were praying for him. Red had been sent to Sunday school as a child but did not belong to a spiritual group at the time of the interviews. However, he did attend church services when specifically invited.

#### History and culture of the spiritual group

Each of the spiritual groups to which the participants belonged has experienced hundreds of years of historical tradition. Also, none of the groups expected their members to undertake behaviours that would cause exclusion from other people in the wider community.

#### Beliefs or truths held by that group

The spiritual groups to which the participants belonged all had specific beliefs and truths, which they expected their members to uphold. In fact, it is the beliefs and truths of some of these groups that determined whether the participants maintained an active membership, or refrained from belonging. Also, the participants were critical of the advantages and disadvantages of possible association with the various groups. For example, Tom told of the pleasure he gained from The Society of Friends, and Rosie mentioned that the people of her church were not able to support her.

However, several other factors probably affected the relationship between participant and spiritual group. In the case of Rosie, she had a mental health illness, which still caries stigma in Anglo-Celtic society. Also, the previous Rector, or priest, of her church had committed suicide less than three years previously. This could have had a lasting affect on her and other members of the church. The priest about whom she complained for not giving her sufficient care reportedly had his own personal problems arising from the fact that a close colleague was jailed for making sexual advances and abusing clients he was counselling. That is, this may have caused Rosie's priest to take a detached position or to keep him at a distance when providing pastoral care.

The participants' level of education may have enabled them to be critical and selective of a relationship with a spiritual group or organisation. For example, Tom said that he could not believe in the Virgin Birth and the Resurrection, and therefore did not belong to a church that has such beliefs as an important part of their doctrines. Instead, he was a member of The Society of Friends (Quaker), which invites open discussion and quite liberal thinking, but at the same time expects members to respect other people and be peaceful towards them. In this way, the group provided sufficient ethos to support his concept of spirituality.

# Relationship and the manner in which the elders treated the participants

All eight participants had the necessary critical skills to state what they liked and didn't like about being a member of their spiritual group. They reported that all of these groups allowed their members the freedom of choice to leave the group if they so wished. This relationship with the spiritual community is important if people need and want spiritual support when ill or troubled. The spiritual groups to which the participants belonged had offered this help, advice and support when requested.

Tom, as a homosexual, was most likely to have been ostracized from traditional religious groups while a young adult, if he had refused to marry or remain

celibate. The manner in which the various spiritual groups act towards homosexuals in Western Australia varies. In the 1950s to late 1980s in Western Australia it was medically recommended that homosexuals marry, and many churches sanctioned this as a "cure" for homosexuality. However, for some churches it is easier for the hierarchy 'not to know' about the sexual relationships of their members or their elders or their clergy. According to Athika, Rosie, Sophie, and Tom, some members of religious organisations do not regard having gay activities as being a sexual relationship and, thus, regard themselves as being "celibate". Such a confusing state of manifestations of spiritual beliefs has resulted in an equally confusing treatment of members of these spiritual groups.

Many organisations exclude a practicing homosexual from spiritual and or worshipping activities. Also, more than one type of Christian church says that homosexuals are welcome to be part of their Church, but when the person is not "cured of their homosexuality" after 12 months they are asked to leave. In my experience, such attitudes towards homosexuality have resulted in some relatives of people in Western Australia who have or have had HIV/AIDS, covering up by saying that the person has died or are dying of cancer or lymphoma. On the other hand, some elders in the Anglican Church, realising that some of the clergy and members were gay, have worked in a non-public way towards more open tolerance (for example, a Church service for homosexuals is held in an inner city area). The aim is not to exclude gays from other Church services, but is primarily to try to meet their specific needs within a separate environment.

# The Third Level or Outer Circle - Participants and Wider Community

All eight participants had connections with the wider community in which they lived, and each of these communities was part of a large town or city. The amenities of these communities offered the possibility of engaging in a range of cultural, sporting and recreation, political, education, and health programs. The participants all enjoyed engaging in the wider community and none were ostracized because of their spiritual beliefs or health problems

The health care facilities within the communities were varied; and none of the participants lived in an isolated community or small town with few or no facilities.

#### Politics and government

The ethos of both main political parties in Australia includes supplying pensions or funds to people who are unemployed, sick, disabled, incapacitated, refugees, new immigrants and elderly with no other means to provide for themselves. These pensions and services allow for housing, health care, and education (Saunders, 1998). This government provision is unique and more generous than that supplied to many people in Europe and the USA (Le Fevre, 1997). For example, most new immigrants and refugees are given a living allowance, and free English lessons on arrival (as well as free health care).

At the time of his third interview, Red, on reading the responses from Tom and Scarlet, made this comment about the Australian government's justice and health care systems:

The cultural differences between the Aboriginal and White Australians are just not understood. The same goes for the gypsy and others. The system has not recognised and allowed the expression of different cultures.

But it is not just the health care system; it comes into the Justice system as well. What about Aboriginal women who have been tried for murdering a twin baby? I can remember a case where an Aboriginal woman is tried because she wanted to kill one of her twins. To her a twin child is not accepted in her tribe's spiritual beliefs. If she quietly killed one, then she could keep the other and that would be spiritually acceptable to her tribe. The court thought she should be made to bring up both the children. They supplied the powdered milk etc., only to find that both twins died a short time later as the mother and the tribe did not spiritually accept the notion of twins. The mother had not fed the twins, but left them to die. Subsequently, she is convicted of manslaughter and imprisoned. (character 30030 to 30830 RED.TXT)

Scarlet spoke of the difference between being a gypsy in Australia and living in the UK and Europe. In Australia, she found that there is no need to have more than one name in order to escape racial discrimination. In fact, she is full of praise

for the Australian government for providing what she termed "the high level of support, education, and health".

#### Availability of health care resources

Health care in Australia is available to all people who seek treatment, through either public or private facilities. That is, either fully funded care provided by the government, or paid for by private health insurance. None of the participants was deprived of health care treatment, although the standard of care they received probably varied (Australian Parliament House of Representatives Standing Committee on Community Affairs, 1991; Australian Steering Committee for the Review of Commonwealth/State Services, 1998). From my experience as a nurse and chaplain, I have noticed that the Government managed hospitals have lower ratios of registered nurses to patients (1:1-1:16), with most patients nursed in large shared wards. There is also no inherent spiritual philosophy, and although there is some funding from the private patients attending the hospital, this is insignificant because there are so few private patients. Although these hospitals will supply some spiritual care within the Judeo-Christian tradition, not all other beliefs are catered for. However, one hospital now provides a prayer room for Islamic patients, but that is some distance from the majority of the wards where the patients are nursed (for some patients the distance would be as much as 800 metres as these patients would not have a direct route to get to the facility). The main emphasis in these hospitals and other government controlled health care organisations is to provide physical care. For example, people admitted to these hospitals are not asked about their spiritual beliefs; nor is their spiritual status assessed by nurses when performing a comprehensive assessment (O'Connell, Rapley, & Tibbets, 1999).

#### Sporting and recreation activities in the community

Sporting and recreation facilities were available in the different suburbs where the participants lived. Their local government councils provided some of these free of charge, and others needed to be paid for. However, none of the participants felt deprived of such facilities. In each area, they had a free government library,

availability of transport to shops, cinema, sporting venues and arts theatres. For example, both Scarlet and Sophie enjoyed walks along nearby beaches and were members of their local library, which not only supplied books and magazines, but also audio-tapes and videos, and use of computers and Internet access. These facilities help to maintain well-being and health in local communities (Mackay, 1993; Rawlins, Beck, & Williams, 1993).

#### SUMMARY

In this essay I have explored the social material construction of the participants' conversations (Bernard-Donals, 1994), in order to understand the communal infrastructures within their communities. It is from this construction that I realise that I have not included any non-English speaking Australians, homeless and/or malnourished people, or those living below the poverty line, or uneducated. Therefore, when writing the recommendations for social change (of including spirituality into education for health care professionals) I need to remember that it can only be directed towards those participants who read, have a home, and have some income to support themselves.