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Understanding palliative care: An ethnographic study of three Australian palliative care services

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**UNDERSTANDING PALLIATIVE CARE:
AN ETHNOGRAPHIC STUDY OF THREE AUSTRALIAN
PALLIATIVE CARE SERVICES**

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**Registered Nurse, Certificate of Oncological Nursing,
Bachelor of Science (Health Sciences)**

**This thesis is presented in fulfilment of the requirements for the degree of
Doctor of Philosophy**

Faculty of Computing, Health and Science

Edith Cowan University

5 August 2005

USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

ABSTRACT

Palliative care commenced in Australia in the early 1980s. Although the value of palliative care has become more widely recognised by the public and other health care professionals, there is still a lack of understanding about what palliative care is and the depth and scope of this specialty area of health care. The research that I present in this thesis is based on examination of palliative care practice in a selection of Australian services, undertaken with the aim of enhancing understanding of *Palliative Care*. The significance of the research arises from the notion that members of the Australian community should be well informed about health care options available to them. Understanding palliative care and the ability to differentiate palliative care from other end-of-life care is important if people are to make informed decisions about supporting, accessing, and using services appropriate to their needs.

An interpretive ethnographic study from a symbolic interactionist perspective was undertaken in three palliative care services, one in each of the major Australian cities of Sydney, Melbourne, and Perth. Each palliative care service had been established for at least ten years, and was part of a larger health care facility. A fourth service, a purpose-built three-year-old unit, was added during the course of the research to provide contrast to the emerging analyses. As an experienced palliative care nurse, I assumed the role of marginal native as the primary research instrument. Data collection was by means of participant observation, formal and informal interviews, and examination of supplementary data sources, with two months spent in each of the three study sites.

Interpretations made from ethnographic observation of these Australian palliative care services showed a diversity of practice, best understood within the context of the particular service. The major findings are presented under the headings of Politics, Place, People, and Practice of Palliative Care. Common approaches to provision of care were found in creating an appropriate physical environment for patients, with an underlying mission to "make the best of things." Patients cared for in the settings were a similar cohort of middle aged to elderly cancer patients. In general, staff shared expectations of appropriate types of patients and showed discomfort or lack of understanding in caring for non-cancer patients, or patients from non-Australian, non-Christian, and non-English speaking backgrounds.

Practice diversity was highlighted by the range of technology used and variations in the availability of social activities for patients in the services. These two areas in particular warrant further research to examine the outcomes associated with these variations, in terms of survival time, quality of life, and service costs.

These findings are particularly relevant at this time when the Australian Government is attempting to enhance access to palliative care. The diversity of practice uncovered in this study suggests that discussions and decisions about allocation of resources and development of services must take into consideration the various interpretations of palliative care services that may exist. The findings also reinforce the need for sound evidence-based studies to examine the impact of variations and the types of populations that might be best served by different types of palliative care support.

DECLARATION

I certify that this thesis does not, to the best of my knowledge and belief:

- (i) incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education.
- (ii) contain any material previously published or written by another person except where due reference is made in the text; or
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It is impossible in this small passage to express appreciation to all the individuals who have contributed to this research and to my learning. It is also impossible to express how much I have been supported by my three supervisors; Professor Linda Kristjanson, Associate Professor Suzanne Nikoletti, and Dr Moira O'Connor. My heartfelt thanks to them for their ongoing commitment, guidance, and friendship.

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Although few of the participants in my research are likely to read this work, I would like to thank them all. During my field work in particular, the generosity of staff, family members, and the patients of palliative care was overwhelming. Sharing their stories, witnessing their lives, and recording their experiences has been a privilege. I trust that this work has been faithful to them.

TABLE OF CONTENTS

USE OF THESIS	ii
ABSTRACT	iii
DECLARATION	v
ACKNOWLEDGEMENTS	vi
TABLE OF CONTENTS	vii
LIST OF TABLES AND FIGURES	x
CHAPTER ONE	1
SETTING THE SCENE	1
Introducing Australian Palliative Care	2
Contemporary Health Care	3
End-of-Life Issues	4
The Australian Health Care System	7
Dilemmas Within Palliative Care	11
Measuring Outcomes in Palliative Care	12
Outcomes of Palliative Care	15
Purpose of the Study	17
Significance	18
The Public Profile of End-of-Life Issues	18
Reported Need for More Palliative Care Services	18
Funding Pressures in Health Care	19
Navigating the Thesis	20
A Personal History of Palliative Care Involvement	20
Continuing the Journey: The Chapters to Come	22
CHAPTER TWO	23
WALKING IN THE FOOTSTEPS	23
Difficulties in Understanding Descriptions of Palliative Care	23
Definitions of Palliative Care	24
Terminology	31
Difficulties in Understanding End-of-Life Issues	37
Attitudes to Death and Dying	37
Palliative Care as a Response to Attitudes about Death and Dying	39
Understanding and Misunderstanding about Palliative Care	40
The Path Already Trodden	46
Summary	49
CHAPTER THREE	50
FRAMING THE RESEARCH	50
Philosophical Orientation	50
Epistemology	51
Theoretical perspective	52
Methodology	54
Methods	60
Conceptual Map Based on Prior Research	60
Summary	70
CHAPTER FOUR	71
BOLDLY INTO THE FIELD	71
The Research Instrument	71
Marginal Native	72
Nurse-Researcher	72
Limitations of the Researcher's Role	75
Gaining Access	77
Building Rapport	79
Leaving the Field	81
Selection of the Settings	82
Participant Selection	84

Key Informants	84
The Ethnographic Research Cycle	85
Data Collection	86
Data Recording	90
Data Analysis: Reframing the Questions	93
Writing the Report	94
Rigour of the Research	94
Truth Value	95
Triangulation	96
Reflexivity	96
Peer Debriefing	98
Ethical Considerations	98
Summary	100
CHAPTER FIVE	101
THE POLITICS	101
The Development of Palliative Care Services in Australia	101
Sydney, New South Wales	102
Melbourne, Victoria	103
Perth, Western Australia	104
Strategic Focus for Palliative Care	106
Naming the Palliative Care Services of the Study	107
Demographic Profile of the Fieldwork Sites	108
Administrations	110
Cooperation and Competition	111
Links with Other Palliative Care Services	116
Waratah and Kookaburra: A Continuum of Palliative Care?	116
Heath: One of Several Palliative Care Units	120
Numbat: Integration in a Small City	125
Serving Two Masters: Palliative Care and The Dollar	126
Summary	128
CHAPTER SIX	129
THE PLACE	129
First Impressions	129
Waratah Royal Suburban Hospital, Sydney	129
Platypus Regional Hospital, Sydney	134
Heath Church Hospital, Melbourne	137
Black Swan Private Hospital, Perth	139
Selection of Sites	142
Physical Features of the Units	143
The Purpose Built Palliative Care Unit	143
Making Do: From a Five Star Resort to the Transformation of a Cupboard	145
Special Features of the Units	155
Summary	156
CHAPTER SEVEN	158
THE PEOPLE	158
Everyone a Participant	158
Patients	162
Family	163
Staff	167
Staff Relationships	180
The Senior Nurse	180
Staff Support	182
Sources of Stress	184
Staff-Patient Relationships	189
Loving Care	190
Part of The Job	192
Summary	195
CHAPTER EIGHT	196
THE PRACTICE	196
Ward Routines, and The Not-so Routine.	196
Medications	197

Vital Signs and Nothing More Can Be Done	198
Technology: Innovation, Invasion or Stuck in a Rut?	200
Basic Care: Nutrition, Elimination, and Hygiene	204
Food: "But if he doesn't eat he'll die!"	204
Bowel Care: A priority in care	208
Hygiene: A Gentle Touch	209
Beyond the Norm: the Extra Touches	210
Social Routines: "Would you care for a drink?"	210
Complementary Therapies: Non-invasive, Comfort Measures	211
Everything Else: Psychological, Spiritual and Social Care	212
Who Does "Everything Else?"	213
Music and Art: Diversion or Therapy?	214
Other Creative Support	216
Social Activities	217
Important Events in Palliative Care	223
Pain: The Palliative Care Emergency	223
Dying: A Lonely Ride or Going the Journey?	224
Death	230
Summary	233
CHAPTER NINE	234
UNDERSTANDING PALLIATIVE CARE:	234
A SYNTHESIS AND DISCUSSION	234
The Research Questions	234
Understanding Palliative Care: Politics	235
Understanding Palliative Care: Place	237
Understanding Palliative Care: People	238
Understanding Palliative Care: Practice	242
Understanding Palliative Care: Competing Tensions	247
Methodology and Limitations	248
Design Limitations	248
The Research Instrument and Rigour	250
Significance of the Findings: So What and What Next?	250
Palliative Care: Philosophy or Practice?	251
Implications of the Research	252
Original Significance of the Research	253
Future Research	255
Conclusion	256
REFERENCES	258
APPENDIXES	276
Appendix 1	277
Appendix 2	317
Appendix 3	327
Appendix 4: Participant Information	338
Appendix 5: Ethics Committee Approvals	347

LIST OF TABLES AND FIGURES

Table 1	<i>A Selection of Palliative Care Definitions</i>	25
Table 2	<i>Major Differences Between the 1990 and 2002 WHO Definitions of Palliative Care</i>	29
Table 3	<i>Terminology - Palliative Care and Selected Synonyms</i>	36
Table 4	<i>Top Responses about Palliative Care given by General Community Members</i>	42
Table 5	<i>Answers to Two Questions Included in the Palliative Care Council of SA Surveys of Public Awareness of Palliative Care and Hospice Services 1995 and 1998</i>	44
Table 6	<i>Results of Surveys about Understanding of the term "Palliative Care" conducted on behalf of Palliative Care Australia, 1999 and 2000</i>	45
Table 7	<i>Ten most frequent responses, beliefs and feelings combined, for each group. From "Attitudes towards palliative care: A comparative study of nurses and community members" (Webster, 1999).</i>	63
Table 8	<i>The trajectory of palliative care experience. From "Long-term palliative care workers: More than a story of endurance" (Webster & Kristjanson, 2002b)</i>	64
Table 9	<i>"Attitudes and Vitality". Concepts about palliative care identified by participants from previous research</i>	68
Table 10	<i>Population Size of the Three Capital Cities</i>	103
Table 11	<i>Pseudonyms for the Parent Hospitals and for the Palliative Care Services</i>	107
Table 12	<i>Demographic Data for Geographic Catchment Areas of Palliative Care Data Collection Sites, from Australian Bureau of Statistics 1996 Census Data</i>	109
Table 13	<i>Major Features of the Study Sites</i>	142
Table 14	<i>Demographic Data of Staff Participating in Formal Interviews</i>	160
Table 15	<i>Demographic Data of Patients and Family Members Participating in Formal Interviews</i>	161

<i>Figure 1</i>	Framework for this research, from Crotty (1998, p. 4).	51
<i>Figure 2</i>	Conceptual framework of the meaning of palliative care for long-term palliative care workers. From "But isn't it depressing? The vitality of palliative care"(Webster & Kristjanson, 2002a).	66
<i>Figure 3</i>	"Attitudes and Vitality". A conceptual map of concepts identified in previous research.	67
<i>Figure 4</i>	The Ethnographic Research Cycle (Spradley, 1980).	85
<i>Figure 5</i>	Numbat Palliative Care Unit: an interdisciplinary team model.	171
<i>Figure 6</i>	Honeyeater or Possum Ward, Heath Hospital: multidisciplinary team models.	175
<i>Figure 7.</i>	Waratah Palliative Care Ward: essential clinical core of doctors and nurses.	176
<i>Figure 8.</i>	Kookaburra: model of a developing team.	178
<i>Figure 9</i>	Relationships between perceptions of the use of technology and quality of life.	244
<i>Figure 10</i>	Diversity of approaches to psychological and spiritual support.	246
<i>Figure 11</i>	Constructs interpreted from observation of palliative care.	248

CHAPTER ONE

SETTING THE SCENE

Palliative care commenced in Australia in the early 1980s. Since then services have expanded and many people have benefited from using them. Although the value of palliative care has become more widely recognised by the public and other health care professionals, there is still a lack of understanding about what palliative care is and the depth and scope of this specialty area of health care. The research that I present in this thesis is based on examination of palliative care practice in a selection of Australian services, undertaken with the aim of enhancing understanding of *palliative care*.

The significance of the research arises from the notion that members of the Australian community should be well informed about health care options available to them. Understanding palliative care and the ability to differentiate palliative care from other end-of-life care is important if people are to make informed decisions about supporting, accessing, and using services appropriate to their needs.

The purpose of this first chapter is to “set the scene” for the remainder of the thesis. In this chapter my aim is to provide the reader with an appreciation of the relevance of the research questions as well as the contribution that addressing these questions will make to the field.

I introduce the topic of palliative care by providing an outline of historical and current knowledge about palliative care. I discuss some of the other end-of-life issues, such as euthanasia, that have gained attention among the general public and that contribute to confounding the understanding of palliative care. I also provide some evidence that points to a lack of understanding of palliative care among the Australian public.

In this chapter I also give an overview of the context of palliative care within the Australian health care environment and the different models of care that are found in Australia. Dilemmas that exist within palliative care are outlined, including the difficulty in finding meaningful outcome measures. These are issues that contribute to confusion in understanding palliative care.

I conclude the chapter with a personal reflection of my experiences of palliative care that further serves to orient the reader to the chapters that follow.

Introducing Australian Palliative Care

A definition of palliative care given by Palliative Care Australia in 1999 is “palliative care is *specialised health care* [italics added] of dying people aiming to maximise quality of life, and assist families and carers during and after death” (Palliative Care Australia, 1999b, p. v). The definition appears in the third and most recent edition of “Standards for Palliative Care Provision” produced by Palliative Care Australia, which is the peak (main) body representing palliative care in Australia. Understanding this “specialised health care”, however, has proven to be problematic and is the basis for this research.

Palliative care is recognised as a way of easing the suffering of dying individuals (Saunders, 1993; Woodruff, 1999; World Health Organization [WHO], 1997). Development of services has occurred throughout the world, and began in Australia in the 1980s. There are now approximately 250 services employing palliative care health professionals in Australia, and a variety of models are used to provide palliative care to more than 24,000 people each year (Currow, 2002).

Although palliative care is considered to be a worthwhile endeavour by those involved in its provision, and significant growth of services has occurred in Australia during the last two decades, people working in the area have labelled palliative care as the “Cinderella of the health system” (Palliative Care WA Inc, 2003, p. 2). In 2003 Palliative Care WA Inc, the Western Australian representative association of Palliative Care Australia, reported that palliative care received less than one percent of the health care budget and that palliative care is only briefly mentioned in both Commonwealth (Australian Government) and State government reports. The low profile of palliative care within the health care system may contribute to people within the community being unaware or having little understanding of palliative care.

Alongside this lack of understanding, people in the Australian community are striving to be more involved in decision making. A lack of awareness about aspects of health care may lead to people making uninformed decisions. A clearer understanding of palliative care by the public, health professionals, and health policy makers is required if people are to make *informed* decisions about health care options.

Contemporary Health Care

One hundred years ago community involvement in health care was the norm. Care for sick and dying people either occurred at home or in local community hospitals. These hospitals were typically small charitable institutions, sponsored and administered by the local community, and offered little more care than could be provided in the home (Haralambos, van Krieken, Smith, & Holborn, 1996). The influence of socialist ideologies of the nineteenth century changed expectations about health care and people began to consider that professional health care was a right, regardless of socio-economic status (Lawson, 1991).

During the twentieth century, due to advances in medical treatments as well as public health strategies such as improved sanitation, many infectious diseases were eradicated. In industrialised countries worldwide, life expectancy increased and child mortality decreased (WHO, 1997). Extraordinary medical advances in life saving and life creating technologies were achieved, ranging from the use of antibiotics to organ transplantation, in vitro fertilisation, and cloning. These trends continue into the present century. One of the consequences of the technological advances in health care has been reliance on a biomedical model of care. Hospitals have become centralised places of technological expertise, providing care that is not possible to provide in the home, and advanced training has become necessary to use the technology. The result has been a move away from community participation in health care to an increasing dependence on tertiary health facilities, and increased autonomy and authority of the medical profession (Davis & George, 1993; Haralambos et al., 1996).

There have also been responses opposing the emphasis on biomedical models, with renewed calls for community involvement in health care. Primary health care, an approach to care that acknowledges that individuals and communities have a right and a duty to be involved in health care, has been one response. As well, community involvement is inherent in public health strategies, which aim to prevent disease and injury in whole communities. A primary care and public health focus led to the WHO Declaration of Alma-Ata in 1978, with the goal of health for all by the year 2000 (WHO, 1979). Increasingly, people's expectations of health care include equity and access to care, community involvement in planning and implementation of health care, and education regarding current health problems including preventative and controlling strategies (WHO, 1978).

A related health trend has been the emergence of the concept of "consumer health", a term used to convey a response to health care that is part of the overall "consumer movement", described as a reaction to the profit-making focus of the business world (Cornacchia & Barrett, 1993). Consumers will stand up for their rights, including their right to choose, to be informed, and to be heard. Although most people have embraced the technological advances in health care, they also have higher expectations about their rights as health care consumers. It is likely that many are reacting to health care systems that are perceived to be bureaucratic and that allow little patient control. Consumers are seeking to make informed choices about the health services they use and many health care providers have endorsed this stance.

There are other trends that have noticeably changed the health care focus away from a biomedical model. Health promotion strategies, for example, encourage better nutrition and increased fitness. Traits such as fitness and youthfulness are actively sought and marketed in modern societies (Cornacchia & Barrett, 1993), and people are seen as key players in maintaining and improving their own health.

In summary, community involvement in health care during the last century has moved from individuals being directly engaged in provision of health care, often within their homes, to a period of technical dominance with little individual or community control or involvement. More recently, the focus has returned to the individual with emphasis on consumer participation in health care and informed health care decision making. Further, the current emphasis on health promotion and "wellness" suggests that people within communities are interpreting the term "health care" differently. In this context, a more appropriate label for the *traditional* idea of health care might be "sickness care."

End-of-Life Issues

Paradoxically, while there has been an increased focus on fitness and youthfulness, there has also been lively public discussion regarding end-of-life care. The principles underpinning a primary health care approach, namely inclusion of individuals in decision-making and a focus on holism, carry over into end-of-life care debates. The advent of the modern hospice movement was a response to care of dying people that embraced similar principles. The hospice movement evolved as a result of the perceived increase in the medicalisation of dying with an associated objectification and lack of inclusion of the individual (Davis & George, 1993).

Care for people at the end of life is currently receiving greater publicity and engaging community members' attention. The cohort of post World War II "baby-boomers" includes people who are now approaching sixty. Many within this cohort are concerned about the quality of aged care that will be available to them in the future (McCallum, 2000). Public debate about topics such as advance care directives, physician-assisted suicide, and euthanasia are evidence that the consumer focus on aged care and end-of-life care is present.

Death and Dying in Contemporary Society

The positive focus on wellness promulgated by contemporary society is at odds with the focus on death and dying associated with palliative care. This tension is illustrated in O'Gorman's (1998) phrase, "death and dying versus health and healing." Further apparent disparity between contemporary health care aims and those of palliative care arises when considering the technological advances that have been made in healthcare. Many of these advances have changed the view of death as an inevitable outcome of many diseases, to expectations that illness is largely preventable or at least curable.

Although the principles of palliative care, such as an holistic patient and family focus (Goodlin, 1997; Saunders, 1993; Woodruff, 1993), resonate with a primary care approach, the association with death and dying may mean that palliative care is still not a subject considered by many people in the community. This presents a challenge when trying to communicate an understanding of palliative care to the general community. A further challenge arises from the association of palliative care with other end-of-life issues such as euthanasia.

Euthanasia

Euthanasia has become a high profile topic for community debate in Australia, especially since the 1995 Northern Territory legislation allowing euthanasia (Eccleston, 1997; Haralambos et al., 1996). Under this legislation, four people were assisted to die before the bill was repealed by the Commonwealth government in 1997 (Cancer Foundation of Western Australia Inc, 1999; Kissane, Street, & Nitschke, 1998). Continued campaigning in favour of legalising euthanasia is ongoing amongst lobby groups and the high-profile champion of the Northern Territory enactment, Doctor Philip Nitschke (Dickens, 2002). A position statement issued in 1999 by Palliative Care Australia clearly stated that palliative care practice does not include the deliberate ending of life (Palliative Care Australia, 1999a). Nevertheless, palliative care and

euthanasia are often linked within the public debates, which further clouds the public's understanding about palliative care.

Debate exists among some palliative care experts regarding support for euthanasia. Hunt (1998) for example, argues in favour of law reform to legalise the practice of euthanasia, which he believes is covertly practiced by doctors, including those working in palliative care. O'Connor and Menon (1998), however, report that studies of palliative care nurses' views about euthanasia reveal that attempts to ascertain attitudes towards euthanasia may be oversimplified. In surveys about attitudes towards euthanasia, people are generally asked to respond to scenarios that suggest patients' requests for euthanasia are related to their ongoing suffering and uncontrolled symptoms. O'Connor and Menon argue that nurses' responses to these scenarios need to be taken in context, and not used to make claims about overall support for euthanasia. They further report that palliative care nurses indicate concern about the lack of resources allocated to palliative care, and the authors argue that the debate needs to shift from legalisation of euthanasia to allocation of resources supporting terminally ill people.

The view that attention to euthanasia is obscuring understanding about palliative care was proposed also by Palliative Care Australia, then named the Australian Association for Hospice and Palliative Care (AAHPC), when reporting to the Australian Senate Committee on Euthanasia in 1997 (AAHPC, 1997a). AAHPC, representing the vast majority of palliative care providers in Australia, acknowledged that there was no agreed view on the question of euthanasia. What was clear was the distinction between palliative care and euthanasia; euthanasia is not a part, nor an extension, of palliative care. Further, the AAHPC expressed concern that the public was linking palliative care and euthanasia, and that this false connection was jeopardising relationships between patients, their families, and palliative care providers.

The extent to which public views on euthanasia influence opinion about palliative care has not been described. However, if confusion does exist within the community about the distinction between euthanasia and palliative care, then such confusion may interfere with good health policy decisions.

Awareness of Palliative Care

Palliative care associations have conducted surveys to ascertain the level of public understanding of palliative care, and report some evidence of poor understanding of palliative care within the wider community. In South Australia in 1995, two-thirds of

a representative sample of the population were reported to have no understanding of the term "palliative care," and in 1998 after various awareness-raising campaigns the figure was still about half (Palliative Care Council of South Australia, n.d.). Nationally, Nightingale (1999), who was at the time President of Palliative Care Australia, reported results from a national survey that indicated as many as three out of four Australians may not know about palliative care.

One of the strategies adopted in Australia to raise awareness about palliative care is a National Palliative Care Week each year. These activities are supported by the Commonwealth Department of Health and Ageing, one of the outcomes of Palliative Care Australia successfully lobbying the government about raising awareness of palliative care. The theme for the 2002 National Palliative Care Week was "Palliative Care: A Community Affair" and this launched a twelve month campaign to increase community awareness, build community capacity, and improve awareness "within the health care system and broader health community" (Palliative Care Australia, 2002, p. 6).

Other ad hoc awareness raising activities, including programs provided for minority groups such as people from non-English speaking backgrounds and Aboriginal people, have been conducted (Health Department of Western Australia, 1997; Kasap and Associates Pty. Ltd., 1996). However, there has been little evaluation of these programs.

These various strategies may increase awareness of palliative care within the general community, yet communicating a clear *understanding* of palliative care remains problematic. This difficulty is also demonstrated by the challenges of succinctly communicating about the benefits of palliative care as well as the various models of palliative care that exist in Australia. Some of this variety may be due to the complexity of health care arrangements that exist between the Commonwealth and the States.

The Australian Health Care System

The health care system in Australia is a mixture of free enterprise, social insurance, and universal service models (Haralambos et al., 1996). Revenue for the health care system comes from the Medicare levy, currently 1.5 % of taxable income, Commonwealth general revenue, State taxes, voluntary private insurance premiums, and individual out-of-pocket expenses. Under the Medicare program, Australians are entitled to full hospital cover as public patients in public hospitals, and 85% of the scheduled fee for non-hospital medical consultations. Voluntary private health insurance

provides rebates for some of the gaps in the Medicare program, and also enables patients to elect to use private hospitals or be private patients within public hospitals (Bloom, 2000).

The Australian health care system has complex arrangements between the three tiers of government, Commonwealth, States (and Territories), and Local Government, as well as private sector involvement (Haralambos et al., 1996). In general terms, provision of services is a State responsibility with Local Governments providing limited services including immunisation and sanitation programs. Funding is primarily from Commonwealth general revenue grants, which is passed on to the States, as well as the States supplementing their health budgets from State revenues. Regulation is essentially a State responsibility. Private sector involvement is also represented in all of these aspects of the health care system. (Bloom, 2000; Davis & George, 1993).

Palliative Care Within the Health Care System

Within these complex arrangements, the Commonwealth has provided “quarantined” funding, which is funding to be used specifically for palliative care services, under various programs. The first of these funding initiatives was in 1988 through the Medicare Incentive Program (MIP). As noted by Smith (2000), another former president of Palliative Care Australia, this was the first time that the Commonwealth made specific reference to palliative care in any of its policy arrangements. Through the MIP, funding was available for palliative care services that would reduce the burden on hospital services. Over the five years of the program nearly \$40 million dollars was provided (Kasap and Associates Pty. Ltd., 1996).

The subsequent Commonwealth funding program for palliative care provision was the Palliative Care Program (PCP). The PCP, commencing in 1993-94, allocated nearly \$70 million for palliative care during the five years of the program. States and Territories received part of these funds, allocated on a per capita basis, and the remainder was used for projects that had a national focus (Commonwealth Department of Health and Family Services, 1998a). The emphasis of the PCP was to support development of community-based and volunteer services (Commonwealth Department of Health and Family Services, 1997).

The “Kasap Report”, an independent review commissioned by the Commonwealth, reported Stage One of this program, the terms of reference being to report on the outcomes of the first three years of this program and to make comment on the appropriateness of current services, identifying any gaps (Kasap and Associates Pty.

Ltd., 1996). In a media release in 1996 the Federal Health Minister, Dr Michael Wooldrige, stated that the Kasap Report had highlighted that the PCP had “considerably accelerated the development of community based palliative care, but also ... there are many artificial barriers to seamless and accessible services – not the least of which is the lack of coordination of current Federal-State funding arrangements” (Commonwealth Department of Health and Family Services, 1996).

The Stage Two review of the PCP was undertaken in 1998 with the aim of identifying principles for the delivery of palliative care services and to report on the use of performance indicators for future monitoring of services (Commonwealth Department of Health and Family Services, 1998a). Within this document it was reported that the States and Territories, funded through both general and specific programs, established their own priorities for development of palliative care. Gaps were noted to exist in both service provision and geographic areas, said to relate to the stage of development of services within each State (Commonwealth Department of Health and Family Services). The review also outlined the multiple sources of funding for palliative care in addition to the Medicare Agreements and Palliative Care Program arrangements. Other government programs as well as non-government programs, volunteers, charities, and community organisations contributed to the funding of services.

The 1998 review led to the development of the document “A National Strategy for Palliative Care in Australia 1998-2003” (Commonwealth Department of Health and Family Services, 1998b). Two key issues were noted and claimed to be addressed in the strategy. The first was the increasing demand for palliative care services in Australia, and the second was the need for an effective range of high quality services. Both issues were addressed within the context of “resource constraints and competing priorities” (Commonwealth Department of Health and Family Services, p. 1). Again, this document was linked to a funding program, in this case the five year Australian Health Care Agreements.

A second edition of the strategy, “National Palliative Care Strategy: A National Framework for Palliative Care Service Development”, was published in October 2000 and is the current policy document for palliative care. The strategy reinforces the notion of providing equity and access of quality palliative care to all people who are dying, and makes mention of several groups of people, including children, people in remote areas, and people with mental illness, who may have particular needs or difficulties in access

to services. The three major goals of the strategy are awareness and understanding, quality and effectiveness, and partnerships in care (Commonwealth Department of Health and Aged Care, 2000).

In the 2002 Commonwealth budget a further \$55 million was committed by the government over four years to support palliative care in the community (Commonwealth Department of Health and Ageing, 2002). The Executive Director of Palliative Care Australia expressed pleasure at this outcome, which was achieved against an overall cut of \$1.9 billion from the health budget. She claimed that this allocation was evidence that "palliative care is now on top of the Government's health agenda for the next few years" (Barnes, 2002, p. 4).

When viewed in terms of overall annual health expenditure, which in the 2000-2001 financial year was around \$61 billion or about 9% of the Gross Domestic Product (Australian Institute of Health and Welfare, 2002), these Commonwealth injections of funding seem minuscule. Certainly palliative care is on the agenda, but seemingly not at the top. These injections of monies have, however, allowed development of particular areas by funding one-off projects and pilot services.

The role of the Commonwealth in palliative care advancement continues to be one of coordination and support to the States. The responsibility for the way in which palliative care services are established, delivered, and funded remains with the States. As an example of State funding, Foley (2002) identified a palliative care budget of \$15 million for Western Australia for the 2000/2001 financial year, of which \$2 million was provided by the Commonwealth through the Australian Health Care Agreement. She stated that this \$15 million represented almost 1% of the total health budget for the state. In 2002, the Western Australian State government committed an additional \$8 million over four years (Foley; Palliative Care WA Inc, 2002). This commitment indicates that support for palliative care is increasing, even though Palliative Care WA Inc (2001) report that the amount still falls short of the desired level of funding.

Current palliative care expenditures remain difficult to identify. Mixed funding models, one-off project funding, services in various stages of development, and immature data collection systems create difficulties in both capturing and comparing data. Many of the costs in palliative care are also borne by families caring for people at home, and are therefore "hidden" from accurate palliative care expenditure. There is need for secured, recurrent funding to develop and maintain services to meet current and future need. As Kasap and Associates Pty. Ltd. (1996) reported, without coordination of

funding arrangements, palliative care services are likely to remain fragmented and uneven in quality and delivery capabilities.

Further complicating the issue of sustaining and creating adequate funding for palliative care provision, is the variety of palliative care models that currently exist. This creates further confusion in understanding palliative care and its aims in the context of the overall health care system.

Models of Palliative Care

Palliative care is practiced in a range of settings in Australia. These include hospitals, stand-alone inpatient units, residential institutions, and in the home and community (Jellie & Shaw, 1999; Kasap and Associates Pty. Ltd., 1996). The various models of palliative care have developed, in part, as a consequence of the setting of care.

Models also reflect the use of available resources within those settings. For example, a social worker may not be part of a domiciliary palliative care team, but is likely to be included in a hospital-based team having been seconded from the general staff of the larger facility. If resources allow, a social worker may be part of an interdisciplinary palliative care team in a stand-alone facility and work solely within that unit. It is likely that not only the composition of palliative care teams differs according to setting, but also many other factors vary according to resources and needs of the particular service.

Although different models of palliative care have developed throughout the country, all are described as palliative care services. It is possible that, due to a range of resources, activities, and interpretations within these various models, the practice of palliative care is not consistent. The extent to which the assumption of homogeneous palliative care practice between services holds true has not been clearly articulated. This further adds to the difficulty in understanding palliative care. Additional dilemmas arise when attempting to describe the outcomes of palliative care provision.

Dilemmas Within Palliative Care

Within palliative care communities, the importance and value of the care is implicit. In the early days of the hospice movement, little concern was given to providing objective evidence of the benefits of palliative care. The subjective feedback from patients and their families was sufficient for practitioners to feel satisfied with their work and the overall endeavour. Many early hospice programs were supported by

charitable organisations, and no provisos were attached to funding of services. With the continuing development of palliative care, various measures of performance have been introduced.

Outcome measures serve to provide a foundation for improved practice and are, therefore, useful clinical tools (Higginson & Carr, 2001). However, much of the impetus to procure meaningful palliative care outcome measures has been driven by the requirements of health care funding bodies and the need for palliative care service providers to meet contractual obligations. Clinical aims and management aims may not be the same, and may lead to different outcome measures or different interpretations of the outcomes obtained. As well, outcomes of palliative care are elusive to define and challenging to measure.

Measuring Outcomes in Palliative Care

The desired patient and family outcomes of palliative care are purported to include easing suffering and improving quality of life (Saunders, 1993). Such outcomes appear to be highly desirable for people who have a terminal illness. However, providing more than anecdotal evidence of these outcomes is problematic.

There are significant challenges in conducting research with palliative care patients and families. Some that have been noted in the literature include methodological issues such as controlling for confounding variables, and the need for multicentre studies to gain sufficient numbers of patients (Addington-Hall, 2002; Higginson, 1999; Maddocks, 2002; Twycross, 1993). As well, there are additional ethical considerations when conducting research with vulnerable groups, such as terminally ill patients and their families (Aranda, 1995; Twycross, 1993). The sensitivity of these ethical issues has sometimes resulted in health professionals, including members of human ethics committees, acting as “gatekeepers” in the belief that research participation will place an unnecessary burden on people at this point in their lives (Aranda, 1995; Lee & Kristjanson, 2003; Twycross, 1993).

Easing Suffering: Symptom Distress

Although there are impediments to conducting research with palliative care populations, there is clinical benefit in providing meaningful outcomes of the work and some research efforts have been fruitful. Various researchers have developed instruments to measure levels of patients’ symptom distress (Bruera, 1998; Holmes, 1989; McCorkle & Young, 1978; Sutcliffe-Chidgley & Holmes, 1996). Symptom

distress scales aim to identify and quantify patients' symptoms. The clinical benefit of these measures has been to indicate specific areas of symptom concern from the patients' perspectives, and identification of these concerns provides direction to clinicians for appropriate care.

Symptom distress measures used to demonstrate the effectiveness of palliative care service delivery must be interpreted carefully. For example, measures of pain severity would hopefully decline over time with appropriate palliative care interventions, and improvement in symptom distress (or more accurately reduction in levels of distress) may be an indication of positive outcomes of palliative care provision. However, other symptoms, such as fatigue, are likely to increase as patients' conditions deteriorate. With disease progression, measurements of distress may not show improvement. Yet this does not necessarily mean that positive patient outcomes have not been achieved through the provision of palliative care.

Quality of Life

Another outcome measure used in health care, including palliative care, is patients' reported ratings of Quality of Life (QOL). There is a vast amount of literature about QOL measurement in health care, and QOL is another complex phenomenon that has been interpreted in various ways. Although measurement of QOL was once considered from an objective viewpoint, the focus now is on the importance of an individual's subjective perceptions of his or her own QOL (Aaronson, 1990).

There are many definitions of QOL found in the literature. Bottomley (2002) for instance, cites six definitions of the term in his review. The concepts contained in his selection include subjective measures of individuals' satisfaction with their overall well being, performance of everyday activities, control of disease, life as a whole, functional effect of illness, and their position within their culture or value system. As well, one definition attributed to Calman postulates that there is an inverse relationship between quality of life and the gap between patients' expectations and their achievements (Bottomley, 2002). A broad interpretation of QOL from these definitions could be that QOL is a subjective measure of a person's wellbeing.

Another debate about measurement of QOL noted in the literature is whether it is appropriate to only take into account health-related aspects of well-being, thereby measuring a health-related QOL (Cella, 1995). The counter argument to this is that QOL is related to the interactions between individuals and all aspects of their environment (Mount & Cohen, 1995). This latter view of QOL is more consistent with

the holistic focus of patient and family centred care that is purported to be the focus of palliative care practice.

QOL debates also occur about which conceptual domains are included, different interpretations of those domains, and also about whether a single item measure of QOL is a valid measure when QOL is often seen as a multi-dimensional construct (Cella, 1994; Gill & Feinstein, 1994). A further debate concerns end-of-life care and the argument that people who are dying have different perspectives about QOL. There is a contention that specific QOL domains and the relative importance of those domains requires measurements that will reflect the construct "Quality of Dying" rather than "Quality of Living" (Steinhauser, Clipp, & Tulsky, 2002).

There are also methodological issues associated with scoring and reporting of QOL outcomes, and ethical considerations about administering rating of QOL instruments to palliative care patients, who may find it physically difficult to participate (Nikoletti & Cohen, 2004). However, QOL measures have been used in palliative care settings, and instrument development in this area continues to be refined (Cohen & Leis, 2002).

The debates surrounding QOL measures add to the complexity of understanding palliative care, especially because improvement in QOL is one of the major concepts associated with the provision of palliative care. The controversies about defining and measuring QOL further contribute to the difficulty in understanding palliative care.

Family Members: Proxies and Consumers

Another barrier to measuring outcomes in palliative care is the inability of patients to actively participate in research activities when their health inevitably deteriorates. Therefore, measurement in palliative care sometimes involves using proxies, such as family members or health professionals, to rate patients' experiences (Donaldson & Field, 1998). Use of a proxy may seem to be inappropriate when attempting to measure subjective experiences of an illness or of care received. However, the use of proxies to estimate patients' experiences may be the only option available to capture this information when patients' conditions preclude them from providing the information.

Several studies have examined the congruence between patients' and families' perceptions. For example, Field, Douglas, Jagger and Dand (1995) examined the congruence between 28 hospice patients and family members about patients'

experiences and the consequences of those experiences, and Lobchuk, Kristjanson, Degner, Blood and Sloan (1997) compared perceptions of symptom distress associated with lung cancer of 37 patient-family dyads. Both studies reported significant congruence between patient and family ratings. The discrepancies that were noted were most likely to occur when reporting about psychological symptoms (Field et al., 1995) and both studies noted that family members tended to rate levels of distress slightly higher than patients' ratings.

Family members serve not only as proxies for patients, but are also themselves consumers of palliative care. They can provide information about the care they receive and the impact on the family of the care the patient receives. Family members' responses may therefore be different from providing a proxy evaluation of patient care, and are a legitimate and separate subjective evaluation of care (Kristjanson, 2003). Measures such as family satisfaction surveys have been used, often after the patient has died, to evaluate service performance.

Outcomes of Palliative Care

I have provided the above discussion to highlight some of the dilemmas involved in providing a sound evidence base to support palliative care. Palliative care outcomes are subjective, difficult to articulate, and difficult to measure. Although some may be highly useful in clinical practice, they may not provide significant evidence of improvement in health status given the inevitable outcome for this patient population. However, several studies have provided some evidence of the positive outcomes associated with provision of palliative care.

For instance, McMillan and Mahon (1994) reported a positive trend in QOL in a study of 31 patient and carer (family member or friend) dyads. They used a 25 item visual analogue QOL measure, the Sentera Quality of Life Index, to compare QOL on admission to a hospice facility with QOL after three weeks in the facility. They reported significant improvement in carers' ratings of patients' QOL in the three week period ($p < .05$), and half the patients' self-ratings demonstrated a trend towards improvement over the three week period, although these changes did not reach statistical significance. Results of this study were discussed as being a positive finding in support of care outcomes, given that patients' conditions are likely to be deteriorating over time, and that intuitively ratings of quality of life would decline when nearing death. The authors noted several limitations to the study, including exclusion of patients whose conscious

state prevented self-reporting of their ratings. They did not report using proxy ratings in these cases.

Studies of family satisfaction with care have been reported. Wakefield and Ashby (1993), in a South Australian study, conducted interviews with relatives of patients who had died and rated various aspects of satisfaction with care. Respondents were grouped according to the place of patient death; home (n=18), public hospital (n=27), hospice (n=22), private hospital (n=19), and nursing home (n=18). Respondents in the hospice care group reported greater satisfaction with care than those in the hospital or nursing home care groups. Other examples have been given by Seale and colleagues, who reported comparisons of family members' experiences of different care settings, hospice and hospital, in England (Seale, 1989, 1991; Seale & Kelly, 1997a, 1997b). Although an early study reported that families' levels of satisfaction with hospice care were higher than satisfaction scores with "conventional" hospital care, (Seale, 1991), later studies showed no significant differences in outcome measures. The authors attributed this to hospitals recognising the value of some of the practices in the hospices during this time period, and adopting care practices similar to those promoted by the hospice. Some of the changes noted in the hospitals' practices included allowing more involvement with patient care, more leniency regarding visiting the patient, and establishment of bereavement support programs (Seale & Kelly, 1997b).

Satisfaction measurement studies have also been conducted in Canadian palliative care services (for example Keizer, Kozak, & Scott, 1992; Kristjanson, Leis, Koop, Carriere, & Mueller, 1997). These studies demonstrated high levels of satisfaction with care, as did a Western Australian study that examined predictors of family satisfaction with care (Medigovich, Porock, Kristjanson, & Smith, 1999). In this study, Medigovich et al. reported that families' understanding about patients' care was related to their level of satisfaction, and suggested that these results were a prompt for health professionals to pay particular attention to providing information to families about care.

These various studies provide some support for the benefits of palliative care. There is, therefore, both anecdotal and empirical evidence of the positive outcomes of palliative care. Nonetheless, the issues of establishing meaningful outcomes and appropriate measurements of these are fraught with difficulties. Researchers in the area, such as Hearn and Higginson (1997), have reviewed various measurement tools considered appropriate for use as outcome measures in palliative care, and development

work continues. Devery, Lennie and Cooney (1999) for instance, argue convincingly for the use of qualitative methods to ascertain outcomes that are meaningful to consumers of palliative care - the patients and their families. In their research of 77 participants, comprising both patients and caregivers, outcomes suggested as important included information (71%), emotional support (60%), and physical support (42%). Important aspects of information-giving in palliative care were clarity, and the way in which information is given. Other qualitative studies, such as McKinlay's (2001) phenomenological study of six palliative care patients, describe the value to patients of being recipients of palliative care.

The difficulties in measuring, describing, and articulating the positive outcomes of palliative care hinder communicating an understanding about palliative care to people who are not closely involved in the area. This is concerning given that community members are seeking to be fully informed about health care services available to them. Communicating about palliative care to policy makers and planners is also affected by the difficulties of providing evidence about the positive outcomes of care and, in addition, they may be significantly influenced by views of the general community when making their decisions about health care options.

Purpose of the Study

In the background for this study I have provided several arguments to highlight the need for a clearer understanding of palliative care. I have included a discussion of the benefits of palliative care and examined the difficulties in providing evidence of these outcomes. There is an argument for the likelihood of negative attitudes towards matters related to death and dying, despite the recent surge of interest in end-of-life issues that runs counter to those attitudes. A brief examination of the Australian health care system has alluded to the tenuous funding arrangements that underpin palliative care. There is also an identified paucity of knowledge about palliative care among members of the Australian public.

The combination of lack of public awareness, confusion of palliative care with other areas of health care, and the diversity of aspects of palliative care practice, makes it important to provide a clear understanding of palliative care. A clearer understanding will strengthen campaigns to raise awareness about palliative care.

The purpose of this study, therefore, is to clarify understanding of palliative care by examining the micro-culture of palliative care practice in a selection of Australian palliative care services, interpreting both the implicit and explicit interactions within

those social contexts. Exploring the internal components, processes, rules, and behaviours within these palliative care cultures will enable the following research questions to be addressed:

1. What is the shared understanding of palliative care among people involved in three Australian palliative care services?
2. What are the differences in understanding of palliative care among these people?

Significance

The significance of these studies arises from three factors; the current public focus on end-of-life issues and possible confusion about these issues, the reported need for expansion of palliative care services, and the associated need for increased palliative care funding from a competitive and diminishing health care budget.

The Public Profile of End-of-Life Issues

Recent controversies over care of the terminally ill and legalisation of euthanasia have increased community interest in this aspect of health care. Smith (2000) commented on the irony that euthanasia, which some may see as the "antithesis" of palliative care, has raised the topic of palliative care in the community (p. 307). Within this window of opportunity it is important that palliative care is neither under-represented nor misunderstood as a result of an inability to define and communicate about the concept. Therefore, research to enable a clearer understanding of palliative care appears timely.

Reported Need for More Palliative Care Services

The aim of the "National Strategy" is to provide access to quality palliative care to all people who are dying (Commonwealth Department of Health and Aged Care, 2000). This aim reflects recommendations that access to palliative care services for people with, for example, Motor Neurone Disease, acquired immunodeficiency syndrome (AIDS), chronic progressive heart disease, and other life threatening or terminal illnesses, would be beneficial to these patients (Health Department of Western Australia, 1997).

Currently, 80 to 90% of patients using palliative care services have a diagnosis of cancer (Aranda, 1999; Eccleston, 1997; Field & James, 1993; WA Hospice Palliative Care Association [WAHPCA], 1996), and the incidence of cancer is projected to increase with an ageing population (Commonwealth Department of Health and Family

Services, 1998a; WHO, 1997). As well, there is a reported shortfall of services available for people in rural and remote areas (Commonwealth Department of Health and Family Services; Health Department of Western Australia, 1997; Kristjanson, 1997; WAHPCA).

To meet the aim of the National Strategy- access to palliative care for all people who are dying- considerable expansion of palliative care will be required. One of the ways this is reflected in the strategy is through “generalist providers”, health professionals who will have some knowledge of palliative care approaches and techniques, and who will have access to specialist palliative care consultancy for support when necessary (Commonwealth Department of Health and Aged Care, 2000, pp. 6-7).

There are some anecdotal reports of concern from palliative care professionals that such arrangements will diminish the essence of palliative care, perhaps becoming what Kearney (1992) described as “symptomatology”, a term he used to convey the notion of restricting caring to merely the curing of symptoms. Nightingale (1998) alludes to this when she discusses the consequences of dissecting palliative care into “tasks” (p. 20), and cautions about making policy with disregard to palliative care experience that may “irrevocably alter the essential character and the unique contribution currently made by palliative care services” (p. 21). Smith (2000) and Nightingale, both experienced palliative care practitioners and administrators, make the point that there is a need, and in particular a political need, to have a clear understanding of palliative care.

Without being able to adequately articulate an understanding of palliative care, claims about dilution of palliative care remain weak. The aim of this research, to provide a clearer understanding of palliative care from observation of specialist palliative care practice, will help to either clarify these objections or ease some of the concerns of the protagonists.

Funding Pressures in Health Care

Although palliative care has received financial support from the Commonwealth and State governments for targeted palliative care projects, there is need for ongoing funding of services as well as additional funding to establish and maintain new services. However, Australian health expenditure continues to grow as medical advances and an ageing population place pressure on the health system (Haralambos et al, 1996). Foley (2002) discusses the choices that are necessary when resources are scarce, and that

significant costs are associated with care in the acute sector for patients who might more appropriately be cared for in palliative care services. Both she and Smith (2000) agree that an increase in funding for palliative care will require a shift in funding from another area of the health care budget. Ultimately, any discussion related to re-distribution of funding requires awareness of the issues to enable informed decision-making. A clearer understanding of palliative care will assist in these choices.

Navigating the Thesis

In this chapter I have provided a background for the research questions, identifying the difficulties associated with communicating a clear understanding of palliative care. I have also highlighted the significance of the project, identifying that a clearer understanding of palliative care will assist in making informed choices about health care options both on an individual level and on a policy level.

In this final section of Chapter 1, I provide an overview of the structure of the thesis and outline the subsequent chapters. At this point I believe that inclusion of a personal reflection about my involvement in palliative care is appropriate.

A Personal History of Palliative Care Involvement

Peshkin (1988) recommends that researchers declare from the outset their subjectivity, and continue to monitor the “subjective I’s” (p.18) that they bring to the research setting. This short section of personal reflection is included in this opening chapter of the thesis to clearly identify the lens through which this research has been conducted and interpreted. Throughout the thesis, reflexive comments are given where deemed appropriate, with the aim of providing the reader with further insight into the subjectivity that I bring to the research.

Throughout my nursing training, undertaken in the late 1970s, I was aware of my particular concern for patients who were dying and the suffering that many of them endured, especially people dying from cancer. Both physical suffering and emotional distress of these patients were evident. The work of pioneers of the modern hospice movement, most notably Cicely Saunders and Elisabeth Kübler-Ross, was filtering across the oceans to Australia, and documentaries about Saint Christopher’s hospice in London were shown on television. However, in practice there was limited knowledge about strategies to address this suffering, such as effective analgaesic regimens, and the comfort afforded to these patients was often less than ideal. Patients’ emotional distress was not ignored, but neither was it fully understood or acknowledged. Even with the

best of intentions, it was often not possible to effect any significant reduction of suffering for these patients. A comment made by an oncology registrar with whom I worked at the time has remained with me. Having expressed my concern about the emotional distress one male patient in particular was displaying he said, "Well, there's no Kübler-Rosses here you know."

Although an Australian-equivalent "Kübler-Ross" may not have emerged, many other palliative care professionals have contributed to the area, and palliative care services have flourished. In Western Australia, the first palliative care unit within a general hospital was established in 1981 and a pilot domiciliary hospice program commenced in 1982 (MacAdam & Shaw, 1989). In 1983 I began working with this domiciliary service, first as a visiting nurse providing direct care to patients and supporting families in their homes, and later in various management positions supporting others who were providing direct care. I spent 14 years with the service.

An issue of particular concern to me during the time I spent working in palliative care was the lack of knowledge amongst the general community of what could be achieved through good palliative care provision. Most people were unaware of palliative care services until their doctor referred them. Both patients and family members were often surprised at the services available and the care that was achieved, both in terms of amelioration of physical symptoms and the emotional support that was available.

In 1984 I wrote a small piece for the internal newsletter of the organisation about my experience of working in palliative care, which ended with "and so, for a living I deal in death, something which has made my life more fulfilled". The first-hand experience of working in palliative care confirmed my belief in the value of palliative care, and the personal rewards of working in the area.

However, I identified that many people in the community, both health professionals and lay people, held negative views about death and dying that impacted on their views about palliative care. Attitudes among peers varied from thinking that palliative care was a "soft option" and would be a waste of professional skills, to being somewhat in awe of those working in the area because it must be depressing work, and therefore the people working there must be "special." These attitudes added to my belief that many people did not know about or understand about palliative care, and the misconceptions and negative views concerned me.

When eventually moving from the practice area to begin research, my area of interest focussed on exploring perceptions of palliative care, with the ultimate aim of

promoting support for palliative care within the wider community. I have undertaken studies in recent years directed towards this aim, and they are referred to in this thesis.

During the period of the research further personal motivation for continuing to explore the area came from the experience of the death of my father. This was my first experience of a close relative dying; a period of nine months from diagnosis with lung cancer to death. During this time the local palliative care service provided care for Dad and our family, and I was also able to personally care for him at home for the final ten days of his life. The experience was sad in the extreme, but not negative. A close family friend, a senior physician but not a palliative care worker, remarked that she found the experience “inspirational,” and I concurred with her assessment. This personal experience further strengthened my conviction of the value of palliative care.

In summary, both as a provider and a consumer, I have found many benefits in palliative care and strongly believe that it is an essential service for people who have a terminal illness. This is the lens through which I have viewed the research presented here.

Continuing the Journey: The Chapters to Come

An in depth review of the literature in relation to understanding palliative care is provided in the following chapter. Chapter 3 outlines the theoretical underpinnings of the research, and also the conceptual map provided by my previous research studies. Following this, Chapter 4 provides a discussion of the practical application of the research methods used for the study.

Chapters 5, 6, 7, and 8 contain the findings of the research. The framework used to mould these chapters has been roughly based on “grand tour” observations (Spradley, 1980), with an accompanying interpretation of the observations that explores the practice of palliative care within the study settings.

Finally, Chapter 9 provides a synthesis of the findings with reference to the literature, previous studies that I have conducted, and suggestions for future research directions. This final chapter also contains a discussion of the limitations of the research that have been identified.

CHAPTER TWO

WALKING IN THE FOOTSTEPS

The challenge of articulating the meaning of palliative care is not novel, nor has it been resolved. Several authors have addressed the question “What is palliative care?” and have provided views of palliative care from various perspectives. In this chapter I provide a review of the literature and discuss the path already trodden. In subsequent chapters I will describe my venture into uncharted territory, to develop further understanding about palliative care.

The chapter begins with a discussion of the issues that make understanding palliative care difficult. Although definitions of palliative care are readily found in the literature, many different versions are used. As well, terminology associated with palliative care is used inconsistently, with different nuances, and different uses among authors. Confusion about understanding palliative care also occurs because of the association with other end-of-life topics, as well as a general reluctance by many people to consider issues surrounding death and dying.

Also reported in this chapter are results of surveys to determine knowledge about palliative care, including a comparative survey of attitudes towards palliative care that I conducted in 1999 (Webster, 1999). These surveys indicate a poor understanding of palliative care within the general community. Other research that I conducted as a preliminary phase to this project was a qualitative study about the meaning of palliative care from the perspective of long-term palliative care workers (Webster & Kristjanson, 2002a, 2002b). Results from this study are referred to in this literature review, and a conceptual framework arising from the preliminary research is presented in Chapter 3. Reports of my previous research are included as Appendixes A, B, and C in the thesis.

Difficulties in Understanding Descriptions of Palliative Care

Understanding palliative care is problematic for several reasons. Examination of the literature reveals that multiple definitions of palliative care are in current use, that some organisations have modified definitions of the concept over time, and that some authors resort to using several definitions at once in attempting to convey an

understanding of palliative care. The literature also reveals that terminologies such as hospice care, terminal care, and supportive care are used as synonyms to palliative care.

Definitions of Palliative Care

The issue of defining palliative care is discussed in one of the preliminary studies that I have undertaken as part of this research program. The study examined the meaning of palliative care from the perspective of an interdisciplinary group of long-term palliative care workers, and identified that the notion of *vitality* was at the core of their construct of palliative care practice. In the first article published from this study, Appendix B, a discussion of a selection of definitions is provided and summarised in Table 1 of the article (Webster & Kristjanson, 2002a), and reproduced here as Table 1. The definitions reviewed were found wanting on several issues, including failure to capture the notion of vitality that was described by the participants of the study.

Table 1

A Selection of Palliative Care Definitions

World Health Organization, 1990

Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families.

Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment.

Palliative care:

- Affirms life and regards dying as a normal process;
- Neither hastens or postpones death;
- Provides relief from pain and other distressing symptoms;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patients' illness and in their own bereavement.

Comment: Major criticism has been that this definition relates to people with cancer.

Woodruff, 1993

Palliative Care provides for all the medical and nursing needs of the patient for whom cure is not possible and for all the psychological, social and spiritual needs of the patient and the family, for the duration of the patient's illness, including bereavement care.

Comment: Not all patients "for whom cure is not possible" will benefit from palliative care. Separates medical and nursing needs from other needs. Assumes an inter-disciplinary approach but fails to acknowledge the team approach.

Canadian Palliative Care Association, 1995

Palliative care, as a philosophy of care, is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with a life-threatening illness. During periods of illness and bereavement, palliative care strives to meet physical, cultural and religious values, beliefs and practices. Palliative care is planned and delivered through the collaborative efforts of an interdisciplinary team including the individual, family, caregivers and service providers. It should be available to the individual and his/her family at any time during the illness trajectory and bereavement. While many service providers may be able to deliver some of the therapies that provide comfort and support, the service of a specialised palliative care program may be required as the degree of distress, discomfort and dysfunction increases. Integral to effective palliative care is the provision of opportunity and support for the caregivers and service providers to work through their own emotions and grief related to the care they are providing.

Comment: A comprehensive although lengthy definition.

Canadian Palliative Care Association, 1998

Palliative care is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with, or dying from, a progressive life-threatening illness, or are bereaved.

Comment: Significantly shortened, this definition was revised from the 1995 version, and in 1998 circulated to representatives throughout Canada. Consensus was not reached.

Australian Association of Hospice and Palliative Care (AAHPC), 1994

“Hospice and Palliative Care” is defined as a concept of care which provides coordinated medical, nursing and allied services for people who are terminally ill, delivered where possible in the environment of the person’s choice, and which provides physical, psychological, emotional and spiritual support for patients and for patients’ families and friends. The provision of hospice and palliative care services includes grief and bereavement support for the family and other carers during the life of the patient, and continuing after death.

Comment: A cumbersome definition. Physical, psychological, emotional and spiritual support may not necessarily translate to holistic care.

Palliative Care Australia – formerly AAHPC– 1999b

Palliative care is specialised health care of dying people aiming to maximise quality of life, and assist families and carers during and after death.

(This definition prefaces the PCA publication of Standards for Palliative Care Provision and is followed by several further statements about palliative care, seven core values for palliative care standards, and six domains - physical, psychological, social, spiritual, cultural and structural - in which palliative care standards are applied.)

Comment: Most recent definition issued by PCA. In this version, the word “hospice” has been omitted. There is no mention of the professional team. Specialised care is not described.

Defining palliative care has been problematic; Canadian and Australian palliative care organisations have revised their definitions over time, and other authors, such as Woodruff (1993; 1999), although referring to other definitions, prefer to use their own versions. Many authors use the WHO (1990) definition of palliative care. It is quoted in palliative care literature such as the “Oxford Textbook of Palliative Medicine” (Doyle, Hanks, & MacDonald, 1998), the United Kingdom nursing text “Palliative Care: The Nursing Role” (Lugton & Kindlen, 1999), an Australian General Practitioners’ Guide (Maddocks, 1993), and numerous journal articles by a wide range of people from different countries, for example the American Society of Health-System Pharmacists (2002), and Australian nurse educators (Nebauer et al., 1996). However, this 1990 definition has been criticised, primarily because of the narrow focus that suggests palliative care is appropriate for terminally ill *cancer* patients (Billings, 1998; Hospice Information, n.d.; Kristjanson, 1997), and has also been revised.

The recently published revised definition (WHO, 2002) is discussed by Sepúlveda, Marlin, Yoshida, and Ullrich (2002), who raise several shortcomings about the 1990 definition that led to the 2002 revision. The deficits in the 1990 version of the definition include exclusion of palliative care for conditions other than cancer, confining palliative care to end-stage care, the implication that pain relief is the major consideration to the detriment of emotional and spiritual needs, and the exclusion of family members’ need for support, in particular bereavement support.

The revised definition is as follows:

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

Palliative care:

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

(WHO, 2002, p. 84)

The differences between the 1990 and 2002 definition are subtle and indeed allow for inclusion of palliative care for patients with diseases other than cancer, which was one of the main criticisms of the original definition. However, much of the content of the 1990 version has been retained. An analysis of the major differences is given in the following table.

Table 2

Major Differences Between the 1990 and 2002 WHO Definitions of Palliative Care

Concepts mentioned	1990	2002
Palliative Care is	The active total care	An approach
The condition	Disease not responsive to curative treatment	Life-threatening illness
Quality of Life	Best possible	Improves Enhances
Defining QOL	Not defined	Prevention and relief of suffering
How	Control of symptoms is paramount	Early treatment of problems
What	Pain, other symptoms and psychological, social and spiritual problems	Pain and other problems, physical, psychosocial and spiritual
Death	Neither hastens or postpones	<i>Intends</i> to neither hasten or postpone
By whom	Not mentioned	Team approach Bereavement counsellors if indicated
When	Many aspects are applicable <i>earlier</i>	Applicable <i>early</i> in the course of the illness
Process	Not indicated	Positively influences the course of the illness
Other treatments	In conjunction with anti-cancer treatment	In conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy
Investigations	Not mentioned	To better understand and manage distressing clinical complications

It is debatable whether the 2002 definition enables a clearer understanding of palliative care, although the revision does address some of the issues raised in

discussion of the 1990 definition. The 2002 version suggests that palliative care is an *approach* rather than the earlier statement that palliative care is *active total care*. As noted in Table 1, other organisations have also modified definitions of palliative care over time. Indeed, if palliative care is an *approach* to care, then any attempt to define the concept will only be relevant for a particular context of time and place.

Various interpretations of palliative care and the practice that results from these interpretations may be dictating that modification of definitions is necessary. This “cart-before-the-horse” approach to defining the concept is likely to result in palliative care practice remaining difficult to articulate, and therefore to comprehend. It also may mean that palliative care practice is subject to individual interpretations. The consequent range of practices may make understanding palliative care difficult, even among others working in palliative care, if they have different interpretations.

Nonetheless, definitions of palliative care continue to be used in the literature when introducing the topic, with the expectation that the definition will convey an understanding of the subject. In Australia, Palliative Care Australia in several of their publications use the definition of palliative care as “... specialised health care of dying people which aims to maximise quality of life, and assist families and carers during and after death” (Palliative Care Australia, 1999b, 1999c). However, on the Palliative Care Australia website, the WHO 1990 definition with minor amendments is included under the heading “Core Values of Palliative Care”, along with several paragraphs describing palliative care (Palliative Care Australia, n.d.). The website also uses a different definition of palliative care, given as “care provided for a person with an active, progressive, far advanced disease with little or no prospect of cure and for whom the primary treatment goal is quality of life”. This definition is an adaptation of the definition of palliative medicine used by Doyle et al. (1998), and uses a description of the nature of the person’s disease that noticeably omits the word “dying”.

There are several possible reasons for not making reference to dying. One may be in response to those who make a distinction between early stages and dying stages of a disease that is not curable. This was one of the arguments of inadequacy regarding the 1990 WHO definition of palliative care, and gave rise to the notion stated in the 2002 version, that palliative care was “applicable in the early stages of a life-threatening illness” (Sepúlveda et al., 2002). Alternatively, avoiding the use of the word “dying” may be considered to be less off-putting to people in communities in which topics about death and dying cause discomfort and avoidance.

Further differences in the use of definitions occur at “official” levels also. Palliative care in Australia has received attention from both the Commonwealth (national) government and individual State governments. It might be expected that governmental agencies would be more consistent in the use of a particular definition, but differences are also found in these documents. For instance, the National Palliative Care Strategy (Commonwealth Department of Health and Aged Care, 2000) uses an adaptation of the WHO 1990 definition; the NSW Palliative Care Framework (NSW Health Department, 2001) uses the PCA definition given previously (the definition found in their documentation rather than that from the website) and Queensland Health uses a definition that combines the WHO 1990 definition and the PCA definition (Queensland Health, 1999).

Many of the definitions given in palliative care publications are accompanied by lengthy passages of explanation about palliative care. It is clear that an understanding of palliative care is not simply conveyed. There appear to be many understandings of palliative care held by different individuals and groups within the community in general. Further confusion results from the frequent interchange of terminology surrounding palliative care.

Terminology

The term “palliative care” is attributed to Professor Balfour Mount in Canada (Billings, 1998; Maddocks, 2000; Saunders, 1993) to describe an approach to care that was akin to the hospice care being practiced in the UK. Palliative care, a term derived from the Latin word “palliare” meaning to cloak (G & C Merriam Co, 1975), was considered to be a more appropriate term than hospice care in bilingual Canada. Hospice was thought to be a concept that would be associated with a place for homeless people, the French word “hospice” as shown in Cassells’ French-English dictionary meaning a refuge, asylum, or almshouse (Douglas, Girard, & Thompson, 1968). The origins of the modern hospice movement are attributed to the work of Dame Cicely Saunders and the establishment of Saint Christopher’s Hospice in London in 1968. Here, hospice care meant a return to care and caring combined with the best of modern medicine (Saunders, 2001b), a place that was much more than an almshouse.

In some cases, the terms “hospice care” and “palliative care” are used interchangeably (med broadcast.com, n.d.). Lickiss (1996) states that in the Australian context this is the case. Indeed, the home care service with which I worked is named the “Hospice Care Service” and *hospice* is interpreted as a philosophy rather than a place of

care. In the USA, the term *hospice* also is noted as pertaining to a philosophy of care (Aranda, 1999; National Hospice Foundation, 2002a, 2002b), although sometimes in American usage it is taken to mean care provided in the home (med broadcast.com, n.d.). Other sources, including some Australian authors, state that the term *hospice* implies a building or place where palliative care is practised (growthhouse.org, n.d.; Palliative Care Australia, n.d.). There is also discussion noted in the literature about the traditional view of hospices as being charity-based places of religious affiliation staffed by volunteer workers, and that this notion suggests that hospice care is a "soft" option that detracts from viewing it as a professional specialty (Aranda, 1999; Maddocks, 2000; Rathbone, 1998).

The national peak body in Australia, Palliative Care Australia, changed its name from the Australian Association for Hospice and Palliative Care in 1998 (Palliative Care Australia, 1998). Many state organisations in Australia also dropped the word *hospice* from their names. General opinion surrounding these changes was that the term *palliative care* was more appropriate as hospice care moved into mainstream health care models, and promoted a more professional image of palliative care within the health care system (Rumbold, 1998). As Clark (2002) suggests, palliative care is the term that captures broadening of the principles of hospice care into hospitals and acute medicine arenas.

Further confusion in terminology arises when distinctions are made between palliative care or hospice care and "terminal care". Palliative care and hospice care are terms associated with care of people who are dying, and are considered to be approaches to terminal care. Doyle et al. (1998) note that defining terminal care can depend on interpretation, a terminal period can be defined as lasting from hours to months. In some instances, such as in America, hospice care has been quantified by imposing an estimate of prognosis tied to funding. The Medicare Hospice Benefit in the USA is available to people who choose not to receive curative treatment for their illness, and that illness needs to be certified by doctors as a terminal illness likely to result in death within six months or less (National Hospice Foundation, 2002a). Some states in Australia have similar views, such as in Victoria, where government policy documents mention palliative care services in relation to people with a prognosis of six months or less (Department of Human Services, 1996). However, as noted with the revision of the WHO definition, if palliative care is implemented in the early stages of a life-threatening illness, then it is not appropriate to only associate palliative care with

the last six months of life. In this context, palliative care appears to be care along a continuum that includes a terminal phase, although defining the terminal phase is also subject to various interpretations.

Yet another term found in the literature in association with palliative care is “supportive care”. Finlay (2001) talks about the philosophies of palliative care and supportive care as being almost identical in their focus on the “consequences of a disease rather than its cause or specific cure” (p. 437). Other authors tend to use the phrase “palliative and supportive care” together, giving no explanation or differentiation between the two terms (for example, Evans & Walsh, 2002). At Flinders University in Adelaide, Australia, the department specialising in palliative care is now called the Department of Palliative and Supportive Services. It has been suggested that using such a title encourages a closer association with acute care services, where people may still feel reluctant to embrace partnerships with hospice or palliative care services because of the connotation of end-of-life care.

Supportive care in the oncology literature is noted as including symptom control, anti-infective measures, central line (intravenous) care management, nutritional support, and blood transfusions (Bakke & King, 2000; Coates, 1997; McLeod, 2002). In this sense, supportive care might be seen to be limited to management of side effects related to anti-cancer treatment. However, some authors further acknowledge that emotional, psychological, and spiritual care is appropriate to include in supportive care (Breitbart, 2002; Coates, 1997). If these aspects are included, then there are significant similarities between supportive care and palliative care.

Caroline’s (1998) review of the book “Principles and Practice of Supportive Oncology” provides one interpretation of the genesis of the terms “supportive care” and “palliative medicine”, and considers that they have come to describe very similar types of care. Although she uses the term *palliative medicine*, which may convey only that part of palliative care practised by medical practitioners, in this debate the substitute term *palliative care* is assumed to be appropriate. (This interchange of terminology further demonstrates the confusion in communicating the meaning of these terms.)

According to Caroline (1998), *supportive care* is a term that has evolved from the medical model of oncology practice, and *palliative medicine* from an holistic hospice model, hospice here again interpreted as “end-of-life” or terminal care. Although the focus of care for these two models may once have been quite different, she suggests that the two models of care have become more similar. In her opinion this has

come about as oncologists have become more involved with care that is not aimed solely on cure, and palliative medicine practitioners have become less focussed on terminal care.

A similar notion of opposing models of care is expressed by Esper et al. (1999) in their description of a supportive care program for men with advanced prostate cancer. They too identify that there have been two separate models of care for people with advanced cancer, one being the medical model and the other the hospice model. The goals of these models have been in opposition, the goal of the medical model being a prolongation of life and the goal of the hospice model being palliation of symptoms for people with a prognosis of less than six months. This is an American-based article and therefore consistent with the American concept of hospice care described above, namely care provided for people with a limited prognosis. Esper et al. in this instance refer to a “supportive care program” that is the combination of acute care and hospice care, where providers from both sectors join together to provide seamless care for patients during the transition of their disease.

Other terminology for palliative care or hospice care includes “comfort care” (growthhouse.org, n.d.) and “continuing care”. It is possible that these terminologies have evolved as euphemisms for hospice care, and even palliative care, as more socially acceptable terms that do not immediately connote an association with death and dying. It may be thought that people offered palliative care might refuse because of this negative association with care of people who are dying.

Further complicating the issue, palliative care is sometimes categorised to include care described as “acute palliative care” (Kellar, Martinez, Finis, Bolger, & von Gunten, 1996). Palliative care has also been described as “active care” that aims to improve quality of life (Lamberg, 2002), and as being a combination of “active and compassionate therapies” (Oleske & Czarniecki, 1999), as well as “total active care” (World Health Organization, 1990). Terms such as *acute* and *active* may be used in association with palliative care to counter notions that “nothing more can be done” for people who have a disease that cannot be cured. However, the use of such terms that are traditionally associated with curative approaches to care further demonstrates the lack of consistency and blurring of terminologies that abound in this area.

Table 3, which follows, summarises some of the synonyms used. There are still other terms that are related to palliative care. Billings (1998) for example, similarly

discusses the plethora of terminology associated with palliative care, and includes thanatology, comprehensive, coordinated, integrated, and humanistic among his list.

In summary, this brief examination of terminologies associated with palliative care indicates the confusion that exists in the literature when attempting to understand the term. The association of palliative care with both terminal care and acute/active care, and the multiple terminologies that can be used, including hospice care, supportive care, comfort care and continuing care, demonstrates some of the difficulty in understanding the intended meaning of palliative care. This discussion has noted several terms in the literature that can be used in place of the term "palliative care" or have particular connotations to some people about an aspect of palliative care practice. Throughout this thesis, however, the term *palliative care* will be used consistently in relation to the practice observed in the palliative care settings. If it is necessary to use another term, an explanation will be given for its use.

Table 3

Terminology - Palliative Care and Selected Synonyms

Term	Conflicting Interpretations
<p><u>Palliative care</u></p>	<ul style="list-style-type: none"> • is used interchangeably with hospice care, supportive care, comfort care, continuing care. • is all medical care that is not curative. • is more than medical care. • is a continuum of care; it starts at diagnosis of a non-curative illness and can continue for years. • includes acute palliative care. • is active care. • includes hospice care. • includes end-of-life / terminal care. <p>Not all palliative care is hospice care.</p>
<p><u>Hospice care</u></p>	<ul style="list-style-type: none"> • is a philosophy of care. • is care provided in a hospice (a building). • is home care. • is terminal care. • is palliative care. • is care in the last six months of life. • is when symptom control is required. • cannot be quantified in terms of prognosis. <p>Not all hospice care is terminal care.</p>
<p><u>Terminal care</u></p>	<ul style="list-style-type: none"> • is care given when a patient has a terminal disease. • is care given in the last six months of life. • is care given in the last weeks, or last days, or last hours of life. <p>Not all terminal care is hospice care.</p>

Term	Conflicting Interpretations
<u>Supportive care</u>	<ul style="list-style-type: none"> • is control of symptoms related to a disease or its treatment. • is care involving life support (such as ventilators). • is psycho-social care. • is palliative care. • is the early part of palliative care that is not terminal care. <p>Not all supportive care is palliative care.</p>
<u>Comfort care</u>	<ul style="list-style-type: none"> • is used as an alternative term for palliative care.
<u>Continuing care</u>	<ul style="list-style-type: none"> • is used as an alternative term for palliative care. <p>No particular connotations are conveyed by the use of comfort or continuing care.</p>

Difficulties in Understanding End-of-Life Issues

Alongside the litany of definitions confusing the issue of understanding palliative care, issues associated with death and dying may be particularly difficult to communicate to people in the general community given that the topic is likely to evoke negative reactions. This factor, together with the profile of some other end-of-life issues, further contributes to the difficulty in understanding palliative care.

Attitudes to Death and Dying

There is a wealth of information about the topic of dying that is found in the popular press as well as in scholarly and academic literature. Anne Deveson, a journalist living in Australia, wrote about death in "Everyone a Customer" (Deveson, 1997), a title that she first used for a documentary she made about the funeral industry. In this piece she reflected about how much death she had seen as a journalist, how "death is sexy for the media" (p. 152). She commented on the paradox of our exposure to thousands of television deaths, both fictional and actual, yet the fear of seeing the body of someone we know.

Observations about responses to death and dying have been the subject of considerable study. Sociologists, for example, view death as more than a biological process or event. Attitudes to death and dying, including rites, customs, and rituals are considered to be reflective of a society's culture. As such, death is a sociological phenomenon (Fulton, 1963/1976; Haralambos et al., 1996). Ariès (1974), a noted

historian on the topic of western attitudes towards death, discussed the social context of these attitudes over different time spans. People facing death in the period up until the twelfth century commonly experienced a "forewarning" of their death. People experienced a sense that they were going to die, allowing them time to organise their own ritual around their dying. Ariès notes that until the mid-nineteenth century dying was considered to be a public event. The dying person in his deathbed was visited by a stream of family, friends, and neighbours and further, until the eighteenth century, there was no attempt to exclude children from being present in these visitations to the deathbed. He further states that there was a naturalness to dying, "death was both familiar and near, evoking no great fear or awe" (p.13). Until the nineteenth century, in fact, death in western countries was a relatively unemotional, natural event (p. 59).

McCue (1995) revisits this sense of naturalness of dying in discussing the death of very old people who have no underlying disease, but who undergo "irreversible fatal declines" (p.274). He uses this example of dying to highlight the notion discussed by Ariès of the medicalisation of death, and the discomfort of physicians in accepting death as natural, even for elderly people who are merely wearing out. McCue suggests that the medicalisation of dying has voided the social and cultural significance of dying, as well as encouraged attitudes of failure, defensiveness, and fear of litigation among the medical profession.

During the twentieth century, along with medicalisation of death, attitudes toward dying moved to what Ariès (1974) referred to as "forbidden death". Death became a secret; it was shameful and forbidden. There was a reluctance to tell the dying person the truth, at first to protect the person, then later Ariès suggests, protecting the society from the ugliness of dying and death and the overwhelming emotion caused by it. With the advent of hospitals, people who were dying no longer stayed at home among family and friends; they were most often transferred to hospitals where they would die alone.

The notion of forbidden death is similar to that of "death as a taboo", which is how Fulton (1963/1976) reported attitudes of the American public toward death. Further, Fulton regarded that the traditional ceremonies surrounding death fulfilled social purposes for expression of anger and lessening of guilt. As the role of religion has declined in modern society, rituals associated with death have decreased, which he found concerning.

Palliative Care as a Response to Attitudes about Death and Dying

Perhaps the most significant reaction against the attitude of forbidden death was the advent of the modern hospice movement. Recognition of this prevailing attitude and the marginalisation of people who were dying were the impetus for this venture. Saunders (1993) reflected on efforts to reverse the attitude of a death denying culture in which telling dying patients the truth was discouraged. She too saw that modern advances in medicine had created an expectation of competence and control over what was once accepted as destiny. She expressed that some of the challenges, and subsequent rewards she has experienced in working in palliative care, has been in caring for patients and families who have replaced ...“the old acceptance of destiny” with ...“a new sense of outrage that modern advances cannot halt the inevitable” (p. v).

Other researchers have made notable contributions to recognising approaches relevant to the particular needs of people who are dying. Glaser and Strauss (1965), for instance, studied interactions between dying patients and hospital personnel. They described four types of “awareness of dying” or awareness contexts; closed awareness, suspected awareness, mutual pretense awareness, and open awareness. The work of Kübler-Ross (1969) is well known for identifying stages in the dying process. The stages of denial and isolation, anger, bargaining, depression, acceptance, and hope were suggested to be sequential steps in the process. Many people have criticised this work, arguing that not all patients travel this sequential path, that patients may skip back and forth through the stages at various times, and not all patients experience all of the stages (Kastenbaum, 1986; Littlewood, 1993). However, even if the substance of Kübler-Ross’ work is open to question, the contribution that it made to raising awareness of needs of people who are dying and issues surrounding dying was ground-breaking.

Kübler-Ross (1969) had various theories about how we perceived our own death that related to the unconscious mind. She suggested that an individual’s unconscious cannot imagine their own end of life as a natural course, but rather death must be an unnatural ending. In effect, death is associated with killing or being killed, and is therefore an event to be feared. The act of killing in turn requires punishment and retribution. Many rituals are explained as being based in both fear of death and in guilt and self punishment. These rituals serve to reduce the anger of the gods, or of society. The main point of Kübler-Ross’ argument was that fear of death has not changed over time, but ways of coping with death, dying, and dying patients have changed. She too concluded that death had become a taboo subject.

In more recent times, a significant contributor to academic study of death and dying has been Allan Kellehear, a sociologist and Foundation Professor of Palliative Care and Director of the Palliative Care Unit at La Trobe University in Melbourne. Kellehear in 1990 wrote the book "Dying of Cancer", which examined the experiences of 100 people in their last year of life and brought a greater sociological perspective to the topic. He has subsequently written "Experiences Near Death" (Kellehear, 1996), and "Health Promoting Palliative Care" (Kellehear, 1999) among other works. In the latter book, Kellehear suggests that the principles of palliative care and health promotion are highly compatible, and proposes that such a union would ensure that the social, spiritual and psychological aspects of palliative care are given as much weight as the physical aspects. Kellehear's vision of the direction for palliative care fits well with the ideas raised by Janssens, Zylicz, and Ten Have (1999). Both place palliative care as a public health issue.

Whether, as Kübler-Ross (1969) suggests, death has evoked fear throughout time, or as Ariès (1974) reports it has only been in the last century that death has evoked intense emotion, attitudes towards death and dying in modern industrialised societies have been death-denying. Death has been a hidden, uncomfortable topic and people have frequently died in hospital, with an absence of family, an absence of ritual, and under the control of medical staff. As people such as Haralambos et al. (1996) note, attitudes to death are again changing. The hospital death, disempowerment of both patient and family, and the ethics of using modern technology to prolong life and suffering, have been questioned by some parts of society. Palliative care has been one response to this medicalisation of dying.

Other responses to the perceived loss of individual control regarding end-of-life care have included support of legislation in relation to Advanced Health Directives (Palliative Care WA Inc, 2002; Waddell, Clarnette, Smith, & Oldham, 1997) and the controversial topic of euthanasia. These end-of-life issues, together with the confusion relating to terminology surrounding palliative care, are likely to confound the understanding of palliative care held by various members of the community. Some evidence about this understanding has been collected.

Understanding and Misunderstanding about Palliative Care

In 1999, I undertook a study about attitudes towards palliative care (Webster, 1999). The study report is included as Appendix A. One group of participants in the study were members of the Perth community who were neither health care workers, nor

had they been exposed to any experience of palliative care services (N=39). Participants in the study were required to express a rating of palliative care along a semantic differential of favourable (+3) to unfavourable (-3). The majority (90%) of this group expressed a favourable attitude towards palliative care. Participants were also asked to report their beliefs and feelings about palliative care, which provided a wealth of qualitative data.

The most frequently reported responses from this group of 39 general community members are given in Table 4.

Table 4

Top Responses about Palliative Care given by General Community Members

Responses	Number of participants	% of group
	N=39	
Frightened at the prospect. A difficult topic to discuss.	18	46.2%
Concerned about the costs. Palliative care is expensive. Who pays for palliative care?	17	43.6%
Overtly supportive of palliative care. "It is an essential service."	15	38.5%
Stated that staff are or should be "special" and experienced.	15	38.5%
Mentioned that the family is included in care.	13	33.3%
Referred to the concept of "dignity", dying with dignity.	9	23.1%
Stated that palliative care is for old people, or suggested some association with aged care facilities.	9	23.1%
Admitted to lacking knowledge about palliative care.	9	23.1%
Concerned that some people do not receive palliative care. It should be available to all people; those with a non-cancer diagnosis, country people, people from all socio-economic groups.	6	15.4%
Referred to the concept "Quality of Life".	6	15.4%
Alluded to patient choice or patient centred care.	6	15.4%

Many general community members admitted to feeling fear or discomfort when considering the topic of palliative care. A similar number were concerned with the expense of services, although almost as many expressed notions interpreted as being supportive of palliative care, such as "it is an essential service". Care issues that might be considered to indicate some level of understanding about palliative care included mention of staff and the need for them to be experienced, inclusion of family, the

concept of dignity, quality of life, and patient choice. Some misconceptions were held, with almost a quarter equating palliative care to aged care, and as many participants acknowledged that they lacked knowledge about the topic. As well, seven participants (17%) mentioned euthanasia in association with palliative care. Of these seven, three people stated that palliative care was a better alternative than euthanasia, two assumed that euthanasia was included in palliative care practice, one indicated that euthanasia should be legalised, and one stated that euthanasia was wrong.

This small study indicated a range of ideas about palliative care held by members of the general public. The study also indicated that people were likely to support the notion of palliative care without understanding it, and in some instances holding misconceptions about the concept. The results found here regarding lack of understanding about palliative care are consistent with reports from other sources. Fainsinger (2000) for example, commented that a Canadian survey in 1997 indicated that only 50% of Canadians had heard of palliative care and only about one third of these had any understanding of the issue.

Larger surveys conducted in Australia include those organised by the Palliative Care Council of South Australia in 1995 and again in 1998 (Harrison Health Research, 1999). Both the 1995 and the 1998 study involved interviews with over 3000 respondents from throughout the state of South Australia. Questions asked at these interviews included what was understood by the term "palliative care", and what was understood as being a hospice. Results indicated that 65% did not have an understanding of the term "palliative care" in 1995. This figure had reduced to 48% by 1998. The wording of the second question about understanding of a hospice suggests that the Palliative Care Council of South Australia assumes hospice to mean a building, rather than the broader term that implies a philosophy of care. Results in the surveys indicated that 62% and later 69% offered some description of hospice as a place of care for terminally ill people. It is not known what public education campaigns may have been conducted in South Australia to effect an increase in understanding about the topic. The figures, however, indicate that even in 1998 a considerable proportion of the population within that state had a poor understanding about palliative care.

Results from both surveys are summarised in the following table, Table 5.

Table 5

Answers to Two Questions Included in the Palliative Care Council of SA Surveys of Public Awareness of Palliative Care and Hospice Services 1995 and 1998

	1995	1998
	N=3016	N=3001
Q: <u>What do you understand is meant by palliative care?</u>		
A: Care/nursing of terminally ill	16%	26%
Pain relief for terminally ill patients	6%	12%
Home care / home nursing	9%	12%
Support / counselling for people as they approach death	4%	7%
Other		7%
Total having some understanding about palliative care	35%	52%
Total who don't know	65%	48%
Q: <u>What do you understand a hospice to be?</u>		
A: A place where terminally ill people go to die	Most frequent	30%
A place where terminally ill people go to receive treatment	a	12%
A place where the terminally ill and their families can receive care and support in preparing for death	a	9%
Like nursing home / convalescent home for the terminally ill	a	8%
Comfortable / nice place for the terminally ill	a	5%
24 hour care for the terminally ill	a	4%
Other	62%	12%
Total offering some description	38%	69%
Total who don't know / have never heard of a hospice		32%

Note: ^aNot all data were available in the 1995 survey report. From Harrison Health Research (1999) and Palliative Care Council of South Australia (1995).

Nationally, Palliative Care Australia has conducted surveys similarly designed to assess the general understanding about palliative care issues and measure effectiveness of awareness raising strategies (A C Nielsen Research Pty. Ltd., 1999, 2000). These surveys were conducted amongst a random sample of respondents, aged 18 years and over, from Sydney, Melbourne, Brisbane, Adelaide, and Perth. In 1999, 507 respondents were interviewed over the telephone. In 2000, the number was 715. Results from these surveys are shown in Table 6.

Table 6

Results of Surveys about Understanding of the term "Palliative Care" conducted on behalf of Palliative Care Australia, 1999 and 2000

1999: Q: What do you understand is meant by "Palliative Care" (unprompted)	1999 N=507	2000 N=715
2000: Q: What does palliative care mean?		
Care for people who are in pain and dying (mentioned both)	4%	7%
Care for people who are dying (not mentioned pain)	22%	22%
Care for people who are in pain (not mentioned dying)	2%	2%
Care for people who are sick (not mentioned pain or dying)	10%	9%
Care for people who are injured (not mentioned pain or dying)	1%	1%
Care for the elderly (not mentioned pain or dying)	11%	^a
Care for people who can't look after themselves	2%	^a
Care in the home	2%	^a
Other	3%	20%
Don't know	43%	39%

Note:^a These responses were not itemised in the 2000 survey.

If it is assumed that a response indicating either or both "care for people in pain" and "care for people who are dying" is considered to be a reasonable understanding of palliative care, then in 1999, 28% of the survey respondents expressed this understanding, and 31% in 2000. These comparisons show minimal improvement in the

understanding of palliative care. Even as recently as 2000 the meaning of palliative care in Australia, and possibly in other countries, is poorly understood among the general public.

The Path Already Trodden

Other people have recognised the difficulties in communicating an understanding of the meaning of palliative care. The theme of the 1998 Australian National Palliative Care Week was "What exactly is palliative care?" and the Palliative Care Australia newsletter published at that time focussed on answering the question by including stories from persons involved in palliative care, including patients, carers, and health professionals. Each told their story and each added a perspective to the meaning of palliative care (Palliative Care Australia, 1998). However, the composite picture provided by these stories was not articulated. The President of Palliative Care Australia at the time, Dr Michael Smith, urged individuals to "spread the message of palliative care", and recognised that support for palliative care would only be achieved through continuing promotion and education (Smith, 1998, p. 3). However, it is necessary to communicate a clear understanding about palliative care if the aim is for people in the community to support and benefit from palliative care.

In earlier years, Jacobson (1984) discussed some of the issues about palliative care that are still being discussed today. Jacobson referred to two systems of treatment available for a person with cancer. One system was about treating a curable disease, the other about relieving symptoms of an incurable illness. He used terms such as active and acute care in relation to the first system, and both the terms hospice care and palliative care, without distinction, for the latter system. Jacobsen, however, clearly saw that there was overlap between the two systems and there was likely to be difficulty in making distinctions between the two, about which patients are suitable for which system of care. In an attempt at clarification he made several statements about what hospice care is not. These included hospice is not a building or place, nor is it terminal care as provided in an acute care setting; it is not anti-therapy nor anti-physician; it is not new, and it is not for every patient or every health care worker.

In attempting to articulate what palliative care was not, Jacobsen (1984) may have been defending some of the notions about palliative care that were prevalent at that time. Interestingly, many of these persist, such as the confusion about whether hospice is a building or an approach, as has been previously discussed. Further, he saw that there needed to be mutual recognition of curative care and palliative care in order to provide

appropriate and seamless care to the patient. This is the notion that Esper et al. in 1999 discussed in relation to a supportive care program for men with advanced prostate cancer. Jacobsen's message was clearly still relevant 15 years later. In the interim, other authors have also attempted to identify or communicate the meaning of palliative care.

For example, Finlay and Jones (1995) felt the need to clarify various aspects of palliative care by providing explanations that distinguish between a palliative approach, palliative interventions, and specialist palliative care. This further separation of aspects of palliative care contributes more to the confusion of understanding the meaning of the concept. This is especially so, given that Finlay and Jones discuss the appropriateness of a palliative approach for all clinicians, that palliative interventions aim to improve symptom control, and that specialist palliative care teams provide advice to general and hospital practice in a cooperative undertaking. These three aspects fail to further elucidate the meaning of palliative care, and add to the growing list of terms associated with palliative care.

The question "What is palliative care?" was asked by Goodlin (1997). Referring to the WHO (1990) definition, she concludes that it is "good medical care" (p. 16). She also suggests, as do Finlay and Jones (1995), that all physicians should acquire the knowledge and approach associated with palliative care. Williams and Wheeler (2001) asked the same question, "What is palliative care?". They first considered three terms; palliative medicine, palliative care, and palliative care nursing, and referred to the definition of palliative medicine given by Doyle et al. (1998) as well as the WHO (1990) definition of palliative care to answer the question. Williams' and Wheeler's distinctions between terms seem merely to refer to the care provided by an individual discipline, medicine or nursing, versus the care provided by the whole team, which they label "palliative care". Both are nurses working in the USA, and are able to provide an overview of issues such as educational opportunities in the USA, palliative care resources, and a brief discussion of symptom management to further answer their question.

These various papers provide further discussion about interpretations of palliative care found in the literature, and demonstrate that understanding palliative care is confusing. Although the authors suggest that they are answering the question "What is palliative care?" the discussions they provide fall short of answering this question any more fully than the definitions already given in the literature.

An alternative discussion is given by Janssens et al. (1999), who offer philosophical and theological perspectives to articulate the meaning of palliative care. They discuss three notions based on the medical, psychosocial, and spiritual realms of palliative care, and place the ideas of medical restraint, authenticity, and hope within these realms. The notion of medical restraint arises from an ethical discussion that they offer and makes reference to the idea of “when in doubt, do not intervene” (p. 39) that has Hippocratic origin. Authenticity they describe within the psychosocial realm as “being at one with oneself despite all suffering” (p. 41), and argue that this notion of authenticity places palliative care within a community context, of providing compassionate caring within the society in which we belong. Further discussion in the realm of spirituality addresses existential issues such as the meaning of life. The way that Janssens et al. introduce this notion, rather than using the term spirituality, is to use the term “eschatology”, which they describe as referring to “things of ultimate importance, to what human life ... is all about” (p. 42). Hope is related to the ultimate meaning of life; that we can envisage an ultimate meaning gives us hope, and conversely, hopelessness is a state without meaning and akin to death itself. In relating hope to palliative care, they suggest that the object of hope may vary throughout the course of terminal illness and approaching death, but fostering hope is central to palliative care because “hope is conditional to a life worth living” (p. 43).

Janssens et al. (1999) provide a thoughtful discussion that may well ring true with many palliative care practitioners, or at least provide the basis for a lively debate. They conclude their article with the statement “the care we give to the dying ... is ... an illustration of the cohesion and morality of our society” (p. 44). They state from the outset that they are providing a philosophical and theological perspective of palliative care. This is in contrast to previous attempts to define palliative care in operational and descriptive terms. Rather than attempting to articulate what is and is not included in palliative care practice in relation to a medical model of care, or defining the province of various palliative care practitioners, this discussion locates palliative care within a sociological arena.

Such philosophical arguments help to understand the difficulty in defining and communicating the concept to those outside the area. However, philosophical arguments may not serve to better inform the general public about palliative care. Attempts to provide an understanding of palliative care within a health care framework are likely to be better understood by people in general.

Summary

Palliative care is difficult to define, and the term is often used interchangeably with several other terms. The concept continues to be poorly understood by members of the community, as evidenced by results of a number of surveys conducted. Several authors have attempted to explicate the concept, revealing that it is a difficult concept to communicate.

The literature review provided here reveals the difficulty in communicating an understanding of palliative care. The purpose of the current study is to develop an understanding of palliative care by observing, describing, and interpreting palliative care practice in several Australian palliative care services. This will add to the current literature and communication about palliative care.

CHAPTER THREE

FRAMING THE RESEARCH

In this chapter I describe the framework that underpins this research. There are two aspects to this framework. One is the philosophical orientation that informs the data collection, analysis, and reporting processes of the study. The second is a conceptual map based on concepts that emerged in earlier related studies that I have conducted. From this earlier work I identified the need to further explore understanding of palliative care, and the conceptual map of these studies provides a reference point for the conduct of the current research.

Although recognising that it is important to remain open to the data and interpretations emerging from this current study, I believe it is equally important to declare at the outset the concepts that I have identified in previous work. My endeavour throughout the project is to make the research process as transparent as possible, and allow the reader to judge the trustworthiness of the process and the interpretation of the data.

Philosophical Orientation

This study was conducted using an interpretative ethnographic approach. There is a great deal of confusion in articulating approaches to research generally, and qualitative research in particular. Numerous terms and overlapping approaches are used that complicate the issues. For a discussion of these issues see, for example Crotty (1998), Denzin and Lincoln (2000), and Grant and Giddings (2002). Patton (1990) uses the term "strategic framework" (p. 36) to refer to the overarching plan of action for a research study that lays out the underlying epistemology and assumptions of the research. Crotty provides a template for this strategic framework that offers a simple and convenient approach to discuss the philosophical underpinnings of a research approach. I have chosen to use this template to articulate the approach for this research. Crotty suggests that any research approach can be described using four elements; epistemology, theoretical perspective, methodology, and methods. The aim of clearly identifying the elements in this string is primarily to ensure that there is consistency

between the elements, which in turn assists in the selection of a research approach that will appropriately answer the research questions. Crotty further indicates that a clear articulation of the orientation, or strategy, at the outset of the research adds to the coherency in developing and addressing the research questions, and informs both the researcher and the reader of the orientation of the project. With these aims in mind the framework underpinning this research is drawn in the following figure and discussed in the following passages.

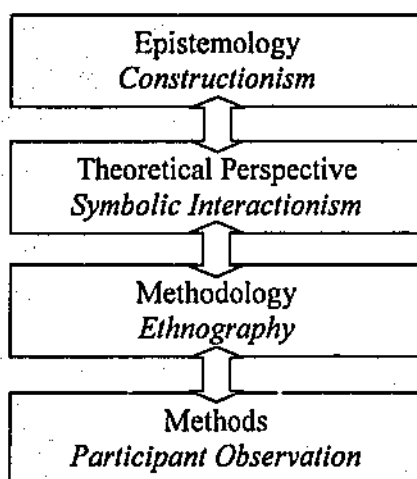


Figure 1. Framework for this research (from Crotty, 1998, p. 4).

Epistemology

Epistemology has been described variously as “the relationship between the inquirer and that being studied” (Polit & Hungler, 1997, p. 11), “how we get knowledge and establish an accurate account of reality” (Bessant & Watts, 1999, p.30), and the “way of understanding and explaining how we know what we know” (Crotty, 1998, p. 3). Following Crotty’s framework, the epistemology that provides the foundation for this research is constructionism, which is contrasted with positivism and subjectivism. Constructionism assumes that the relationship between the inquirer and the object of study is a construction between the two, and that what we know and understand about the world is acquired via the meaning we construct from this relationship. In contrast, “positivism” implies that meaning exists within the world, regardless of interpretation, and is merely waiting to be discovered. “Subjectivism” assumes that all meaning is created and exists only because of the subjective individual. Constructionism neither

discovers nor creates meaning, but rather constructs meaning. The epistemology of constructionism embraces the notion of "Verstehen", a term introduced by German philosophers to mean "understanding" as found in the human and social sciences, in contrast to the term "Erklaren" meaning "explaining" that is often the aim in researching in the natural sciences (Crotty).

The background work that I conducted and that led to this research (Appendixes A, B, & C) is consistent with a constructionist epistemology. The findings suggest that people's understandings of palliative care are constructed via the meaning arising from their relationships with palliative care. For example, palliative care workers and bereaved people share an understanding about palliative care from their respective involvement with palliative care. They also express some differences in understanding about palliative care, based upon their individual construction of that understanding. Therefore, adopting a constructionist view, understanding is not merely created as would be the case with subjectivism, nor does understanding about palliative care exist as a single truth merely waiting to be discovered, independent of the meaning of the relationship with the individual, as would be the case from a positivistic stance. Understanding of palliative care is *constructed* by people involved with palliative care from the meanings created through the relationship between palliative care and the individual.

Theoretical perspective

The theoretical perspective or philosophical stance (Crotty, 1998) of this research is interpretivist. Interpretivism is consistent with an epistemology of constructionism in that it is concerned with the construction of reality between the researcher and the researched. Further, as Crotty describes, that construction is an interpretation of the social life-world, "culturally derived and historically situated" (p. 67).

Several theoretical perspectives are considered to be interpretivist and embrace cultural and historical contexts. These include hermeneutics, phenomenology, and symbolic interactionism. I have identified that symbolic interactionism is an appropriate perspective to address the research questions of this study, as the following discussion indicates.

Symbolic Interactionism

The basic principles underlying most qualitative research, such as communication, verstehen, and everyday life, have emerged from symbolic interactionism (Sarantakos, 1994). Blumer (1969) first coined the phrase “symbolic interactionism”. He states that the approach was built on the work of George Mead and other American philosophers and social scientists of the early twentieth century.

There are three basic assumptions to Blumer’s symbolic interactionism. The first is that people ascribe meaning to things, the second is that the meaning that is ascribed is formed from the perceived meaning that other people have towards these things, and the third is that people’s reactions to things are filtered through the interpretation of these meanings. In his words:

Human beings act toward things on the basis of the *meanings* [italics added] that the things have for them ... the meaning of such things is derived from, or arises out of, the *social interaction* [italics added] that one has with one’s fellows ... these meanings are handled in, and modified through, an *interpretative process* [italics added] used by the person in dealing with the things he encounters. (Blumer, 1969, p. 2)

Blumer used the word “things” to include any object - physical, social, or abstract - that people might act towards. He stressed the importance of social interaction, which he argues forms human behaviour rather than merely being an arena in which people behave. As he explained, “human beings in interacting with one another have to take account of what each other is doing ... [and] handle their situations in terms of what they take into account” (Blumer, 1969, p.8). The concept of self is also considered in his model because the interpretative process constitutes an internal conversation, an internalised social process (Blumer), in which meaning is processed through “reflexivity” (Porter, 1998), a term taken broadly to mean “self-awareness” (Baillie, 1995).

Within these processes there are “significant symbols” (Crotty, 1998), such as words in a language and non-verbal actions, that are part of communication systems. Significant symbols have shared meanings and contribute to the interpretative processes. Social life is expressed through these symbols. Meaning, and therefore understanding of the world, is learned through interaction, reflection, and interpretation (Edgar, Earle, & Fopp, 1993; Patton, 1990; Sarantakos, 1994).

The actor selects, checks, suspends, regroupes, and transforms the meanings in the light of the situation in which he is placed and the direction of his action. Accordingly, interpretation should not be regarded as a mere automatic application of established meanings but as a formative process in which meanings are used and revised as instruments for the guidance and formation of action. (Blumer, 1969, p. 5)

Application of symbolic interactionism to the palliative care settings of the research appears appropriate, Patton (1990) stating that the research question arising from this theoretical perspective is "What common set of symbols and understandings have emerged to give meaning to people's interaction?" (p. 75). Palliative care settings are environments where social interaction is constantly occurring between patients, family, visitors, and staff. The symbols present within the physical environment of health care settings in general, as well as within relationships in these settings, create a variety of interpretations that contribute to the social life of those institutions. Examination of these interpretations is important when seeking the common set of symbols and meanings in relation to understanding of palliative care within these settings.

Methodology

The next element in Crotty's framework is methodology, which he describes as the "plan of action, process or design ... linking the choice and use of methods to the desired outcome" (Crotty, 1998, p. 3). Ethnography was chosen as the methodology appropriate to answer the research questions in this study because it embraces the concept of culture.

Culture

This thesis evolved from recognition that the meaning of palliative care was not fully captured in definitions or theoretical descriptions, nor were a selection of long-term palliative care workers able to fully articulate the meaning of the concept (Webster, 1999; Webster & Kristjanson, 2002a, 2002b). Greater understanding of palliative care required closer examination of the concept, examination that would require observing palliative care practice "in vivo", observing and interacting with the people in those settings. This realisation prompted the notion of capturing the "culture" of people participating in palliative care services.

There are difficulties, however, in defining culture. Fetterman (1989) noted that culture can be viewed from various perspectives, such as a materialistic viewpoint that

focuses on behaviour, and from an opposing ideational view that includes cognitive concepts of ideas, beliefs, and knowledge. Both viewpoints can be useful in exploring the culture of a group of people. Spradley and McCurdy (1972) discussed the meaning of "culture" in anthropology as being "nearly everything that has been learned or produced by a group of people" (p. 7). For the purpose of their text, which was to introduce undergraduates to ethnographic research, they settled on a definition of culture as "the knowledge people use to generate and interpret social behavior" (p. 8). Germain (1993) gave a similarly broad definition of culture as "the learned social behavior or way of life of a particular group of people" (p. 237). Indeed culture has been recognised to evolve in any group of people who are together for a period of time (Patton, 1990). It therefore seems appropriate to assume that in palliative care settings an exploration of the culture that has evolved within those settings will add to understanding of palliative care.

Social behaviour, explained in symbolic interactionist terms, is the patterns of behaviour among different individuals engaged in various activities, each interpreting those behaviours in terms of the perceived interpretation of others' behaviours. Blumer (1969) referred to this as "joint action", and described it as the "societal organisation of conduct of different acts of diverse participants" (p. 17). Blumer also stated that, although repetitive and pre-established forms of joint action have been labelled by other social scientists as "culture", it was naïve to consider that human social life remains constant. From an interactionist viewpoint, each joint action brings with it interpretative processes, so that even repetitive and pre-established forms are subject to new interpretations. Blumer cautioned that norms, values, and social rules are subject to a process of social interaction, and that they do not dictate the culture of a group of people but rather the joint actions of the people establish their norms, values and rules. "It is the social process in group life that creates and upholds the rules, not the rules that create and uphold group life" (p. 19).

With this caution in mind, the research questions that guide this study were framed to explore understanding of palliative care, while acknowledging the different acts of diverse participants involved in social organisation, and with the clear aim of forming some collective or shared understanding of palliative care. Therefore, the aims of the research are to formulate both the shared understanding and the differences in understanding, by examining the components, processes, rules, and behaviours that contribute to those understandings, both between and within the selected palliative care

settings. This is considered to be consistent with a symbolic interactionist approach. Recognition of the diversity of interpretation of people's understanding of palliative care, a symbolic interactionist perspective, underpins the research study and frames the research questions, which are as follows:

What is the shared understanding of palliative care among people involved in three Australian palliative care services?

What are the differences in understanding of palliative care among these people?

Ethnography

The methodology appropriate for this study is ethnography, which has been broadly defined by Fetterman (1989) as "the art and science of describing a group or culture" (p. 11). The foundations of modern ethnography are attributed to two major areas of influence. One area of influence is from social anthropologists such as Malinowski, Boas, and Mead who, in the early twentieth century, studied non-western cultures. The other influence is from sociologists, such as Park and later Whyte, arising from the so-called "Chicago School", the University of Chicago's Department of Sociology. These sociologists turned their attention to studying various marginalised groups within American culture, and coined the term "participant observation" (Brewer, 2000; Holloway & Wheeler, 1996; Vidich & Lyman, 2000).

Application of ethnography.

Ethnography has gained acceptance in many fields and is commonly used in areas such as education, organisational studies, criminology, and nursing (Tedlock, 2000). Several researchers have conducted ethnographic studies in palliative care settings. McNamara (1997), a medical anthropologist, conducted an ethnography in local palliative care services in Perth, Western Australia. Her findings provided a refocussing of the original concept of "the good death" to "the good enough death", which she described as an acceptance among palliative care professionals of the reliance on biomedical practices, rather than the uncertainties associated with psychological, social, and spiritual care. A further ethnographic study involved participant observation in a palliative care day unit, where patients were observed talking about their illness and death. The researcher observed that the form of this talk was "light-hearted", and proposed that a social environment where this activity was considered appropriate and was encouraged provided an important psychological function, comparable to one-to-one counselling (Langley-Evans & Payne, 1997). Although not addressing the topic of

understanding palliative care in general, which is the purpose of this research, these studies support the use of ethnography as an appropriate methodology for use in palliative care settings.

Debates within ethnography.

Not every author discusses ethnography as a methodology. Chambers (2000) states that “ethnography is principally defined by its subject matter, which is ethnos, or culture, and not by its methodology, which is often but not invariably qualitative” (p. 852). Indeed, several authors note that there are a variety of philosophical underpinnings represented in ethnographic studies (Brewer, 2000; Fetterman, 1989; Germain, 1993), and various criticisms have been levelled at approaches taken.

Some of the debate has been about positivism versus naturalism and around quantitative versus qualitative approaches. Early ethnographies were criticised for not meeting the rigours expected of quantitative studies. More recently, from the 1980s, critics have expressed concern that ethnography has remained too close to quantitative traditions (Hammersley, 1990; MacDonald, 2001). Brewer (2000) raises concern about a positivistic approach to ethnography that seeks to find social causation to explain human behaviour. He also expresses concern about issues of postmodern ethnographies, in which he argues that deconstruction of society into multiple truths render ethnographic accounts meaningless.

A further confusion is that the term “ethnography” can be applied to both the process of investigating the culture of a group of people, that is the methodology, and to the research product or outcome of the investigation, namely a written ethnography (Tedlock, 2000). Ethnography therefore appears to be a term that is used broadly, that does not assume or dictate a philosophical standpoint, nor a specific methodological framework. It is a research *approach* that is suggested by the research problem itself.

These debates clearly demonstrate the complexity of defining an ethnographic research framework. However, given that the epistemology and theoretical perspective underpinning the methodology have been clearly articulated, the assumptions of a constructionist, symbolic interactionist approach to this ethnography clearly establishes the methodology employed for the research. It is in this sense that ethnography is referred to as the methodology guiding this study.

Aims of ethnographic research.

The aim of ethnographic studies in this context is to understand the worldview as defined by the people in that cultural group, the *emic* perspective of the culture (Polit & Hungler, 1997). Brewer (2000) provides a more comprehensive definition of the concept.

Ethnography is the study of people in naturally occurring settings or "fields" by means of methods which capture their social meanings and ordinary activities, involving the researcher participating directly in the setting, if not also the activities, in order to collect data in a systematic manner but without meaning being imposed on them externally. (p.10)

Several components that typify an ethnographic approach are contained in this definition. Holloway and Wheeler (1996) summarise the main features of ethnography in four points.

1. Collection of data from observation and interviews. The researcher is the main research instrument, often engaged in participant observation.
2. "Thick" description and the naturalistic stance. Observations are interpreted in context, with exploration and interpretation of the underlying meanings for the people involved in the culture.
3. Work with key informants. Selective sampling of individuals within the culture who become "active collaborators ... rather than passive respondents" (p. 86).
4. The emic-etic dimension. Initially the aim of the researcher is to discover the emic or insider's view of the culture, what people do and why they do it, or the meanings they attach to it. The etic, or outsider's view, may be formulated by the researcher as an abstraction of this, interpreting the cultural meanings in respect to a theoretical view.

These approaches have been embraced for this ethnographic research study. However, it remains necessary to further identify the *type* of ethnography conducted. The ethnographic literature provides several classifications of ethnographies that further refine the approach taken. Therefore, a brief discussion of some of the typologies is given, and the focus of this research further articulated.

Types of ethnography.

Germain (1993) comments on the complexity of classifications of ethnography. Some classifications are based on the unit of analysis, for instance the group involved,

others use a binary system, urban/rural for example. The variety of sub-groups and cross-classifications is noted to further confuse the issue. Some ethnographies are described as “critical” ethnographies and contrasted with descriptive or conventional ethnographies (Holloway & Wheeler, 1996). Critical ethnographies explore larger social issues such as power and hidden agendas, whereas descriptive ethnographies describe and uncover patterns within a culture (Germain, 1993; Thomas, 1993). It is the latter approach that is taken to explore the meaning of palliative care in this study. The complexity of understanding palliative care is considered to be worthy of further explication without further confounding the issue by examining the power relationships that may operate within the field.

Boyle (1994) provides an overview of classifications of ethnography that further frames this study. Traditional approaches to ethnography have been associated with the anthropological study of non-Western, non-industrial, non-literate societies while living amongst the people and observing all aspects of their everyday behaviour (Kottak, 1987). Such approaches are referred to as “classical ethnographies” (Muecke, 1994) and have long been criticised because of the assumed authority of the researcher (Savage, 2000), the patronising stance with which researchers have entered into the field (Holloway & Wheeler, 1996), and the ethnocentrism of the researcher (Tedlock, 2000). Partly due to these criticisms, but also because these tribal-type communities have largely disappeared, classical ethnographies are rarely conducted these days (Boyle, 1994). Classical ethnographies are also considered to be “holistic ethnographies”, which are ethnographies that aim to describe entire cultural systems (Boyle).

In contrast, a “particularistic ethnography” is one in which the aim is to apply an holistic approach to one part of a culture, such as one particular social unit or “isolatable human group” (Boyle, 1994). The palliative care settings of this study represent isolated human groups, although the study design includes several of these because it covers several palliative care settings. It could, therefore, be more accurate to categorise the current study as a “cross-sectional ethnography”, another category mentioned by Boyle, in which people involved are selected on the basis of their shared culture, even if they do not share a geographical location.

However, the focus of this study is to understand the meaning of palliative care within palliative care settings. A more appropriate categorisation is “focused ethnography” (Boyle, 1994, p. 172), which suggests a topic-oriented approach, in this case the topic of palliative care. This approach has also been called a “mini”

ethnography, defined by Leininger (1985, p. 35) as a “small-scale ethnography focused on a specific or a narrow area of inquiry” in contrast to “maxi ethnography” which refers to the classical approach of “comprehensive study of general and particular features” of a culture.

The approach chosen as appropriate for this study therefore, can be more fully categorised as a descriptive, interpretative, focussed, cross-sectional, mini-ethnography.

Methods

The methods employed in the research are included in this chapter to complete the elements included in Crotty’s (1998) framework. A more detailed discussion of the methods undertaken in the study is provided in the following chapter where the conduct of the research project is discussed. Chapter 4 contains a discussion that includes methods of collecting data, maintaining rigour, and addressing ethical considerations involved in planning and conducting the research.

As has been noted in describing aspects common to ethnographies, fieldwork is the salient feature of this methodology. The issue underpinning this research is primarily a perceived inadequacy in articulating an understanding of palliative care. Methods that allow investigation of both the overt and the implicit or unarticulated aspects of palliative care culture are essential.

The literature suggests that ethnographies employ an eclectic mixture of methods in order to maximise exploration of the underlying culture. Participant observation, in depth interviewing, and examination of supplementary data such as documentation used within the settings and archival records, are considered appropriate methods for this study (Brewer, 2000; Fetterman, 1989; Germain, 1993).

Conceptual Map Based on Prior Research

Prior to entering the field for this ethnographic study, I reviewed the studies I had previously conducted, and constructed a conceptual map of the data that emerged from them. From the data and analyses of these previous studies, I identified that there was a need for further research to answer the question of understanding of palliative care. It was also from the analyses of these prior studies that the research design evolved. It emerged that close observation and interpretation of palliative care practice was required to more fully ascertain people’s understanding of the concept, and that an ethnographic approach was the most appropriate to achieve this understanding.

The first study, "Attitudes towards palliative care: A preliminary survey of nurses and community members" (Webster, 1999) provided data that showed overwhelming support for palliative care when people were asked to merely provide a favourable or unfavourable attitude score towards the concept. Participants were asked to rate their attitude towards palliative care on a semantic differential scale of -3 to +3, and 96% of 160 participants gave a positive (favourable) score. The study also required that people self-generate statements about their beliefs and feelings with regard to palliative care, and score these responses according to the contribution that the particular response had to their overall attitude score. The scoring system proved to be problematic: responses indicated that people experienced difficulty differentiating between scoring the degree to which their responses contributed to their attitude and the strength of the response, and the quantitative results were inconclusive. However, the study yielded a large amount of qualitative data, approximately 1600 individual responses, and revealed a wide range of beliefs and feelings about the topic. Further detail of this study is provided in the report, included as Appendix 1. The following gives an overview of the main points identified from this study, and Table 7 that follows lists the top ten responses given for each group of participants in the study.

Palliative care nurses' responses indicated concern about health service issues, such as resources, facilities, and access to palliative care, as well as education for other health professionals and the general public. Care issues included family, team, and patient choice. Non-palliative care nurses generally gave fewer responses than palliative care nurses, but overall they were supportive of palliative care. About 15% of these participants noted funding and lack of profile as issues. The main aspects of care provision mentioned by the non-palliative care nurses were inclusion of family and pain control. Some non-palliative care nurses expressed frustration about doctors from other areas not referring patients early enough to the palliative care team.

Several bereaved family members expressed concern for issues of funding, however, most responses from this group were related to their personal experience of palliative care. The highest-ranking item was feeling supported, although admitting that it was a difficult and sad experience. Care issues were related to dignity, dying at home, and expressions of dissatisfaction with care such as lack of information from doctors (12%).

Many general community members (46%) admitted to fear or discomfort when considering the topic of palliative care. A similar number (43%) were concerned with

the expense of the services, although many in this group expressed support for palliative care. Care issues included mention of staff and the need for them to be experienced, inclusion of family, and again the concept of dignity was mentioned. Some misconceptions about palliative care were expressed by this group, almost one quarter equating palliative care to aged care, and about the same number acknowledged that they lacked knowledge about the topic.

Table 7 shows the ten most frequent response categories for each of the four groups. Financial concerns were a common theme among the groups. Issues of funding for palliative care were of concern to palliative care nurses, non-palliative care nurses and bereaved persons, with financial concerns expressed as the expense of palliative care by community members. Other themes common across the groups were the notion of palliative care offering support, and the concepts of "patient choice" and "dignity" were among the ten most frequent responses for three of the four groups.

Table 7

Ten most frequent responses, beliefs and feelings combined, for each group. From "Attitudes towards palliative care: A preliminary survey of nurses and community members" (Webster, 1999).

Palliative Care Nurses (n=39)	Non Palliative Care Nurses (n=39)	Bereaved Persons (n=43)	Community Members (n=39)
• Funding	• Support	• Reassured	• Frightened
• Family	• Family	• Dignity	• Expense
• Team	• Pain control	• Sadness	• Support
• Availability	• Special staff	• Support	• Special staff
• Low profile	• Patient choice	• Pain control	• Patient choice
• PC education	• Funding	• Home care preferred	• Reassured
• Support	• Dignity	• Dissatisfied	• Dignity
• Patient choice	• Holistic care	• Funding	• Aged care
• Holistic care	• Late referrals	• Poorly informed by doctors	• Lacking knowledge
• Bereavement care	• Low profile	• Depressed	• Availability

Following the "Attitudes Study" and the disclosure of many different views about palliative care, it seemed appropriate to investigate the meaning of palliative care from experts in the field, people who had worked in palliative care for a significant period of time. The next study conducted in the program of research, therefore, was a qualitative study of the meaning of palliative care for six long-term palliative care workers. Participants were purposively selected on the basis of having a minimum of five years experience working in a palliative care service, and each represented a different discipline in palliative care; nursing, medicine, social work, psychology, chaplaincy, and volunteering.

I interviewed each participant on a one-to-one basis. Two major findings emerged from this research. One finding was about the process of working in palliative

care. Each participant told a similar story of the trajectory of his or her experiences and progress through several stages of working in palliative care. These stages, the Awakening, Making the Connection, Committing to the Philosophy, Reaping the Rewards, and Soldiering On, are outlined in Table 8 with descriptions of the events, experiences and consequences occurring in each phase.

Table 8

The trajectory of palliative care experience. From "Long-term palliative care workers: More than a story of endurance" (Webster & Kristjanson, 2002b)

Phase 1 The Awakening	Phase 2 Making the Connection	Phase 3 Committing to the Philosophy	Phase 4 Reaping the Reward	Phase 5 Soldiering On
<u>Events</u>				
Interest	Comparison with other health care experiences	Involvement with family and patient	Making a difference	Economic considerations
Charismatic leaders	Exposure	Involvement with the team		Restructuring
	Opportunity			
<u>Experiences</u>				
Personal values	Personal experiences	A discovery of honesty	Lessons from dying patients	Changing roles
		Finding meaning		Team dynamics
<u>Consequences</u>				
Awareness leading to a point of no return	A better way	Personal growth	Sense of fulfillment	Frustration
	Seeing the value	A privilege	Not depressing	Perceived impact on patients and families

The trajectory of experiences for this group of people gave insight into the meaning of palliative care for them. Further analysis of the data provided the second finding of this study, the notion of “vitality” as the core meaning of palliative care. Contrary to the popular notion that working in palliative care is depressing, this group of people expressed their experiences as being full of growth and life.

They expressed the vitality of working in palliative care as being “A Way of Living” for them, of “Unity with Self”, the professional values of the workplace being congruent with their personal values. They expressed experiences in the workplace that had “Touched them to the Heart”, and also experiences that had enriched them and offered “Personal Meaning” to their lives.

Three elements of “Palliative Care” were commonly described in the study, “The Patient and Family”, “Holistic Care”, and the “Inter-disciplinary Team”. Again, participants related aspects of these elements that indicated the underlying vitality they experienced in palliative care work. These various concepts were captured in the conceptual model, which I have included here as Figure 2. Also included in the model are elements of the external environment, some of which impinge on the vitality of palliative care. The direction of the arrows depicts the forces opposing those of the vitality that radiate through the layers of palliative care from its core.

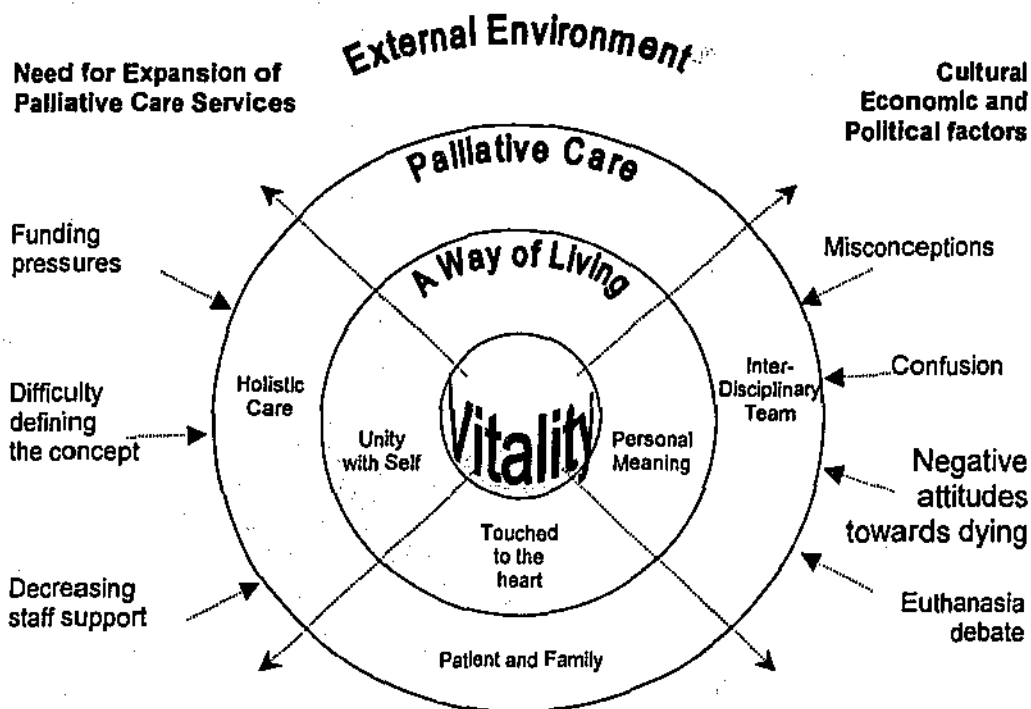


Figure 2: Conceptual framework of the meaning of palliative care for long-term palliative care workers. From “But isn’t it depressing? The vitality of palliative care” (Webster & Kristjanson, 2002a).

Figure 3 represents the combination of concepts identified in the attitudes study and listed in Table 8 with the conceptual framework from the “vitality” study, depicted in Figure 2. The resulting conceptual map, therefore, represents the background of research that frames the current study. The table that follows this map provides a listing of the concepts as well as identifying the source or sources of the concept (Table 9).

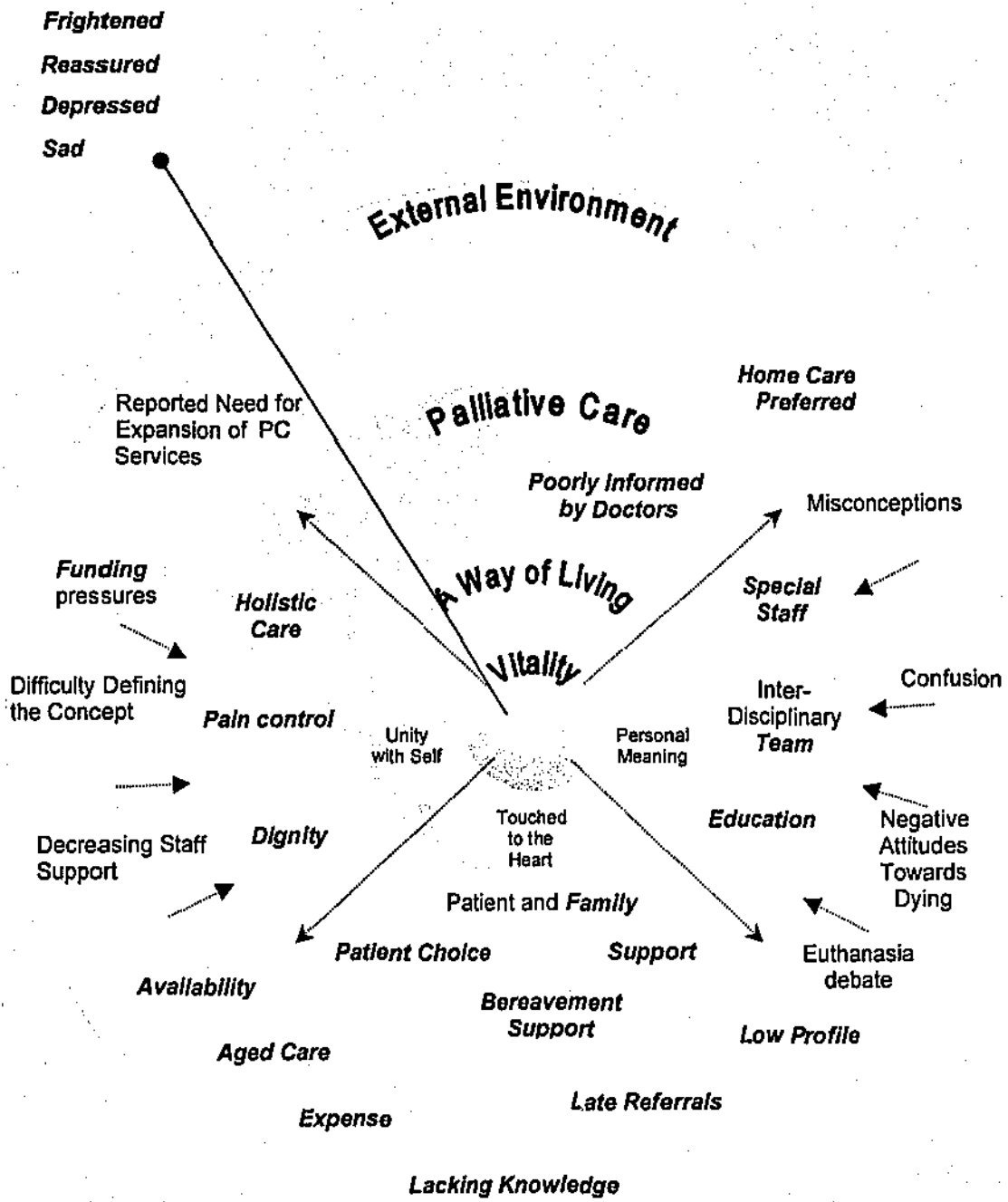


Figure 3. "Attitudes and Vitality". A conceptual map of concepts identified in previous research.

Table 9

"Attitudes and Vitality". Concepts about palliative care identified by participants from previous research.

	Palliative Care Nurses	Non Palliative Care Nurses	Bereaved Persons	Community Members	Long-term Palliative Care Workers
<u>Factors Within the External Environment</u>					
Need for expansion of services / Availability	✓			✓	✓
Funding	✓	✓	✓		✓
Expense				✓	
Low profile	✓	✓			
Late referrals		✓			
Home care preferred			✓		
Lacking knowledge				✓	
Aged Care				✓	
<u>Elements Within Palliative Care</u>					
Family	✓	✓			✓
Team	✓				✓
PC education	✓				
Support	✓	✓	✓	✓	✓
Patient choice	✓	✓		✓	✓
Holistic care	✓	✓			✓

	Palliative Care Nurses	Non Palliative Care Nurses	Bereaved Persons	Community Members	Long-term Palliative Care Workers
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Elements Within Palliative Care continued

Bereavement care ✓

Pain control ✓ ✓

Special staff ✓ ✓

Dignity ✓ ✓ ✓

Poorly informed by doctors ✓

Personal Factors / Feelings

Vitality ✓

Reassured ✓ ✓

Sadness ✓

Dissatisfied ✓

Depressed ✓

Frightened ✓

I have attempted not to impose these previously identified concepts onto the subsequent analyses of the current research. However, reference to these concepts is made when appropriate, again providing transparency to the emerging analyses.

Summary

In this chapter I have provided the theoretical and conceptual frameworks on which this research is based. My intent has been to orient the reader to the underlying paradigm I have adopted for the research. I believe that a clear statement of the theoretical underpinnings as well as an overview of findings from previous research prepares the reader for the tenor of the research findings to follow.

Before embarking on a discussion of the findings of the research, which commences in Chapter 5, the next chapter, Chapter 4 contains a discussion of the process of the research. In this I describe the methods I used to conduct the research project.

CHAPTER FOUR

BOLDLY INTO THE FIELD

The previous chapters have provided the background and theoretical frameworks for this research. In this chapter I discuss the conduct of the research. This begins with identifying that the research instrument in this study is the researcher, and I provide a discussion of the implications that this brings to the research process. Gaining entry to and disengaging from the field is considered, as well as the criteria I used for the choice of research settings and research participants. I introduce the framework of the “ethnographic research cycle” to illustrate the iterative process of data collection and analysis, and discuss the methods used for collection, recording, management, and interpretation of data for the study. Also in this chapter I consider the ethical implications of the study and the steps taken to ensure rigour throughout the research process.

The Research Instrument

Ethnography seeks to discover the cultural behaviour, cultural knowledge, and cultural artefacts of a social group, and their meanings to the “actors” in the field. Ethnography requires observation of social situations in their natural environment. In ethnography the observer, the researcher, is considered to be the primary research instrument. The researcher makes observations, extensive recordings of those observations, and detailed analyses, to reveal the embedded culture of the group (Germain, 1993).

The role required of the researcher is not an easy one. A symbolic interactionist perspective implies that all data are interpretations of interactions, influenced not only by the interpretations of those being observed, but also by the interpretations of the interactions in which the researcher is involved. In other words, the researcher is *in* the research, and not an objective collector of data but the principal source of interpretation of those data. The researcher interprets the world through his or her own lens, which involves interpreting others’ reactions (in turn influenced by the researcher), combining his or her own reactions, and capturing that interpretation. The researcher then conveys

that interpretation to others through the written report. The readers also bring their interpretations to the reading. Researchers in this position of being both in and outside the research have been labelled “marginal natives” (Freilich, 1970).

Marginal Native

As the research instrument in this study, I assumed the role of a marginal native. Freilich (1970) introduced this term to capture the role of the anthropologist who lives on the margin, in two societies, and often in two antagonistic cultures. As the application of ethnographic studies has extended beyond the traditional anthropological roots of conducting fieldwork in non-Western, “primitive” societies, the meaning of the term has broadened to indicate the somewhat blurred boundary of the researcher being both in and apart from the culture under investigation (Gerrish, 1997; Tedlock, 2000). As a marginal native, I identified that my position entering the field was defined by being a nurse within Australian palliative care culture, and at the same time being naive to the particular palliative care cultures of the study. I was, therefore, both “part of” as well as “apart from” the culture of the study.

An obvious concern about conducting ethnographic research within one’s own culture is whether the researcher has the ability and insight to uncover tacit knowledge about a culture in which he or she is already immersed. On the other hand, there are advantages to this position, such as ease of entry, speaking the same language, and engagement with participants (Field, 1991; Lipson, 1991; Smyth & Holian, 1999). The pros and cons of being an insider have been discussed in the literature. Gerrish (1997) for example, a nurse researching in a nursing arena, admitted that her position as a marginal native may have limited the objectivity of observations and her explication of tacit knowledge. She highlighted the positive feature of having greater rapport with participants, which resulted in greater acceptance amongst members of the cultural setting. Overall, she suggested that her marginal native status added to trust in her as a researcher, and to the process of the research overall. Comments such as these encouraged me to undertake this research.

Nurse-Researcher

The dichotomous nature of the marginal native, or “insider-outsider” position, is further complicated by the role of the *nurse-researcher*. Several nurse-researchers have written about nurses conducting research within nursing settings and the potential role conflict that may result for the researcher who is also a nurse (Baillie, 1995; Beale & Wilkes, 2001; Lipson, 1991). Even when not formally employed as nurses in the study

site, nurses are noted to feel a sense of guilt when observing (the researcher role) and not “doing” (the nursing role), and may experience further discomfort if they observe practice that they consider to be inappropriate (Baillie, 1995; Morse, 1991).

Beale and Wilkes (2001) specifically investigated the role among 20 nurse-researchers and concluded that, although nurse-researchers are principally concerned with maintaining the integrity of the research, situations within clinical settings can prompt nurse-researchers to move into a nursing role. An individual nurse-researcher’s response, they believe, is made on underlying perceptions of factors such as duty of care, ethical position, and degree of threat to a subject. Beale and Wilkes concluded that this dichotomous role was worthy of further debate. They suggested that sharing of experiences and discussion of possible solutions to alert future nurse-researchers to the inherent difficulties of the role may better prepare nurses to undertake research within familiar settings. Although this current research was designed to observe the culture of palliative care practice, and not confined to nurses and *nursing* practice, I prepared to undertake the role of nurse-researcher cognisant that role conflicts may arise.

Negotiating the Level of Participation

From the start of my research project I was acutely aware of the dualities in the role I was adopting, being a palliative care professional observing palliative care practice, as well as a nurse conducting research in a health care setting. I considered the balance that was required between participation and observation, although I could not anticipate how this would manifest. In the chapters that follow some of the conflicts that I encountered are discussed. Before entering the field however, I could and did prepare some groundwork for the level of participation that I anticipated, and this required negotiating with staff from the research settings about my involvement.

In planning the research, I wanted to participate in the palliative care units as a willing helper, but not as a Registered Nurse. I had no intention to, and nor did I, seek employment within the units as I did not want to have responsibilities for duties beyond the scope of the research project. However, I did wish to appear willing to assist in activities within the unit as an act of reciprocity (Germain, 1993). As Fetterman (1989) suggests, ethnographers owe something in return for the amount of time we ask of our participants.

Further, I believed that to gain access to the units, to establish rapport, and for participants to act in an everyday manner, it was important that both the researcher and

the research that I was undertaking appeared credible. I further believed that this credibility would be enhanced by participating in some way within the units rather than merely being an observer standing in the corner with a clipboard. At the same time, I did not wish to create any legal or ethical difficulties for the managers of the units by undertaking any tasks for which they may be liable.

I met with the ward managers at the beginning of each fieldsite visit and established the boundaries of my role. They all agreed with this position of moderate participation, and we negotiated that I would assist with activities such as making beds, serving meals, feeding patients who needed assistance, answering telephones, and so on. We also agreed that we would each report back any difficulties relating to my presence on the units. At each site, for security reasons, I was required to obtain and wear an identification badge issued by the particular institution. I was identified as a "Research Nurse" on these badges. Both the badge and the inclusion of *nurse* in my "job" title added to the legitimacy of my presence on the units, particularly with patients and their visitors.

Although the logistics were negotiated individually at each site, the first research site was somewhat of a testing ground for many of these details. The nurse manager and I discussed how I should dress, and agreed that I would wear neat day clothes and avoid wearing anything that resembled the navy and white uniform worn by the nurses employed on the unit. I continued this practice on the other units. It was also at the first site that the Medical Director of the unit suggested that I not introduce myself as a PhD student, but rather as a research nurse because she felt people in general reacted negatively to the label of *student*.

I was also aware that there might be situations that would be particularly challenging, such as observation of practices that I considered unsafe or unprofessional. I acknowledged that as a Registered Nurse, situations could arise where I would need to immediately respond, or where I may feel compelled to react in some way. I resolved that, depending on the perceived consequences of the situations, if intervention was required I would first approach the individuals involved to address the situation. Only as a last resort would I report the matter to senior staff. I also resolved that, if possible, I would initially discuss the situation and seek advice from my academic supervisor or another member of my research committee.

Limitations of the Researcher's Role

In reviewing the literature prior to commencement of the project, there were two other areas associated with the researcher as research instrument that I identified as having the potential to hamper the research. These potential limitations of the researcher role are that of "Going Native" and the "Hawthorne Effect", described below. With prior awareness of these phenomena my hope was to safeguard against their occurrence, although in practice these experiences did occur. By being alert to the possibility of these events, I recognised when they were happening and acted to minimise the impact on the research.

Going Native

"Going native" is a term used for a researcher identifying too closely with the participants in the study culture, a position in which the marginal native crosses an invisible line to become a complete member of the group (Hammersley & Atkinson, 1995; Tedlock, 2000). The suggested danger associated with going native is that the researcher is so closely enmeshed in the culture under study that he or she is unable to recognise or articulate that culture – it becomes part of the researcher's everyday world. In reality, I suspect that crossing the line does not automatically imply that there is a point of no return. The researcher can move between various levels of involvement in the research culture in response to different situations and at different times in the research project. This was my experience, moving from a marginal position to one of immersion and back again, many times throughout the research.

Early in the research I was given the opportunity to reflect on aspects of over-identifying with the nurses in the wards. In the early stages of the fieldwork this was brought to my attention by one of my research supervisors. A non-nurse member of my research committee, she challenged me by commenting that my field notes were reflecting the use of a nursing lens to view the culture. We had ongoing conversations about my role, and the various lenses through which I was viewing and reporting the research. This peer review assisted me through the progress of the research to become more skilled at identifying and avoiding "over-rapport" with the participants in the study.

At other times during the fieldwork I became aware of my immersion in the palliative care culture without the need to be challenged by my research peers. In particular, I felt extremely "comfortable" on the occasions when I accompanied palliative care nurses on their home visits. Home care had been my area of clinical

expertise; I felt comfortable, competent, and a great deal of satisfaction in once again being involved in this environment. It felt like I was “coming home”, although I was acutely aware that it was not my place to engage in clinical issues with the patients we were visiting. Nonetheless, I found that I did do this to some extent, often with the encouragement of the nurse I was accompanying, who was grateful for the clinical support. An awareness of “going native” allowed me to stand, at least at a short distance, and view my actions and reactions rather than merely experience them.

Researcher Presence

A further issue in ethnographic studies is recognition that the presence of the researcher in itself alters the activities of the setting, and by implication, the culture. In extreme cases, presence of the researcher can result in the “Hawthorne Effect” (Groenkjaer, 2002; Polit & Hungler, 1997). This term has been borrowed from Management Practice and describes a phenomenon first noted in the early twentieth century in which workers’ performances improved irrespective of changes to their working environments. The improved productivity was eventually related, not to conditions of the workplace, but to the workers’ knowledge that their productivity was being measured, and that they were being observed (Robbins, Millett, Cacioppe, & Waters-Marsh, 1998).

In relation to ethnographic studies, Germain (1993) states that after several days of researcher involvement in the study site, any guarded behaviour tends to disappear as people turn their attention to the events of their usual life style. Field (1991) similarly suggests that the research observer is soon ignored in the staff-patient interactions once the “business” of clinical tasks needs to occur. In other words, these authors suggest that people who are engaged in a workplace may be distracted for a short time by the novel event of a researcher in their midst, but they quickly adapt to the change in order to carry out the requirements of their work.

In the main, my experience of participants’ responses to my presence appeared to support these views. Patients and visitors seemed to accept my position on the ward from the outset. Staff members were overtly welcoming, several being most concerned about ensuring that my needs were being met, rather than I interfering in their routines. In many instances, participants were keen to know more about the research, why I was doing it, and what I was finding. At least one participant specifically mentioned “the Hawthorne effect”, and asked how that might impact on the research. I answered questions honestly and openly, heeding the advice of Fetterman (1989) to be willing to

discuss the research without deception, and to be willing to discuss it in depth if people are interested in the methodological or theoretical detail.

Towards the end of the research period I specifically sought feedback from participants in each site, staff members in particular, about the influence my presence had made. No specific issues arose from this questioning. No doubt my presence in the research sites and conduct of the research impacted in some way on the study settings. However, unlike the Hawthorne studies, I was not observing levels of efficiency or concentrating on specific behaviours, aspects that might have been influenced by my presence and awareness of my observation. In many ways, the responses and reactions of participants to my presence, and direct questioning about the participants' worlds, added to my research aims because these responses revealed aspects about the culture of the palliative care sites. As Hodgson (2000, p. 4) states, "rather than studying people, ethnography means learning *from* [emphasis added] people". My presence in the research sites, far from contaminating the culture under observation, allowed exploration and explanation among the participants in my search to capture their culture.

The researcher as research instrument also must consider the process of engaging with participants in their natural world, planning how to access the field, and how to optimise the time while there. The following sections discuss these aspects of the research process.

Gaining Access

Brewer (2000) acknowledges that there are various ways and means of accessing the research field site, which can vary from having close ties with a member or members of the group to literally "hanging out" in the vicinity and hoping to be noticed. As a member of the palliative care community prior to commencing the research my approach was the former, seeking members who could assist in gaining access to communities that would serve my research.

Selection of field sites, as is discussed in a subsequent section of this chapter, was largely dependent on my perception of the degree of difficulty in accessing the services. Preliminary discussions with palliative care associates, contact persons whom they suggested, and various other personnel who became known to me during the course of investigating potential research sites, established the feasibility of conducting the study in various sites. Ethics approval was obtained for the selected sites and, with considerable planning, I stepped boldly into the field. Although the relationship I had

with member contacts differed in each of the sites, I adopted a similar procedure for entering and accessing the research field. I did, however, adapt the process according to the perceived feedback from participants regarding acceptance of me and of the research.

My strategy was to seek "step-wise" acceptance, first addressing the staff in the units before making any direct approaches to patients. The personnel I contacted initially to establish approval for the research were asked to assist me with introductions to the senior staff in the clinical areas. I hoped that these senior clinical staff were informed about my impending visit to the unit and had received information I had forwarded regarding the research. This was not the case. I, therefore, spent the initial stages of the fieldwork ensuring that these senior clinical personnel were informed about the research, my requirements, and the perceived impact on their clinical workplaces. With the help of these staff, I gained access to the other staff members within the units, and was able to introduce myself to them and to the research I was conducting.

Most often this process occurred at team meetings, regular meetings scheduled within the units to discuss patient progress as well as general business of the unit. I requested five or ten minutes to talk about the research, and to distribute Information Sheets that outlined the research (see Appendix D). The research was explained as being entirely separate from any work requirement or audit, that participation was in no way compulsory, and that there would be no penalty for choosing not to be involved. Prior to the team meetings, I had sought assistance from a member of the unit to act as a contact person for the staff should they wish to decline from being involved in the research, or had any concerns that they did not feel comfortable discussing directly with me. This person was chosen on the basis that he or she did not have any influence on the performance management of staff, but rather someone who would be seen as a peer, so that there was no coercion to participate in the research. Not all regular staff were present at the team meetings, so I attended several shift handover meetings to speak to those additional staff.

At each step in this process, verbal consent was sought in the form of giving people the opportunity to choose not to be included in recorded observation, or engaged in informal conversation about my observations. In each of the sites, the first week was spent informing staff about the research, giving them time and opportunity to ask questions about it, and begin to know me. I also spent this time generally orienting

myself to the physical layout of the unit and the hospital in which it was situated. Throughout this time I was keen to explain that I was experienced in, and therefore sensitive to, palliative care but that it was some time since I had been in the clinical setting. This was to allay any notion that I was there to judge clinical competence. I also made it clear that I was not reporting back to management, or looking to suggest any changes to the units. I was there to try to understand their world.

When I was reasonably confident that the staff accepted my presence and understood my purpose in the unit, I began meeting the patients. I commenced by asking the shift coordinator or charge nurse if I may introduce myself to the patients. These staff indicated who, in their opinion, were not appropriate, which included patients they believed were too ill to be further disturbed or who were particularly emotionally upset at that particular time. I began introducing myself, explaining the research, and leaving an information sheet for the patients to consider whether the observation would be a problem to them.

In due course, I began introducing myself to the patients' visitors. Many of them already knew about the research as the patients had informed them. At the first site, at the suggestion of the unit manager, a sign with my photograph and a statement of who I was and that I was currently conducting research in the unit, was placed at the entrance to the unit. This was repeated at another unit, although the third site did not wish to display a sign. At the fourth site, added during the course of the research, I did not make the offer. Information Sheets were left in prominent positions on the front desk in each of the sites.

Throughout the research there was little resistance to my presence in the unit or objection to the research generally. Only one patient declined to be included in the research and, respecting his refusal, I did not pursue his reason for this. I did use a great deal of discretion when approaching patients. I avoided disturbing patients or families of patients who were confused or obviously close to death if I had not established a relationship with them prior to the patients' deterioration. I was also mindful and respectful of the emotional impact on people at this time, even when I had an established relationship with them. This was part of the rapport that I attempted to bring to the research.

Building Rapport

Many ethnographers have written about the importance of establishing relationships of trust with participants in ethnographic studies (Agar, 1996; Brewer,

2000; Fetterman, 1989; Hammersley & Atkinson, 1983). In building rapport, these authors have considered not only aspects of friendliness in approaching participants in the field, but more subtle communicators such as dress, language, and non-verbal cues that will build rapport and engage people towards participation in the research.

I was mindful of making a positive impression, and pleasantly surprised at the ease with which I was accepted into the units and the assistance offered to me. In the early days in each of the sites I felt particularly self-conscious, very much aware that I was a stranger in the midst of busy workplaces, asking to be accepted into peoples' worlds and offering little in return. However, it did not take long to fit into the routine of the wards and be able to offer assistance with some of the tasks. This seemed to be appreciated. Early on in one ward I offered to help staff by assisting a patient with his meal. This was greeted with some amount of surprise and appreciation by the staff. At other times, however, when I saw staff who were busy, in particular nurses, I felt frustrated that I could not offer my help because of the limitations of my role as a researcher. Generally this seemed well understood and was probably more difficult for me to accept than for the staff, one of the issues related to being a nurse-researcher as previously noted.

As I have previously discussed, the effect of my presence on the ward was difficult to gauge. It was my perception that the staff continued to behave in the way they would have done if I had not been present, although I certainly was not invisible. Some staff and patients made quips about my presence with comments such as "Better be careful, the 'fly-on-the-wall' is watching." I took these comments to indicate that, of course the participants were aware of my presence and purpose on the unit, but also that they felt comfortable and accepting of me as a person and were able to make jokes about my observational role.

When I specifically probed about the effect I had on being in the settings, a few staff admitted to feeling some anxiety about being observed. They were aware of taking shortcuts, of gaps in the service, and that my presence made them more conscious that things could be done better. Although they were aware of this they also said that they did not do things any differently, and that the gaps in the service were unavoidable, my presence merely highlighting what they already knew. Some of the senior staff saw that there were benefits to my being in the units. Their opinion was that awareness of the research project and exposure to my questions and probes encouraged staff to reflect on their practice and palliative care generally, which these senior staff welcomed.

There were a few occasions when I was excluded from activities of the units. At one site I requested to attend some extraordinary staff meetings and was advised that it would not be appropriate. I accepted this decision without argument, although I reflected that this seemed to be a paternalistic attitude on the part of the staff member organising the meetings. On another occasion, a manager requested that I not attend meetings at which a particular staff member was making presentations to her colleagues. It was explained to me that this person felt uncomfortable speaking in front of people generally, and would feel even more nervous speaking in front of me. I respected the request, although I was disappointed that I could not share in the session. At the same time, I appreciated that the manager had felt able to discuss the staff member's difficulty with me and to make the request. There were other instances of minor gatekeeping throughout the research, but in the main I was granted free access to the units.

Overall, acceptance of my presence at the field sites was positive. There were occasions when I was considered an outsider and excluded from certain activities. There were other occasions when I was very much included, sometimes being invited to join in social activities outside the ward settings. Overall, the role of insider-outsider was constantly being negotiated.

Leaving the Field

Brewer (2000) writes about two aspects of leaving the field; one is concerned with the physical exit, the other the emotional disengagement. In my research, physically leaving the field in the interstate sites was a planned event, governed at the outset by the length of stay. In the local site, exiting was not as distinct. For some months after the initial period of observation at this site, I continued to return and conduct further data collection. The local site was the first in which I conducted my fieldwork and was in many respects a testing ground to pilot my skills as an ethnographic researcher. I returned to the site in the periods between travelling interstate, and again when the interstate travel had been completed. These return visits allowed me to expand on prior observations generally, as well as target specific aspects as data became more refined, building and contrasting with analyses made at other sites. Nonetheless, even though return to the study site was justified in many instances, I was aware that it was personally rewarding to remain engaged with the place, the people, and the culture.

I was aware of an emotional attachment to each of the study sites although the strongest attraction, and the most difficult to disengage from, was with the local palliative care unit. The ability to come and go from this site no doubt delayed "leaving the field". Physical disengagement occurred once intense report writing overtook the observational aspects of the research project. I have a long history with the local palliative care community and continue to be a part of that community and to mix with staff from the study sites. A final disengagement may never occur, although completion of this report will be another milestone in the disengagement process.

Selection of the Settings

Initially, three palliative care inpatient units were selected for observation in this study, and a fourth was added during the period of fieldwork. The criterion for selection of these sites was inclusion in the Directory of Hospice and Palliative Care Services (AAHPC, 1997b), and thereby the assumption that the services are recognised palliative care service providers. A further criterion was that the services provided inpatient care, either in a free-standing unit or in a special unit within a hospital. Detailed descriptions of the services are included in a subsequent chapter, Chapter 6, "The Place."

The decision to include three services in the study was a pragmatic one. I was keen to extend the study beyond the familiar, local palliative care services. During the twenty years that I have been involved in palliative care I have attended various events where I have mixed with palliative care professionals from other services in different parts of the country. Conversations with these colleagues have indicated that interpretations of palliative care differ, and impetus for this current research was fuelled by this knowledge. I desired to explore services not only in Perth, the city where I am most familiar with palliative care practice, but also in other Australian cities. Further, I am aware that some people can be somewhat dismissive of activities occurring in Perth. This attitude is based partly on the city's isolation from other major cities in the country, and also on the markedly smaller population of Perth than some of its eastern-state counterparts. I considered that inclusion of services other than in Perth would add to the authority of the project.

After discussion with my thesis committee about the number of study sites and the length of fieldwork, observation periods of two months in each of three cities were decided to be appropriate. Inclusion of multiple sites was considered to be important because of the suspected differences in palliative care practice between the states. The comparatively short period of observation in each site was recognised as being a

limitation. Germain (1993), for example, suggests that one year is a reasonable period to spend within a subculture. A one year recommendation most likely stems from the traditional anthropological studies where it was assumed that a society would go through most of its major variations in a one year cycle (Freilich, 1977). However, focussed ethnographies or "rapid ethnographic appraisals" (Muecke, 1994, p. 198), such as are commonplace in health care, are not as concerned with the temporal cycle of events and a shorter period of observation may be appropriate.

In the case of this research study, a twelve-month period of observation in each of the sites would not have been feasible. Consideration was given to the timeframe of the PhD program, disruption to other routines resulting from spending time away from home, and the associated financial burden of living away from home during two periods of interstate fieldwork. Alongside this, the logistics of conducting a multi-site study meant not only multiple applications to conduct the research, but also coordinating travel and accommodation arrangements that would further extend the period of the research. A total of six months fieldwork was decided as being practicable for this project.

Several services were considered before deciding on the final three. I made contact with colleagues in other states and explained the intent of my research, asking their suggestions about services that may be suitable for the project. I did the same among the local services. At this point, the criteria for inclusion expanded to include services that were likely to accommodate the style of research, most notably my presence as a participant observer within the ward settings. Considerations included the likelihood of meeting ethics review committee requirements, acceptance by the perceived gatekeepers of the parent facilities as well as the palliative care communities, and stability of the palliative care units at the time. For instance, I wished to avoid services that were undergoing major change, preparing for accreditation audit, or heavily involved in other research projects. I assumed that these activities would impact on the perceived "stress" to the unit as well as possibly interfere with practice and thus impact on my observations of palliative care. Despite my attempts to filter out services encountering these additional burdens, as it happened these activities were happening in the services I visited and, even with the most meticulous planning, would have been hard to avoid. These practices, although initially assumed to be aberrant, emerged as being part of routine practice today.

Participant Selection

All people involved in activities of the units were potentially participants in this study. This included staff, patients, visitors (family and friends of patients), bereaved persons on occasion, consultant staff to the ward, outpatient clinic patients and staff, and people involved in home care teams.

Fieldwork was initially planned to include observation of all shifts over the 24 hour period. However, it became apparent that in a two month period, allowing for a period of gaining entry and establishment of rapport with the patients and visitors, time was limited. I made the decision to observe parts of the night shifts, rather than staying entire shifts through the night. Had I observed throughout entire night shifts I would have had to significantly alter my sleeping patterns, further reducing the time available for observation at each site. I did, however, attend the units during periods when night staff were coming on and off the wards, and I made a point of including evenings, weekends, and public holidays in my observational times. This ensured that a different group of participants and ward routines were captured in my observations, these periods being times when fewer hospital staff were present and more family members were visiting.

People who did not speak English, who were younger than eighteen years of age, and who may not have been mentally competent were ostensibly excluded from being participants. However, it was impossible to exclude observations of these people if they were present in the research sites, and no doubt their presence and interactions with others in the settings added to the overall observations. In fact, many "casual" participants contributed significantly to my observations and interpretations. Academic colleagues, palliative care personnel, friends, and family have all been included in the process of this research, as well as the innumerable people who have been on the peripheries of the research sites and contributed to the overall settings by their mere presence. Both consciously and unconsciously my observations, experiences, and interactions with these many people have shaped this research.

Key Informants

In some instances, I specifically sought out key informants to add vital information to my collection of data. Key informants are described as people who have extensive knowledge of the culture and who are able to act as liaison in providing access and direction to the researcher (Germain, 1986). I sought key informants in each of the research settings. They in turn identified other persons who became key

informants. I spoke at length to these people, and with some I conducted formal tape recorded interviews to capture specific information.

There were also a few people who were more than key informants. In each of the study sites I was fortunate to meet with at least one person who took particular interest in the needs of my research. These people were not only prime sources of information, but also extended support of the project to practical help such as providing access to photocopying and email facilities, and even sharing their offices. These were very welcome courtesies and greatly assisted the conduct of the research in the field sites.

The Ethnographic Research Cycle

The previous chapter outlined the theoretical underpinnings of the ethnographic approach taken for this study. There is another framework that underpins this study, the iterative process of research conduct known as “the ethnographic research cycle” (Spradley, 1980). A diagrammatic representation of the ethnographic research cycle is shown in Figure 4.

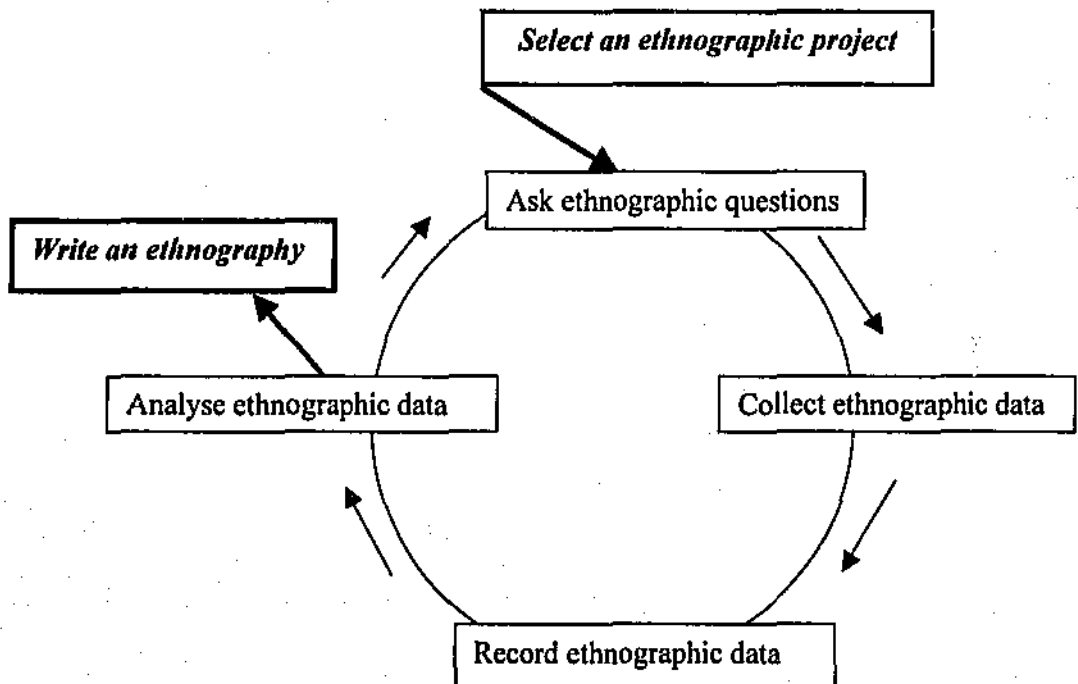


Figure 4: The Ethnographic Research Cycle (Spradley, 1980)

This cycle, which represents the process by which the ethnography was conducted and therefore frames the method of the research, begins with selection of an

ethnographic project and ends with production of a written report, an ethnography. Each research cycle considers the following four aspects; asking ethnographic questions, collecting ethnographic data, making an ethnographic record, and analysing ethnographic data. This cycle is an iterative process, data collection at first involving observations that are descriptive and give a broad overview of the social situation. Recording and analysis of these observations leads to generation of new ethnographic questions, narrowing to more focused observations, with subsequent recording, analysis, and generation of further ethnographic questions. This process becomes more selective through the cycles, while maintaining broad descriptive observations throughout (Spradley, 1980).

This cycle is similar to the interactive model of data analysis offered by Miles and Huberman (1984) that uses the terms data collection, display, conclusions, and data reduction. This is depicted as an iterative process and is typical of the analytic processes used in qualitative research.

Data Collection

An ethnographic approach allows for a variety of data collection methods to be used. The aim is to observe things in their context, to capture the trivial, obvious, and seemingly insignificant things that add to the understanding of the context.

Participant Observation

Participant observation has been noted to be the principal data collection method of ethnography (Freilich, 1977; Germain, 1993; Spradley, 1980), and simply stated means "observing the behavior of a group while participating in its community life" (Freilich, p. 1). The researcher immerses him or herself in the everyday lives of the people under study, developing close relationships with the people, perhaps even living amongst them, learning about their beliefs, hopes and fears. In addition, Fetterman (1989) states that this is done while maintaining a "professional distance that allows adequate observation and recording of data" (p. 45).

Tedlock (2000), however, argues whether a professional distancing is possible, and suggests that the duality of this traditional approach to participant observation is an oxymoron. She has difficulty with the concept of the researcher being simultaneously engaged with and detached from the research field and the people in it. She suggests that there has been a shift in ethnography where the researcher *acknowledges* the subjectivity of his or her research experience and that ethnography therefore becomes a

representation of both the self and the other, which Tedlock expresses as the "observation of participation" (p. 464).

Although I have chosen to continue to use the more familiar term "participant observation", Tedlock's point of view is valid, and one that echoes the underlying assumptions of symbolic interactionism. The form of participant observation as a method of data collection that I have used for this study has included not only "observing the behavior of a group while participating in its community life" (Freilich, 1977, p. 1), but also observation of my participation within that community life.

Participant observation is the hallmark of ethnography, but not the only means of data collection. In addition to observing, ethnographers also ask questions.

Interviews

There are several levels on which asking questions can be conducted in a field setting. Questions can be asked informally as part of general conversations, or formally as part of pre-arranged interview processes. Formal interviews can also be of varying types. Structured or semi-structured interviews consist of pre-determined questions and are "verbal approximations" of questionnaires (Fetterman, 1989, p. 48). Structured interviews can follow a standardised schedule, asking several informants the same set of questions (Patton, 1990), and questions can be open-ended or closed-ended (Fetterman). All combinations and variations are possible and appropriate in ethnographic data collection.

At the outset of the research I anticipated that I would conduct formal interviews with up to ten key informants at each site. This number was an arbitrary figure, an estimate of the involvement of time and human resources that was a requirement in the application process to ethics committees of the various institutions. These formal interviews required a further degree of consent, involving exchange of more detailed written information about the research study, signed consent forms, and tape recording of the interviews. (Samples of these documents are included in Appendix D). I anticipated that after a period of time in the field I would have specific questions to ask of identified key informants and that this method would be the most appropriate to collect these data.

Once in the field sites, however, it was often awkward to arrange such formal processes and to develop a set of specific questions. Questions were far more appropriately asked during the course of the normal activities of the units. Fetterman

(1989) notes that asking questions in the context of informal interviews is often easiest, although sometimes the questions may “impose an artificiality” (p. 49). Certainly, my experiences of merging interview with conversation in this way, and the serendipitous comments that sometimes resulted, hugely informed the research. The greatest disadvantage was that informants’ comments were not recorded verbatim and, therefore, I relied on recall of what informants had said as well as my interpretation of the exchange.

As well as these informal, conversational type interviews, I also requested time with various key informants to ask “survey-type” questions (Fetterman, 1989), where I sought to discover more about the job roles of these participants and the organisational processes of the institutions. There were several participants with whom I sought an audience, but did not seek a formal interview, forgoing the requirement to obtain written consent and, therefore, permission to tape record the sessions. In retrospect, a more formal process including an audiotaped record of these encounters may have been appropriate for these interviews, although at the time I considered that the formal process of obtaining written consent was unwarranted and would have placed a burdensome “artificiality” on the encounters.

The protocol I had developed for seeking consent for tape recorded interviews, and which the various ethics committees involved in this research study had approved, was cumbersome, although I did adhere to the process when conducting these more formal interviews. When requesting participation in a formal interview I generally discussed my request with the potential informant, left the paperwork with them for further consideration, and followed up the next day to check on his or her response to the request. If the person agreed then a suitable time and place was arranged. This process could take several days. On several occasions I had spoken to patients about undertaking these interviews and left them to consider the request. By the time I followed up to check their response, their condition had deteriorated and in two instances, the patients had died in the interim. In retrospect, the time delay between request and interview was too long, but I set this criterion to enable participants time in which to fully consider the request rather than feeling any coercion to comply.

In all, I obtained written consent and conducted 15 formal tape recorded interviews with key informants. These participants included staff, patients, and families from three of the four study settings. I targeted these participants for various reasons. With some of the staff, I asked survey-type questions that I identified would further

orient me to the history, formal and informal structures of the services; other staff held key positions across various areas and were able to provide "bigger picture" views of the services. The formal interviews with patients and families were more opportunistic. I selected these participants because they were articulate, were physically well enough to participate, and most importantly because I identified that they would contribute significant stories to the research. As patients and family members, they had expressed some indication that their experiences in the palliative care unit were different from other health care experiences, and I wished to explore these notions further.

As well as formulating specific questions or areas of questioning for these formal interviews, I also encouraged participants to talk freely about palliative care experiences in general, and probed areas that seemed to offer potential for revealing more about the palliative care cultures. I reflected some of my interpretations of the culture, and sought comments from the participants about these preliminary findings. All participants of these formal interviews were offered the opportunity to review verbatim transcripts of their interviews, with only six requesting to do so. One of these six participants died before the transcript was available, and of the five transcripts that were returned, no changes or withdrawals were requested.

Supplementary Data Sources

Numerous other data sources added to the collection for this study. Of particular relevance were the brochures advertising the palliative care services that were available within the units and throughout the hospital environs. These documents provided an insight into the overt culture of the palliative care services, giving an indication of how the service managements portray their services.

I did not have access to patient records, other than to the few patients from whom I had sought specific consent to interview and view their notes. However, within the study settings I did have access to ward documentation that included message books in which staff left notes to each other, daily work books, procedure manuals, and educational and orientation materials for staff. I also referred to historical documentation about palliative care in the geographical areas and occasionally articles of local interest, such as newspaper clippings about the unit or a staff member from the unit, that had been saved in a scrap book and kept on the ward.

Other relevant documents included, for instance, health department strategic plans for palliative care, providing insight into the bigger picture of palliative care

within a region, state, or even within the country. How these documents were being used also added to the interpretation of the local palliative care cultures.

In addition to this collection of documentation, I also attended and continue to attend many lectures, seminars, and conferences about palliative care and related areas. Some lectures were conducted by staff from the research study sites and were held during the periods when I was undertaking fieldwork, for instance palliative care specialists delivering lectures to medical students as part of students' coursework. I have encountered some of the staff from the units at various conferences and seminars, and some have been presenters at these venues. All of these sources have added to the ethnography, both directly because they pertained to the particular research sites, and indirectly by adding to my overall awareness and interpretations of the emergent data in the context of palliative care in Australia. This was, and continues to be, a time of immersion in palliative care culture.

Data Recording

Throughout the research I recorded copious notes of my observations, thoughts, feelings, preliminary analyses, and questions to be explored. In order to manage the volume of these records, I attempted to maintain several different notebooks and computer folders to organise the data by type, although often one category blended into another. In general terms, however, I separately maintained field notes, transcripts of interviews, personal journals, preliminary analyses, and preliminary reports, these latter forming the basis for early drafts of this thesis.

Field Notes

Field notes form the basis of an ethnographic record, and include impressions and decisions made by the researcher even before observation commences. The bulk of field notes, however, are the detailed descriptions of observations that are made in the field, using informants' language without interpretation or simplification, and describing as vividly as possible the context of the observations.

Fetterman (1989) and Spradley (1980) suggest making condensed notes in the field, using exact words and phrases to prompt accurate recall of the observation, and making expanded accounts from these notes as soon as possible after the observation. Heeding their advice, I kept a notebook with me in the units, and occasionally during a period of observation I would retreat to a quiet office and write a few key words and phrases to jog my memory at a later time. I also carried a small dictaphone tape

recorder, and would use this as well to record a few thoughts during the fieldwork. In the main I refrained from recording notes while actually in the field. The majority of the field notes were recorded immediately after leaving the units. I used the tape recorder to capture the events of the day, sometimes recording as I drove home. Later that evening, or the next day, I would transcribe these notes into an electronic document, often expanding on the thoughts recorded as I typed. This provided two periods of reflection about the day's activities and resulted in large amounts of descriptive accounts interspersed with many reflective comments. These notes were time and date stamped and kept in chronological order.

Throughout the thesis I have inserted excerpts from these field notes. These passages are marked with the notation "Fieldnote" and the date the observation occurred. When a direct quote is included in the passage, it is indicated in quotation marks. An example of this is as follows:

Fieldnote: 15 October 2001

Today in the train, such a mixture of people. All nationalities, all ages. The guy in the next seat, with a boy about seven with him. I thought it was a woman, until I noticed the shadow of a beard on his face. Long hair in a plait, fine features. Just different. ...Then later when I was out with Marilyn there was a guy changing his pants on the station. Wasn't lewd or anything. Changing from shorts into track pants. Apparently this is no big deal. "A common sight in Sydney" was Marilyn's comment.

Transcripts of Interviews

As previously mentioned, I conducted 15 formal interviews with key informants, and tape recorded each of these. Each tape recording was transcribed verbatim, ten by a professional transcriber, and five I transcribed myself. I listened to all tapes and edited all transcripts to ensure that they represented a verbatim replication of the interviews.

Insertion of excerpts from the interview transcripts is marked by indenting, in the usual manner for quotations, and indicating at the beginning of each passage the name (or pseudonym) of the speaker, as shown in the following example.

Eve: I like the funny places up in Queensland.

Judi: I don't know Queensland very well.

Eve: Cairns, Townsville?

Judi: Yes, I've been to Cairns a couple of times but I don't know it very well, just on holidays.

Personal Journals

The third category of data recordings are from personal journals I kept throughout the periods of fieldwork and beyond. Many of the journal entries were thoughts about the process of the research, my involvement and reaction to the process, the people I was meeting, and the progress of the research generally. I included thoughts, questions, possibilities about what I was observing, and plans for future observations and hunches to follow up.

Entries in the journal were not always made on a daily basis, and often made reference to events that had occurred in the past, or thoughts about activities planned for the future. The formatting used for these entries when included in the thesis is indented, italicised, and dated, as in the following example.

Personal Journal: 7 March 2001.

I also feel in a quandary about having too much input [to the ward]; and again at yesterday's meeting. I haven't been to the hospital today. I was just reflecting in the shower about what's been going on.

As well, from time to time throughout the research, I have written expressions of concern about the process. This has helped to clarify my role within the research, and aided me to trust in the process of the research as it was evolving. Some of these reflections are included in the research findings of this thesis, although many of the thoughts were of a cathartic nature and would be inappropriate to include in this research product. Nonetheless, this was an important activity in the research process.

Where included, these notes are inserted at points throughout the text with the intention of providing insight into the interpretations that are being made throughout the study. These Personal Notes are undated, and included as indented, italicised comments as follows.

Personal Note: When including these reflections I need to keep to the point. I think it's important to convey my thoughts and feelings about the process, however, I'd hate it to come out as merely navel-gazing!

The vast quantities of recorded data that have accumulated throughout this research are not merely records of raw data. Recording has been a process of inquiry

and of framing and reframing questions. The writing is itself a way of learning, a form of analysis, and is ongoing (Punch, 1998).

Data Analysis: Reframing the Questions

Analysis for this study occurred throughout the research process. The ethnographic research cycle demonstrates the iterative process that I have undertaken with this work; the continual data collection and interrogation that has formed the ongoing analytic process of the study. Observations have been made, reflected upon, and questions formed. I have returned both to the data and to the field to verify, modify, and reframe the questions.

Ethnographers such as Spradley and Fetterman discuss the analytic process in ethnography as alternating between wide-angle and close-up views of the field. Spradley (1980) suggests framing the initial ethnographic questions to provide a "grand tour" of the setting; Fetterman (1989) refers to this as "mapping the cultural terrain". These grand tour or survey questions are designed to provide a broad picture of the setting from which the boundaries and plan of the research may begin to emerge. From these, the ethnographer hones to specific questions, modelled from categories emerging from the broader survey questions (Fetterman).

Starting with broad survey questions, I developed various categories or "index codes" (Brewer, 2000) by which I sorted the data. Initially, I imported field notes and interview transcripts into NUD*IST version 4, and later version 5, a computer software package for management of qualitative data. I hand drew flow charts and mind-maps using colour codings and diagrams. I constantly moved between identifying themes, sorting data, and searching for examples in NUD*IST, returning to the field to further investigate, and so on back and forth.

Foci within this milieu included searching for "key events" (Brewer, 2000; Fetterman, 1989), those occurrences within the study sites that gave particular insight into the culture. The analyses of these key events include the impressions, interpretations, and ambiguities that arose from them. Muecke (1994) states that the process of discovery in ethnography cannot be documented, and indeed it has at times been difficult to map the analytical processes that have occurred. Analysis has been through an eclectic mix of interpretation, interrogation, and investigation. Fetterman talks about moments of "crystallisation", what I referred to throughout the process as my "penny-dropping moments", when images and impressions came together to give an insight into the culture in which I was immersed.

These various processes have provided the analyses represented in the following chapters of this work. Indeed, writing this report, although depicted in the ethnographic research cycle as the point of stepping off the cycle, continues to be part of this process. As Fetterman (1989) profoundly states, "writing clarifies thinking" (p. 105). It is likely that, even with submission of this thesis, this current work will be but one end-point of this study with subsequent reports, articles, and even books yet to be written.

Writing the Report

Whether ethnographies are recorded as doctoral theses, reports, academic texts, or popular novels, the hallmark of writing is the use of "thick description" to convey to readers the cultural meanings of the observations (Fetterman, 1989; Geertz, 1973). Thick descriptions provide context, intentions, meanings and interpretations of phenomena, and often include verbatim quotations of people in the culture (Brewer, 2000). I have attempted to provide such excerpts throughout this thesis with the intention of involving the reader as closely as possible to the field so that he or she may share in the interpretations that I have made.

Within ethnographic literature, the status of the author is sometimes discussed. Brewer (2000) and Van Maanen (1988), for example, have written about realist, post modernist, confessional or impressionist authors among others. Having already stated in Chapter 3 the epistemological underpinnings of this research, the "status" I have attempted to adopt is that congruent with a constructionist worldview.

In writing this report, my endeavour has been to provide an interpretation of the observations I have encountered, remaining faithful to the voices of the participants as far as my interpretation within a symbolic interactionist framework extends. I have also imbued the research with a considerable number of *reflexive* commentaries, with the intent of allowing the reader to gauge the worth of the outcome. Any further discussion of the status of the author is, I believe, unwarranted for this research.

I provide further discussion about reflexivity in the next section in relation to the overall rigour of the research process.

Rigour of the Research

The issue of rigour in qualitative research is one of ongoing debate (Kirk & Miller, 1986; LeCompte & Goetz, 1982; Morse, Barrett, Mayan, Olson, & Spiers, 2002). Lincoln and Guba (1985) are credited with introducing the term "trustworthiness", which has come to include aspects of rigour relating to credibility,

transferability, dependability, and confirmability in qualitative research (Guba & Lincoln, 1989). The term trustworthiness was used intentionally to emphasise the difference from rigour in quantitative studies, which are traditionally associated with notions of validity and reliability.

Morse et al. (2002), however, have recently argued that avoidance of the terms validity and reliability in qualitative research has had a deleterious effect on the rigour applied to qualitative studies. They suggest that as an emerging trend, rather than applying rigour throughout the research process, the focus on ensuring trustworthiness relies more on post-research evaluation of criteria associated with trustworthiness. They suggest that a return to issues of validity and reliability, applied in appropriate ways to qualitative research, would ensure that rigour is built into the process of the research, rather than application of external checks once the research is complete.

Rigour in ethnographic studies further adds to the confusion in addressing these issues. Cresswell (1998) notes that ethnographers generally are not extensively concerned with "verification" of their studies, that they perhaps assume the methodology itself implies a trustworthiness in accurately reporting accounts of the native view of reality. In ethnography, propositions are verified with participants (member checks) and from multiple sources of data (triangulation).

It has been my intention throughout this ethnography not to engage in the various arguments of what constitutes rigour and how best to defend it, but to endeavour to conduct a rigorous study throughout the process of the research, and to trust that the evaluation of the product proves satisfactory. To these ends I consider that self-correcting models, such as using the iterative process of the ethnographic cycle, have ensured that the conduct of the project has been rigorous. As well, I have provided evaluative cues throughout this report, such as transparency and reflexivity, for the reader to judge the merit of the endeavour. In the following sections I consider specific issues of ensuring rigour; namely truth value, triangulation, reflexivity, and peer debriefing.

Truth Value

The primary aim of research is perhaps the truth value of the endeavour. Throughout this study my attempts of discovery have been geared to finding the "truth", from participants' perspectives, and acknowledging from a symbolic interactionist perspective that there will always be different interpretations of that truth. Throughout the research my endeavours to seek and understand palliative care have been

principally through the process of the ethnographic research cycle. As I observed the culture and explored emerging themes, I generated new research questions that returned me to the field to explore, verify, or repudiate these themes in the natural setting. As well, I sought informants to interview and provide member checks, or what Hammersley and Atkinson (1983) call “respondent validation” (p. 195), of my findings and postulates of my analyses.

Further, throughout the period of the study, I made presentations of preliminary analyses to various groups, including members of the research sites, post-graduate researchers, lecturers, and visiting fellows within my university, and several state, national, and international conferences related to nursing, cancer care, and palliative care. In each of these venues feedback was encouraged and subsequently incorporated into the ongoing analyses of the study.

Truth value has also been explored using a variety of methods and sources for comparison and confirmation. The process of comparing studies of a single phenomenon using more than one source or method in qualitative research is known as *triangulation* (Kimchi, Polivka & Stevenson, 1991).

Triangulation

Comparison of analyses from multiple sites, space triangulation, was used to provide confirmatory evidence, and sometimes to redirect the analyses and explore alternative interpretations (Mathison, 1988). I also used different methods to triangulate data. For this, I returned to previous studies that I had conducted, one using survey and free response methodology (Webster, 1999) and the other qualitative interviews (Webster & Kristjanson, 2002a, 2002b), to confirm themes emerging from this study.

Triangulation of data sources on a micro scale also occurred. This included using multiple sources of data such as observation, written reports, and verbal accounts of particular behaviours and incidents, as well as interviews with multiple people about the same observation or incident. Often, participants representing different groups within the workforce, for example doctors, nurses, patients, and family members, were used to provide potentially different perspectives of the same event and further clarify my interpretations.

Reflexivity

Reflexivity has been referred to as self-awareness of the researcher and is acknowledged as an attempt to improve the credibility of qualitative studies by

acknowledging researcher biases (Baillie, 1995). Brewer (2000) explains reflexivity as the researcher giving attention to the social processes that impinge upon and influence the data, and he suggests that influencing factors can include the location of the setting, the sensitivity of the topic, and the nature of the social interaction between the researcher and researched. Ethnographic approaches generally, in which the researcher actively participates within the field, require reflexive attempts to identify interpretations of data that are influenced by the researcher's preconceptions, relationships to participants, and worldview generally.

I use the term "reflexivity" to convey the duality of my role as researcher and participant and the insight that this brings to the research (Streubert & Carpenter, 1995). In the first chapter, I identified my "subjective self" in relation to personal experiences of palliative care. I believe it is important to have declared this position from the outset. In relation to an ethnography about understanding palliative care it is relevant that I declare my experience as a nursing professional in the area, and also as a bereaved daughter and former care-giver to my beloved dad. Neither of these experiences were forgotten when I was in the field, and at times I was particularly conscious of my past experiences and the influences on my reactions. This is part of the self-awareness that I have attempted to bring to this research. I also suspect and acknowledge that at times I have been unaware of the influence of these, and other past experiences. Therefore, it is important that the reader is aware, at least in part, of my subjective self and interprets the data presented here through his or her lens and with that background knowledge about me, the writer.

As recommended by Baillie (1995), my thoughts and reflections about potential influences have been captured in personal journals throughout the research, and excerpts included in this thesis where appropriate. Again, this is an attempt to allow the reader insight into the lens through which I have observed this research, and to judge the merit of what I am presenting.

Reflexivity, I believe, is crucial to providing rigour to this research. Elsewhere I have discussed the implications of the researcher as the research instrument, and the changing emphasis from participant observation to observation of participation. Inherent in these discussions is the concept of reflexivity. Throughout the following chapters I have interspersed reflexive thoughts with observations and discussions. I trust that the reader finds these insertions relevant and enlightening rather than self-indulgent on my part.

Tedlock (2000) mentions that many ethnographers have published both a scholarly ethnographic account, and subsequently a personal autobiography based on the same work. It is likely that this dissertation represents the former, and that at a later date more of my story will be revealed in the production of an ethnographic novel. Already I am aware of the urge to expose more of my personal experiences that are not appropriate to include in this formal work. My intention is that the reflexive comments throughout this thesis provide the reader with insight to my research world, and add rigour to the process.

Peer Debriefing

Another strategy that I have consciously encouraged throughout the research has been to remain as transparent as possible, and constantly open to challenge and feedback. Part of this transparency has been to be openly reflexive, to avoid any known deception, and to seek regular feedback from my peers and supervisors.

During the course of the research I have met regularly with members of my supervisory committee and conferred widely with other experienced researchers and clinicians. While I was out of the state conducting fieldwork I maintained phone contact on a regular basis with my supervisors. One supervisor is an authority on palliative care nursing, another a senior nurse lecturer and researcher with a quantitative background, and the third a senior psychology lecturer who is an experienced quantitative and qualitative researcher, and is also researching in the area of palliative care. The wider reference group has included a medical anthropologist who has undertaken ethnographic studies in palliative care, professorial staff in the field of cancer and palliative care nursing, senior research fellows who have undertaken qualitative doctoral research studies in nursing, and former colleagues who are senior clinicians in palliative care settings.

The consultations with this reference group have added to the overall quality and content of the study. Most importantly, the relationship I have with my three supervisors, each bringing a different perspective to the research, has allowed rigorous peer debriefing that has challenged some of the potential bias that I may have brought to the research.

Ethical Considerations

Ethics approval for this project was necessary to obtain from the Edith Cowan University Committee for the Conduct of Ethical Research prior to any data collection,

as well as from ethics committees at each of the study sites. Two of the institutional ethics committees required further information in respect to the initial applications. These requests represented an apparent lack of understanding on the committees' parts of the qualitative approach to the research. Specific queries were elucidated and approval was granted. Copies of these approvals are included in Appendix E.

These applications addressed specific ethical issues included obtaining informed consent, confidentiality of information and safety of record keeping, ensuring personal safety of participants, self-determination of participants including the decision to withdraw from the study at any time without penalty, opportunity to withdraw or request exclusion of specific personal information, and opportunity to receive reports on findings of the study. These principles guided the conduct of the study throughout, and represent the standards that are commonly considered in all types of human research.

There are, however, specific ethical issues pertaining to qualitative studies that several researchers have written about. Agar (1996) touched on the ethics of informed consent and disclosure of the purpose of the ethnographer when discussing the "presentation of self". Punch (1994) wrote about politics and ethics in qualitative research and Hammersley and Atkinson (1995) added a chapter on ethics to the second edition of their guide to ethnography. Some of the issues these authors have raised include informed consent, privacy, harm, identification, and confidentiality, ethical issues that specifically caught my attention throughout the process of the research.

I have already discussed some of the concerns that not all people who were observed were informed about the research, many people being "accidental" participants on the peripheries of the research sites. It is also not known how fully people understood my presence and the purpose of the research, despite being given information and opportunity to question.

Other ethical issues relate to the vulnerability of patients, especially dying patients, and their families, and the private exchanges that occur in these public places. My presence in the research sites was generally well accepted by the staff of the palliative care units and, as a consequence of that, was most likely passively accepted by these patients and families. Although I remained mindful of the privileged position I held in these environments, I remain unsure of how consensual people were to the research.

A final ethical issue of concern throughout the study has been that of disguising individuals' identity and maintaining confidentiality. The cities in which the research

was conducted were genuinely Melbourne, Sydney, and Perth, and people in Australia familiar with palliative care services may be able to recognise these services despite using pseudonyms in this work. Of greater concern is that through identification of the services, individuals might be identified. I have used pseudonyms for all participants and made changes to incidental details in efforts to disguise key personnel. I trust that identities remain protected and that no individual is harmed or embarrassed in any way by this research.

One further point to make is that at no time throughout the research have I attempted to rate the services or make comparison about issues of quality or competence. This was never the intent of this research. If readers of this manuscript choose to benchmark their services against those described here, then I trust that this only serves to improve palliative care provision generally, and does not reflect inadequacies or incompetence on the part of any service or individual.

Summary

In this chapter I have provided a comprehensive discussion of the research process that I undertook as I stepped boldly into the field to conduct this project. It has been my endeavour to give an understanding of this process to provide context for the findings and interpretations of the research that follow.

I commenced with a discussion of my role as marginal native, which included my experiences of being a palliative care professional researching in a palliative care environment. I discussed how I gained entry to the field, built rapport with participants, and how I continue the process of disengagement from the field. I have provided details of how the research sites and participants were selected. The ethnographic research cycle maps the process of data collection, recording, and analysis that I employed and that underpins the rigour of the research. Ethical issues related to the conduct of the research are also given. Indeed, the implications of stepping into the field have been incredibly bold.

With this background explicated, the following chapters delve into the content of the research findings. I begin in Chapter 5 with setting the political context of the study sites, move to a discussion of the physical environments in Chapter 6 "The Place", and in Chapter 7 the people encountered throughout the research are revealed. Chapter 8, entitled "The Practice", explores the various activities I witnessed throughout the study. A final chapter synthesises the work, and offers questions for future exploration.

CHAPTER FIVE

THE POLITICS

In the previous chapters I discussed the theoretical and practical underpinnings of this research. The remainder of the thesis reports the findings and my interpretations of them. Although this chapter is the first in which I discuss the findings, much of its content was the last to be researched. The chapter's subject matter evolved from the process of the ethnographic research cycle. Questions, driven by observations in the research fields, led me to investigate the backdrop to palliative care in order to understand more fully the context of practice in these settings.

In this chapter I outline the context of palliative care within the three Australian cities of the study. Here I describe little about palliative care practice, but rather factors that govern the practice and impinge on understanding palliative care in these settings. Because of this I have entitled the chapter "The Politics", and the discussion contained within the chapter is about the local backdrop in which to frame subsequent data.

I begin with an historical overview of palliative care development in the three Australian states, and the current status of palliative care within Australia. The demographic profile of each region is described, as well as the cultural nuances in which the palliative care services operate, including those dictated by the parent services. The chapter concludes with a summation of the context of palliative care within the areas.

In subsequent chapters, I discuss findings in relation to what Spradley (1980) considers are the three major features of all social situations; space, actors, and activities. These three "grand tour" categories give rise to Chapter 6, "The Place", Chapter 7 "The People", and Chapter 8 "The Practice". Overall, I provide an extensive interpretative description of palliative care practice in the four study sites, framed by "The Politics" contained in the following sections.

The Development of Palliative Care Services in Australia

Although palliative care started in Australia in the early 1980s, the development in different geographical areas was dependent on local advocates at the time. Present

day models of care reflect those early influences, despite the growth of services and the linkages forged between the states through associations such as Palliative Care Australia, the peak body for palliative care in Australia.

The study sites in this research include services in Sydney, Melbourne and Perth, the capital cities of three Australian states. Through a combination of anecdotal reports, discussions with key personnel, and review of the available literature, I briefly outline development of palliative care in these three cities in the following sections.

Sydney, New South Wales

The forerunners of modern palliative care services are more aptly described as “homes for the dying”. These were places, often run by religious orders, offering support mainly in the form of nursing and spiritual care (Baxandall, Hodder, Redpath, & Wannan, 1989). Such services existed in New South Wales under the auspices of the Sisters of Charity, namely Sacred Heart established in Sydney in 1890, and the Anglican church who ran the Homes of Peace, now Hope Healthcare (Redpath, 1998). These establishments continue as palliative care services today.

Several medical practitioners are attributed with initiating modern palliative care services in Sydney. Anaesthetists and physicians Dr Brian Pollard, Dr Brian Dwyer, and Dr Paul Laird are credited with having significant influence in the establishment of consultancy services in major hospitals such as St Vincent’s, Concord and Royal Prince Alfred. (Redpath, 1998; K. White, personal communication, May, 2002). Professor Norelle Lickiss, a physician associated with the University of Sydney, was also mentioned by several palliative care consultant physicians during the conduct of my research, as being a driving force in palliative care development, and influential in their training in palliative medicine.

At the same time as inpatient consultancy services were developing, so were community palliative care services. These services were reported to have a strong emphasis on nursing leadership and coordination with general practitioners. Although there was significant collaboration between the two arms of palliative care provision initially, the medical model supporting palliative care specialist physicians has gained in dominance over time. Nowadays, much of community palliative care is provided by generalist programs rather than specific palliative care services (Redpath, 1998). Palliative care services in Sydney predominantly cater to inpatients either in dedicated palliative care units (PCUs), or referral of patients to consultant palliative care services set up within the tertiary facilities.

Redpath (1998) notes that, due to difficulties associated with the size of Sydney's population, coordination and integration of services has been hindered. (See Table 10 for comparative population sizes of the three cities over twenty years.) However, attempts are being made to address the issue of improving coordination, as well as the perceived inequities of palliative care service provision that exist throughout NSW. In March 2001 the Palliative Care Framework, a guide for palliative care provision in NSW, was published (NSW Health Department, 2001). The framework is noted as being "an important first step" (p.15) in the planning process.

Table 10

Population Size of the Three Capital Cities

	Sydney	Melbourne	Perth
City Population 1980 ^a	3,257,500	2,787,400	899,400
City Population 2000 ^b	4,085,578 (+25.42%)	3,466,025 (+24.35%)	1,381,127 (+53.56%)

^a Australian Demographic Trends 1997 (Australian Bureau of Statistics, 2001b).

^b Australian Demographic Statistics Quarterly (Australian Bureau of Statistics, 2001a).

Melbourne, Victoria

In Victoria, specific services for care of dying people up until the 1980s were under the auspices of religious orders, namely the Catholic-based services Caritas Christi and the Little Company of Mary (Palliative Care Task Force, 1995; Redpath, 1998). In this way the historical basis of service development is similar to NSW. In 1979 Melbourne Citymission, supported by the Kellogg Foundation (USA) and the Australian Commonwealth Health Department, undertook an overseas research project into the feasibility of palliative care services (Baxandall et al., 1989). In 1981 they established a home-care service and 10 inpatient palliative care beds within their nursing home (Palliative Care Task Force, Redpath). Other key initiatives that heralded the commencement of modern palliative care services within the state were identified by Redpath as being commencement of home-care services in the Geelong area, and the Mercy Hospice Care service in the western suburbs of Melbourne. Development of palliative care services continued, albeit with ad hoc arrangements for funding, and was

largely reliant on individual community influences rather than any planning on the part of government or health care bodies.

The Victorian government began efforts to address the haphazard nature of service delivery and established a Palliative Care Task Force in 1993. The task force's brief was to advise government on strategies relating to the development, funding, and monitoring of palliative care services and on the provision of palliative care education for staff (Palliative Care Task Force, 1995). They identified an inequitable distribution of services among the health regions of the state that had resulted from the ad hoc development. Redpath (1998) made comment on some of the problems inherent with this haphazard pattern of expansion. Issues she identified included confusion about boundaries of care provision and duplication of services. She also noted the difficulties of sustaining services that had been set up with small "seeding" grants, yet needed community support for ongoing funding of staff salaries.

The Victorian government implemented programs to redress the inequities of service provision and create "an integrated and comprehensive palliative care service system" in the state (Department of Human Services, 1996, p.v). A tendering process for service provision was undertaken in 1998 in an attempt to redress the inequities and provide coordination of services.

Perth, Western Australia

Interest in caring for terminally ill people started in Western Australia in the late 1970s and was championed by a group of oncology staff at one of the major teaching hospitals. Dr (now Dame) Cicely Saunders from St Christopher's Hospice in London was invited to visit Perth and deliver a series of lectures to the local community. From this initial interest, the Cancer Council (also known as the Cancer Foundation) of Western Australia commissioned a feasibility study looking at the care of terminally ill people in Perth (Redpath, 1998). This was undertaken by Dr David Frey from the Centre for Advanced Studies in Health Science, Western Australian Institute of Technology (now Curtin University of Technology.)

Arising from this report, recommendations were made for the establishment of a community service, as well as a dedicated palliative care inpatient facility. It was decided that an appropriate strategy was to use the infrastructure of the well-established home nursing service, the Silver Chain Nursing Association, to create a specialist palliative care community service. In 1982 a joint venture between the Cancer Council and Silver Chain resulted in a pilot program commencing, the Hospice Palliative Care

Service (HPCS), caring for terminally ill patients in their own homes. The service was deemed a success by the local community and expansion of services commenced in 1983, such that by 1985 the HPCS, now called the Hospice Care Service (HCS), provided 24 hour palliative care services to the entire Perth metropolitan area (Working Party of Cancer Foundation of WA et al, 1986).

Dr Douglas MacAdam was appointed in a part-time capacity as the first medical director of this service, with further medical support coming from interested General Practitioners within the community. Nursing was well represented, with another of the chief instigators of service development being Miss (now Dr) Joy Brann, a senior nurse and educator, and Miss Nora Hook, Director of Nursing of Silver Chain at the time, being highly supportive of the initiative. From the outset, although recognising the need and value of an interdisciplinary team, it was also recognised that “nurses in the long-run are the people that carry out the necessary caring responsibilities” (Frey, 1981). This reference to nurses’ responsibilities most likely related to the chosen model of care that relied on 24 hour availability of nursing staff, with support from those in other disciplines who worked part-time or were “on-call”. Nurses, therefore, were at the forefront of the service, coordinating care of patients and being supported by team members.

Inpatient facilities also commenced at this time (Redpath, 1998). Dr Rosalie Shaw, a physician, and former nurse and teacher, started a PCU at Hollywood Repatriation Hospital in the early 1980s, and inpatient beds were also made available at Fremantle Hospital. The Cancer Council, following recommendations of the Frey report, established a small inpatient unit in November 1983. This unit, Queensleigh, established at Bethesda Hospital, was to be the forerunner of the Cancer Foundation’s Cottage Hospice, a 26 bed purpose built facility opened in 1987 (Oliver, 1992). The predominance of the nursing role and the focus of specialised community care were in stark contrast to the medically driven hospital based models of care evolving during this time in Sydney services. Perth also was advantaged by its smaller population size, which in 1980 was about 900,000. The size and population of the city allowed for coordination and integration of services (MacAdam & Shaw, 1989).

Personal Note: Reflecting on the origins of palliative care has been an enlightening exercise. Obviously, I “know” so much about the local Perth scene - after all I grew up with it. I’ve tried to find colleagues with similar histories in Melbourne and Sydney, and have talked to them to learn their stories about how things happened, what were the underlying

cultures, and how they have changed. This hearsay, mingled with what literature is available, is the product.

The evolution of services in different geographical locations within Australia was influenced greatly by the different models of care introduced by the "pioneers" of the time. These models were a reflection of the area of impact of the individuals driving these initiatives as well as the resources that could be mobilised at that time. Further, characteristics such as the size and populations of the cities impacted on the coordination and integration of services across the metropolitan regions.

Strategic Focus for Palliative Care

Palliative care development in all states in Australia has continued to flourish over the last twenty years. Each state has a representative palliative care organisation, which in turn is affiliated with the national peak body, Palliative Care Australia. In recent years, Palliative Care Australia has adopted a strategic focus for palliative care provision in Australia, the mission of the association being "to improve palliative care options available to ALL Australians through advocacy and policy development, setting of standards, and fostering the generation and application of relevant knowledge" (Palliative Care Australia Strategic Plan 2000-2003, p.3).

One of the major achievements of Palliative Care Australia has been the development of Standards for Palliative Care Provision, first published in 1994, with various subsequent revisions. In conjunction with the Accreditation Council for Healthcare Standards (ACHS), accreditation guidelines based on these standards have been developed, and many agencies have sought accreditation based on these guidelines (Redpath, 1998). Lobbying by various groups, including Palliative Care Australia, has resulted in governments at both State and Commonwealth level developing working parties to provide direction for palliative care development. In October 2000 the National Palliative Care Strategy was launched by the Commonwealth Department of Health and Aged Care (Commonwealth Department of Health and Aged Care, 2000).

The strategic focus that is emerging for palliative care is an indication of the state of maturation of palliative care provision within Australia. Where once services emerged as a result of isolated interest and community support, and development occurred along an uncharted path, today there are coordinated efforts to provide direction to service development and measurement of outcomes that can be compared and contrasted with other services. It is likely that, over time, palliative care services

will tend to adopt more unified approaches and the differences resulting from the different origins will become less apparent.

As discussed in Chapter 3, one of the factors governing the decision to conduct the study in various Australian cities was to avoid the suggestion that only a parochial view of practice is provided. A further impetus is the awareness that the driving forces behind the origin of services in the various states differs, and that the relatively recent national coordination efforts are not yet likely to have homogenised services to any great extent. Therefore, I chose to seek a composite picture of palliative care practice in Australia today by incorporating services in different states for this study. On the other hand, given the time and resource restrictions of the project, the study is limited to include only one service in three of the eight states and territories of Australia. A second service in Sydney, a purpose built modern PCU, was added during the course of the research, to allow contrast with the other units. Physical aspects of all units are discussed in the next chapter.

Naming the Palliative Care Services of the Study

As discussed in the previous chapter, the issue of confidentiality and disguising the identity of individuals is of concern. I have, therefore, chosen not to use the actual names of the palliative care services or the parent hospitals but to adopt pseudonyms. I have, however, identified in which state the services are located. I believe that it is important to consider the services in the context of the differences in the political contexts of palliative care development within each state. The pseudonyms are given in the following table.

Table 11

Pseudonyms for the Parent Hospitals and for the Palliative Care Services

	Parent Hospital	Palliative Care Service
Sydney (1)	Waratah Royal Suburban Hospital	Palliative Care Ward
Sydney (2)	Platypus Regional Hospital	Kookaburra Palliative Care Unit
Melbourne	Heath Church Hospital	Honeyeater Ward Possum Ward
Perth	Black Swan Private Hospital	Numbat Palliative Care Unit

Demographic Profile of the Fieldwork Sites

General impressions from my observations of the areas in which the fieldwork was conducted are provided in the passages that follow. Some of the subjective interpretations of the areas are borne out by the 1996 census data obtained from the Australian Bureau of Statistics (2000), as shown in Table 12, and other supplementary information sources. Triangulation of these data has allowed me to provide a composite picture of the catchment areas in which I conducted the research.

Table 12

Demographic Data for Geographic Catchment Areas of Palliative Care Data Collection Sites, from Australian Bureau of Statistics 1996 Census Data

ABS census	Total: all Australia	Waratah area ^a	Platypus area ^a	Heath area	Black Swan area
Population	17,892,423	270,586	232,219	70,326	20,876
Area – sq kms	7,688,965	134	240	22	20
Median age	34	33	29	36	39
Median weekly individual income	\$200-299	\$200-299	\$300-399	\$300-399	\$300-399
Median weekly household income	\$500-699	\$500-699	\$700-999	\$500-699	\$500-699
Ave household size	2.70	2.80	3.10	2.30	2.70
Unemployment rate	9.2%	9.5%	9.1%	8.7%	4.7%
Language					
Speaks only English at home	81.2%	56.6%	69.8%	67.9%	85.1%
Born overseas in a non-English speaking country	13.2%	31.6%	23.9%	26.6%	13.6%
Main non-English language spoken at home	Italian 2.2%	Cantonese 4.6%	Tagalog (Filipino) 4.6%	Russian 4.3%	Cantonese 1.8%

ABS census	Total: all Australia	Waratah area ^a	Platypus area ^a	Heath area	Black Swan area
Religion: Percentages represent the % of the total population for the area					
All Christian religions	70.3%	68.8%	77.6%	46.4%	68.7%
Main Christian religion	Catholic 26.8%	Catholic 50.6%	Catholic 37.8%	Catholic 19.5%	Anglican 29.9%
Non-Christian religions	3.4%	12.3%	5.3%	23.1%	3.5%
Main non-Christian religion	Islam 1.1%	Islam 7.3%	Islam 2.5%	Judaism 20.2%	Buddism 1.5%

^aData provided for these two areas use boundaries of local government areas, which only approximate the catchment areas of the health facilities contained in those areas. Source: Australian Bureau of Statistics (2000).

The catchment areas of the palliative care services selected for this research show a range of demographics, the most relevant being the size of the areas, population sizes, unemployment rates, migrant populations, and to some extent, predominant non-Christian religions. The palliative care services within these areas, therefore, provide a broad representation of practice in Australia. Descriptions of these services are given in greater detail below.

Administrations

The organisational setup differs for each of the services in the study. Waratah and Platypus in Sydney are public facilities, and are part of the NSW State government health department, located in one of nine metropolitan area health services. In Melbourne, Heath Hospital is run by a Catholic Order of sisters, one of the Order's health facilities throughout Australia. The beds at Heath are designated "public" with a joint funding arrangement between the State health department and the Catholic parent body. Perth's Black Swan Hospital, designated as a private hospital, is one of several health care facilities throughout Australia owned by a particular private health care group. Black Swan, however, is the preferred hospital for veterans in Perth, and is funded by the Department of Veterans' Affairs for qualifying veterans and widows or widowers. Black Swan also accepts private patients, who are either self-funded or funded through private health insurance companies. At the discretion of the Medical

Director of Numbat, up to 20% of the beds within the unit are made available for public patients if required.

Cooperation and Competition

Observations from the field highlighted some of the difficulties of not having independent administrations for the PCUs. Waratah (Sydney) provides a good example. The eight palliative care beds within this facility are the only beds to be "quarantined" in the hospital. This means that, even when there is pressure for beds on the rest of the hospital, empty beds in Palliative Care Ward cannot be used by other than palliative care patients. This decision, assumedly one that has been approved by authorities of the hospital, is not always popular with individual hospital administration staff. Senior nurses, who have responsibility for deciding on admissions to the hospital, regularly visit the wards to inquire of the staff if there are any problems, and try to grasp an overall view of the activity of the hospital at that time. One of these supervisors, I was informed, has a reputation for paying particular attention to the bed status when she visits Palliative Care Ward, apparently disapproving of the preferential arrangements made for palliative care. Staff in the ward, knowing that this particular supervisor was on a shift, would be relieved when they had a full complement of patients and thus were able to avoid any potential conflict with this particular person. On one occasion, to conceal an empty bed, the staff purposely left a patient's name on the ward notice board, even though the patient had been transferred to another facility some hours earlier. This seemingly trivial act demonstrated the underlying conflicts in dealing with staff from other areas of the hospital.

Another example of these prevailing attitudes was shown in the allocation of staff to the ward. Palliative care staff at Waratah have been negotiating with the administration for several years to increase the allocated number of nurses from two to three per shift, as Janet, the Nurse Unit Manager, discussed with me. Nursing administration has agreed to an increase in staffing levels on a trial basis, and is reviewing the situation.

Fieldnote: 16 October 2001

The staffing in the unit has recently been increased to three per day shift. Janet was telling me how difficult it was with two, especially when it came to medication rounds when two were needed to check all the DDs [Schedule 8 drugs, such as Morphine, frequently used in palliative care practice], and of course there was no-one to attend to the other patients at that time.

However, when for example, the number of palliative care staff available for a shift is reduced because someone is on sick leave, the hospital administrators do not always provide a replacement staff member, or sometimes do so only for a few hours of the shift. This attitude is seen to reflect a lack of understanding of the work done, and results in the palliative care staff feeling frustrated and unappreciated, further fuelling the conflict with other areas of the hospital. Gill, the Clinical Nurse Consultant for Palliative Care, talked about some of the ramifications of the staffing levels.

Judi: And is the three per shift is that only a...

Gill: That's a temporary measure. Yes. We are still working on a submission. I think we'll get it but yes it's only a recent thing that's been happening.

Judi: It would be hell with two.

Gill: It was awful. It was awful. We never got the work done. We would, Janet and I would be out there and we would be flat out all working on the wards. There would often be four of us and two of us would be reasonably senior and we still would be busy. So after-hours was a nightmare and people - I think we lost a lot of staff and we got a lot of staff who were incredibly tired as a left over; and we struggle many days with three. And we worked!

Staff recognised that the administration was considering the request. It had, however, taken a long time to get to this point and there was no guarantee that the increased staffing allocation would be maintained beyond the trial period.

At Platypus Hospital (the second Sydney site), a similar routine occurs with a senior nurse doing rounds of the hospital to ascertain what is happening overall. At Kookaburra PCU however, the staff appeared to be more relaxed with this process, and there was no apparent questioning or antagonism in the exchanges between staff members. Rather, it was more a social visit. Kookaburra, the PCU at Platypus, is contained within a separate building and, although under the overall administration of the hospital, seems to operate more independently than Palliative Care Ward at Waratah. An example of this emerged when talking about people's job titles.

At Waratah, as with other wards I encountered in both Sydney and Melbourne, the senior nurse on a ward is called the Nurse Unit Manager. The equivalent position at Kookaburra is titled "Unit Manager". The incumbent explained that this was a politically driven decision when setting up the unit. Rather than merely a matter of

semantics, this management position appeared to have a degree of autonomy associated with it that allowed the unit to run in parallel with the rest of the hospital, in contrast to the tension that I had observed at Waratah. This was an interesting situation given that both Waratah and Platypus operated within the same health care region and were both responsible to the administrators of that region.

Administrators at Heath Hospital (Melbourne) have a greater appreciation of what happens in the palliative care wards, which is not surprising as two of the three wards of the hospital are palliative care wards. Further, the overall mission of the hospital strongly reflects the Christian ethic of the Sisters' order, which was founded over one hundred years ago in England. From those early days the vision was of establishing a community that not only prayed but also cared for the sick and dying, as stated in the Mission and Values of the hospital, "tending with maternal care those suffering in body, mind and soul". Some of the senior staff mentioned the Mission of the order in relation to practice and decisions about supporting people. The junior staff were much less likely to make reference to the Mission and Values of the hospital, despite the fact that these statements were well displayed around the hospital. Pamphlets were always available at the front desk and the ward desks, and were pasted on the wall in the foyer and in the lifts. I noted some of the references in my fieldnotes.

Fieldnote: 26 May 2001

Someone else has said to me that they [Heath] do have a culture of helping people, not turning people away. ... There is also a Director of Mission, one of the nuns. ... The mission "A Community of Carers Expressing Love in Action" is well displayed around the hospital.

Fieldnote: 20 June 2001

[Discussion at a team meeting]. There were also four discharges this week. There was some discussion about what might happen to some of these people. Fiona, the admissions coordinator was there, and she said well, one of our missions is social! The implication being that if things did fall apart, then these patients would be welcomed back to Heath. I think this was particularly meant for one patient, who was keen to go home but was known to have an unsupportive family situation.

I met with the Director of Mission, a statuesque woman with a kind smile; quite a charismatic person. She discussed the history of the order, caring for dying people since the late 1800s. I asked her about the mission and how it translates to practice at Heath.

Fieldnote: 6 June 2001

She said that it is helpful to reflect on the mission when conflict arises. There is an underlying respect that she has found helps to resolve situations. ... I wonder what impact she has on staff, if she epitomises the order and this carries through the culture of the hospital, or if it is largely insignificant?

Personal Journal: 15 June 2001.

I went to a "Mission" meeting today, with some of the senior staff and the Sisters and reps from each of the wards. The latter were obviously there because they had to be, not because they were interested. They really didn't get the Mission stuff I'm sure. One said to me later, "well that was a waste of time wasn't it?" And I thought back to some of my workplaces, pre palliative care, and I would have thought the same. But now, I'm actually quite impressed with the Mission and Values here, that I find congruent with those of palliative care.

I reflected later on some of this. I wondered if I had been carried away with the ethos and whether it did exist among some of the staff. The nurse at this meeting obviously did not have an understanding of the underlying culture. I started to reflect about whether this was necessary to work within the culture of Heath, and how that might reflect in working within palliative care culture.

One conflict that I did perceive at Heath was an administrative decision to assign eight of the 19 beds in one of the palliative care wards to the category of "Geriatric Evaluation and Management" (GEM). The GEM program is a health department initiative for patients with complex conditions who require either stabilising of those conditions, or medical review regarding ongoing management (Department of Human Services, 2000). One of the senior staff at Heath explained that these patients had been at acute hospitals for initial treatment and assessment, and had come to Heath for continuing treatment and review, prior to any final decision regarding their ongoing care and placement. In other words, Heath was a type of half-way house for these patients. This theoretically resulted in freeing acute care beds while maintaining care and postponing decisions about these patients' future places of care, such as whether they could return to their homes or would require placement in aged care facilities.

It was further explained that recent consolidation of palliative care beds by the State health department had brought about the need to be more creative with the use of beds at Heath. Often, the patients admitted to Heath under the GEM program were little different from the patients admitted under the palliative care program, as I noted during the fieldwork.

Fieldnote: 26 June 2001

At times it was difficult to distinguish between the two types of patients. Some of the palliative care patients were elderly, maybe demented, maybe having mobility problems, strokes etc, and their cancer diagnosis (presumably the reason for being a palliative care patient) was really not causing their main problems. On the other hand, some of the GEM patients may be having significant symptoms from malignancies. A few times I overheard the admissions nurse discussing the situation. I think that she made up the category as it suited at the time. A political decision rather than a clinical one.

However, staff on the wards perceived that the GEM patients had different, and sometimes competing needs, from the palliative care patients. One nurse, Jane, after a particular night shift, was frustrated about the mix of patients.

Fieldnote: 30 May 2001

At the morning handover I met the night staff. It had been a busy night, two patients had died, one wasn't really expected to. One of the nurses, Jane, said she had been there for about 8 years and was still a "newcomer" as some people around had been at Heath for 20 to 30 years. She works set nights, does one night in the other ward. She doesn't like the mix of GEM patients with palliative care patients. Doesn't think it works, especially on nights when the GEMS with dementia etc can be demanding. Also for families of dying patients, seeing demented patients naked around the ward and other inappropriate behaviour.

Jane was particularly frustrated after that night. Some of the GEM patients had become confused and required almost constant attention, while several of the palliative care patients were in terminal stages and two patients died. Although Jane was expressing concern for the bereaved families that night, the concern was also that she had wanted to support the families as she believed she should, yet there were competing needs in the ward that she attributed to an administrative decision regarding the mix of patient groups.

At Black Swan in Perth, the administration of the hospital impacts to some extent on the Numbat PCU. There are similar checks of the ward by senior nursing staff. The physical location of the ward is a little removed from the main areas of the hospital, although it is not a separate unit like Kookaburra. However, there is no evidence of other wards, and the unit is not generally a thoroughfare for people getting from one part of the hospital to the other. This seems to reduce the awareness, not just of the palliative care staff, patients, and families to the other areas, but of the other areas to the PCU. There are, however, occasions when staffing levels are questioned, especially if there are staff needed in other parts of the hospital. In more recent times, demand for

beds at Black Swan has put strain on other areas, and Numbat was approached to accept four general medical patients. To my knowledge this was the first time that the beds in the unit had been used by other than palliative care patients, although there are often "outliers" (palliative care patients) on other wards of the hospital when Numbat has been full and beds have been needed.

During my fieldwork there was increasing focus on building relationships with other areas in the hospital, not just in terms of bed availability, but consulting about patient care and even sharing care of some patients. This is a conscious strategy being driven by the Medical Director, and to a large extent, the Nurse Manager, who recognise that there are benefits, such as sharing of knowledge and gaining acceptance of palliative care, by developing close relationships with other areas of specialty.

Links with Other Palliative Care Services

Within each of the geographical areas there are other palliative care facilities. The relationships between these other facilities and the units included in the study are quite varied, both in terms of funding and of service provision.

Waratah and Kookaburra: A Continuum of Palliative Care?

Within the Sydney area health service in which Waratah and Kookaburra palliative care services are situated there are two other inpatient facilities accepting palliative care patients. Staff perceive that patients with different needs are better served at particular facilities. For example, Waratah Palliative Care Ward is viewed as "a short term acute symptom control ward" (from the ward's information sheet) and, theoretically, patients admitted to Waratah have complex problems requiring some of the specialised facilities available at a tertiary referral hospital.

The next in the continuum of acute care provision is Kookaburra. Kookaburra has immediate access to the tertiary facilities available at the adjacent Platypus Hospital, although Platypus is smaller and not as highly technologically equipped as Waratah Hospital. Kookaburra, however, admits patients for longer term respite care and for terminal care.

The other two palliative care services within the health region are not dedicated PCUs. One facility also caters to patients requiring rehabilitation and respite care, and the other service provides nursing home type care for longer stay patients. Both services are noted as providing appropriate care, including good symptom control, for palliative care patients. On occasion, a patient might be transferred from one of these services to

Waratah for investigation or treatment of a particular problem, returning to the original service once this has been achieved.

The palliative care Clinical Nurse Consultant at Waratah, Gill, described a sliding scale of care provision associated with a sliding scale of cost of bed days. Waratah Palliative Care Ward has the most expensive bed days, then Kookaburra, and then the other facilities. My interpretation of this disclosure was the notion that palliative care practice encompassed a continuum of palliative care needs, and services were geared to provide different care to patients at different points in the continuum. I put this idea to Gill.

Judi: There seems to be a continuum of palliative care. ... Some of the stuff that you were talking about where people come here for the acute palliative care and then ... get shipped off elsewhere for the less acute and then the terminal if you like. Is that an accurate sort of perception?

Gill: That's sort of pretty much how it is. Yes.

Judi: I've also been out at Kookaburra, do you think they perceive that sort of continuum?

Gill: I think ... that it doesn't flow as well. ... I think the theory is that. However in practice we actually do it all. ... I think we do ... what I would term as that acute palliative care, symptom control stuff, we do that just plodding stuff, and we do the terminal care. So I don't think it is quite as clear cut as that. I think the other units do all that we do, but they just have them for a bit longer. ... I think we sometimes think we do more specialist palliative care but in actual fact we don't. ... It's about cost and it's about that if people need to come in acutely we've blocked our beds. So we do move people on quicker. The other units have nowhere else to move people on to, so that would be the main difference to me. That we have an option to move somebody on for that convalescence period and we do use it just so that we get a flow-on for the more acute care, but it doesn't mean to say that a lot of these acute care people couldn't be managed elsewhere. They could.

Judi: So there is kind of an overlap?

Gill: I think there is a huge overlap. I think that we do probably a little bit at the end that's very specialised that can only be done here and everything else anybody can do.

Gill went on to discuss the "luxury" of having access to other services, such as Radiation Oncology and Medical Oncology. This gives advantages to the patients who,

although not able to be cured are not yet actively dying, and for whom radiotherapy or chemotherapy may be of benefit. Gill gave an example.

Gill: There's a lady coming in now for dyspnoea. Now she has to see the surgeon, the radiation oncologist and the endocrinologist here. So her dyspnoea could be controlled at [another PCU] but we are going to control it here so that she can have access to all of those other people in that same time too. So the flow works better here. So I think there are more subtleties of using a unit in that way.

Community Services

Patients living in their own homes use community health services. However, the availability of palliative care expertise within the health service area is variable. A few areas can access a newly established visiting medical consultancy service, some areas have palliative care nurses, and some have generalist community nurses (GCNs). The level of competency in palliative care among the GCNs is variable, as is their consultancy with palliative care services for advice. Some GCNs are thwarted in their quest for knowledge in the area by lack of input from their superiors. I captured some of Gill's frustration about liaising with community services in the following fieldnotes.

Fieldnote: 18 October 2001

I heard Gill ringing up to make a referral for community nursing. She was spelling out many words, names were problematic, but she was also spelling and explaining medical terms. I thought from what I was hearing my end that this was strange and asked her when she got off the phone what was happening.

[She elaborated]. The person taking the referral is not a medical person and she [Gill] does have concerns that the right messages actually get through to the nurse. She said one day she had to spell the word "cancer!" At that point she said she was hanging up, and made a complaint to the service that it was a waste of her time talking to someone who didn't understand English.

Gill commented that it is very frustrating with community care. The quality of service really does depend where you are living. Some areas are very good, have nurses who are trained in palliative care who will visit daily and work in with the orders from the team at the hospital. Others may think that a monthly visit is all that is required and will change the orders to do what they think.

These are some of the stories of the community services that were described to me by Gill and other staff at both Waratah and Kookaburra. Home care services in

Sydney operate as separate services. I did not include any of these as study sites and, therefore, have no direct observational data to further interpret these practices.

Coordination within Waratah Health Service

Within the health service area, however, an attempt to support and coordinate the care of palliative care patients is being made. One measure that has been implemented is a database that holds details of all patients associated with any of the palliative care services in the area. The Area Medical Director of Palliative Care (Harvey) talked about his hopes for the coordination of palliative care within the area.

Harvey: The vision that I have actually been pushing here is for a single, not a single point of contact, multiple entries into a single system. In other words that you become registered with the palliative care program for [the region] and that once you've been registered by a common and agreed registration process ... There's a database which we've now developed which you need to be on before you are considered to be a palliative care patient, and we've got more or less agreement on how you actually get onto that database. That the intention is that once you are on you have access to the palliative care units of [service 3], Waratah and Kookaburra automatically. You have access to [service 4]. You have access to Community Health or to community palliative care, which would incorporate community nursing as well as the others, and that having been registered you get all those, automatically. Access, so that's access.

The decision at the time as to which of those components of the package you actually use is based on your clinical need and what's available at the time. You know those sorts of processes, the clinical admission type processes and so on that occur with any inpatient unit. Where is the bed? Where is the bed best suited for your needs? If for example you've got a spinal cord compression and you're going to need an MRI [Magnetic Resonance Imaging] it's fairly pointless admitting you to Kookaburra (Platypus Hospital) then trying to get you here to Waratah, even though you might say "No I want to go to Kookaburra". Well we'll organise for you to come into Waratah to get treated because that's the place where you need to be. Similarly if you've got constipation we try and keep you out of Waratah and put you in one of the other units if you have to be admitted for your constipation. That doesn't always work out. It's still a source of concern to me that we admit people to the quaternary referral hospital of [the region] with constipation. Seems an awful waste of bed space.

Member Check: August 2002. I assumed I knew what Harvey meant by the term "quaternary," however, some time after this interview I realised that I had not clarified his meaning. I subsequently did this, and his definition was that a quaternary facility is a hospital providing services that are not provided by any other service. In relation to Waratah,

Harvey's view was that the hospital provided services that were not available anywhere else in the state, and perhaps even in the country. I did not seek specific examples of these services.

Another feature of the coordination of services within Waratah region is that patients who have been registered on the palliative care database also have access to a 24 hour telephone service. This service rings through to the ward staff at Waratah Palliative Care Ward. One phone in the ward is strictly reserved for these incoming calls on the "help line." Staff advise patients and family members on discharge from the various units in the area that they will be cared for in the community by their GCN or their General Practitioner, but if these people are not available then they are able to ring for advice on the help line. When calls are made into the ward on this line, staff on duty either deal with the problem directly or contact one of the palliative care medical specialists, one of whom is on-call each night. Sometimes these calls result in the admission of the patient to an inpatient service, although most often the problem is resolved without this being necessary.

Beyond the Unit: Consultancy Services

Other aspects of palliative care provision within the area are those of consultancy services and outpatient reviews. During my time at Waratah, I accompanied the palliative care medical consultants on several visits to other areas of the hospital while they reviewed referred patients. At both Waratah and Kookaburra I also attended outpatient clinics run by the palliative care medical consultants. These services provided another view of palliative care practice, which was emerging as a continuum of care rather than a discrete entity.

Heath: One of Several Palliative Care Units

Health care services in Melbourne also operate within health care regions, and in recent years the State government has attempted to provide geographical equity of services, as well as supporting growth of community palliative care services. However, in practice there does not appear to be any great emphasis on coordination of palliative care services. Unlike the situation in Sydney, there is no Area Director of Palliative Care, nor any equivalent coordinating person or committee to direct the flow of palliative care patients within the region.

Heath Hospital exists within a health region that is also serviced by three other palliative care inpatient facilities. One is a 15 bed PCU attached to a major tertiary teaching hospital, another is a 20 bed PCU that is part of a smaller regional health care

service, and a third is a newly established private PCU of 22 beds. Each of these facilities has been purpose built in recent years, and each provides beautiful surroundings for their patients. I was able to tour these three facilities during my time in Melbourne, and the following are some of my reflections on the surroundings of one of the units, typical of the purpose built facilities that I saw.

Fieldnote: 28 June 2001

Certainly it is very well appointed. A large open lounge/dining area and nurses' station is at the front of the unit, with the patients' rooms scattered around the site. Each is a private room, with ensuite, fridge, couch that converts to a bed so that families can stay. There is a chef onsite and a small café where relatives can purchase meals and coffees. Wheel chairs and shower chairs are concealed in large cupboards.

[The manager] feels that people come in and see the lovely surroundings and relax. She said "a five star hotel." She never has to advertise for staff. ... [She] believes that the environment does contribute to good palliative care. She feels that the staff appreciate it and feel valued too by the nice environment.

Within the health region individual units are identified as having particular strengths or foci of care. For instance, the PCU attached to the major teaching hospital is regarded as providing "acute" palliative care and is known to discharge patients who no longer require medical management of symptoms. At the other end of the scale, Heath is seen as a place for terminal care, a place where people go to die.

Perhaps due to Heath's overarching mission of accepting rather than refusing admission of patients, some people perceive that Heath is a "dumping ground." Patients are referred to Heath when other facilities are unwilling or unable to take them. Other perceptions are that patients are admitted "too early", that Heath keeps patients when there is nowhere else for them to go, and also the perception that it is a place where people go to die. I asked David, a senior doctor at Heath, about some of these perceptions.

Judi: Since I've been here, various people have said things like, "Heath's a dumping ground: People come here to die: People know why they're coming here." Do you agree with those sorts of statements?

David: Well, I don't know what you mean by dumping ground.

Judi: Yes, that's probably separate from the other ones [questions]. It seems that there's a perception that people will be discharged from acute

hospitals to here, when they probably need to be going to a nursing home.

David: Inappropriately admitted here? Yes. That's true. We get quite a few like that. And sometimes they need to be moved on. But it's always difficult to move people on from here.

Judi: Yes. Why is that?

David: Well, I think generally we're too soft. Compared with an acute hospital, you know when they, people are given their marching orders, that's it. And here, we give them marching orders, and nothing happens.

Judi: So, that's too soft in your opinion? ... Why do you think that happens?

David: Well, just occasionally, I mean it's only a very small percentage we're talking about, but when we do decide somebody should be moved on, the wheels fall off. But that's administrative issues. ... I think no-one likes to get too pushy in this setting. Yes. I think there's a bit of that. People expect to be moved out of an acute hospital.

Judi: Yes. OK. And what about the other perceptions? That people see Heath as a place to come to die. That, you know, you come in the door [and] you don't leave. Is that an accurate perception?

David: Well for some people it is. And for some people it's an awful shock. Probably for everybody it's a bit of a shock I suppose. For patients. Some people take it better than others, some people actually quite like that, they know they're going to die, they're at peace with themselves, said their goodbyes and it can be lovely. Other people fight it all the way, make it hard for themselves and hard for their families, and hard for the staff. So, most people are somewhere in between. There's a few, quite right.

Another doctor, Grant, a Registrar who was doing a rotation at the time in the other ward at Heath, was covering both Honeyeater and Possum Wards on a Monday public holiday. He added his perspective of palliative care services. Unlike David, whose only experience of working in palliative care had been at Heath, Grant had worked for short periods at two other units in Victoria. From our meeting I noted the following.

Fieldnote: 11 June 2001.

I met the doctor on call. ... He was saying that although he just covered at the weekends, and so he didn't really know what happened in the wards, that it wasn't the palliative care that he was kind of used to. He'd been in palliative care at [a unit attached to a tertiary hospital] and also down in [rural area] he'd worked in palliative care. He said it was a lot more acute, and a lot more active palliation if you like, inserting stents and so on. He actually said that he wondered if patients came here too soon, to Heath, that it was a bit of a dumping ground. ... It seemed like people perhaps coming from [the private PCU] because they've run out of private insurance actually haven't even been the route of being offered some of the active treatment and palliation.

Grant's use of the term "dumping ground" was different from the meaning I had attributed to the term in the interview with David. Grant implied that people came to Heath prematurely, that perhaps more acute care was appropriate for some patients but for various reasons they were admitted to Heath, where that acute care was not available. When I clarified with David what I had meant by the term, I suggested that people came to Heath when more appropriate care could have been provided in a less acute setting, such as a nursing home. In both instances, however, it appeared that Heath was considered to be a place where patients were sent when other facilities were unavailable to them.

The private PCU to which Grant referred was proving problematic to several patients and their families whom I encountered at Heath. Admission to that unit seemed to be a matter of patient choice as well as private health insurance coverage. However, the length of stay in the unit seemed to depend on the conditions of the insurance fund. I met patients at Heath who had come from the private facility because their private coverage had "run out."

One of the patient's daughters, Sally, was particularly upset about this situation. Sally is a social worker, but she was "trying not to let that show" while visiting her mother in Heath. However, she confided to me some of her concerns about her mother's treatment. Her mother had been in the newly opened PCU, but had been moved to Heath after 14 days, apparently because of health insurance issues. Sally's interpretation was, "If people don't die there, within the allocated time, then they are shipped out." A further concern about this was that there had been no consultation about the move. She said the move was not discussed with her or her mother. Her mother had been sent off in an ambulance to Heath. Other patients at Heath had similar stories about having to move on after a period of time.

Home Care Services

Although Heath operates as an independent palliative care service within the health care region, it also hosts a large community palliative care service. Because of my domiciliary palliative care experience I was interested in exploring home care practice in Melbourne, and spent two days "on the road" with the community service, as well as attending some of the community team meetings at Heath Hospital. I was interested in the notion of "seamless care" that might be present with patients moving from home care services to inpatient services within the same facility. I raised this with Joan, one of the nurses I accompanied on home visits, and the differences she perceived between home care and inpatient care.

Fieldnote: 29 June 2001

Joan also talked a lot about the differences between community and inpatient services. Having worked in both [areas] she felt that the wards are far more task oriented. The staff don't do primary nursing, it's team nursing. I asked her about the so-called "seamless care" between community and inpatient. She said it didn't really exist. There wasn't much communication at all between the two teams. The only thing that was shared were the case notes. I remembered a conversation with the ward clerk on one of the wards saying that she had instigated a quality project to improve the writing of the community staff in the case notes. [The ward clerk was not so much concerned with improving the sharing of case notes, but about improving the legibility of notes when they were made.] ... [I reflected.] ... A lost opportunity in such a setting.

My comment about lost opportunity reflected my thinking that sharing records between inpatient and community services would be of benefit to patients and to staff. I recognised that these thoughts were based on my previous experiences of working in the community. Although I did not openly share my thoughts on this subject with Joan, she suggested that increased communication between the two arms of the service was desirable.

Overall, there appears to be little communication between the two arms of Heath. Each service is aware of patients that they share, there is some sharing of case notes, but little effective coordination of care. Each arm operates as a discrete service although under the same health care administration.

Heath's Community Palliative Care Service is reasonably large and well established. However, it does not provide home care for the entire catchment area of the hospital. Other services provide care for some of the areas, and there are a variety of models. One service runs exclusively as a community based palliative care service, and

other programs have joint arrangements with the general community nursing service, the Royal District Nursing Service (RDNS), and work cooperatively to provide palliative care in the home.

Numbat: Integration in a Small City

In Perth, Numbat is one of three PCUs operating in the Perth metropolitan area, serving a population of about 1.5 million people. Numbat provides 22 palliative care beds, the others 22 and 26 respectively. The total number of palliative care beds in the entire metropolitan area of Perth is approximately equal to that of the one health service area in Sydney, and the one area studied in Melbourne.

Unlike Sydney, where all palliative care services are public facilities, and in Melbourne where most are public facilities, most of the palliative care beds in Perth are designated as being for private or veteran-affairs entitled patients. Each facility does make provision for acceptance of public patients, although financial factors can be a consideration when seeking admission to a facility in Perth. Largely, however, decisions about admission to particular facilities are a matter of bed availability and choice of geographical location.

Within each of the three major public hospitals in Perth there are established palliative care consultancy services. In the private sector, staff at Numbat provide consultancy services to the other wards at Black Swan, and the Medical Director sees outpatients in his rooms within the unit as well as liaising with other hospitals to provide palliative care consultancy outside Black Swan. Although consultancy services were not a major focus of my fieldwork, I did attend one of the outpatient clinics while at Numbat.

Home care palliative care services are provided for the entire Perth metropolitan area by Silver Chain Hospice Care Service. However, Numbat PCU has a home care service also. The service works within a designated radius from the hospital and only accepts referrals of patients who have been involved with inpatient care at Numbat, or who are DVA patients. I spent two days in the field with home care nurses, and often spoke with them during the fieldwork at Numbat. Unlike the service at Heath, the home care office is located within the Numbat unit, and staff from the ward rotate through the home care service from time to time. In this situation there is more communication between the inpatient and home care service, and some sharing of documentation.

Similar to Melbourne, there is no coordinator or coordinating body for palliative care provision in Perth. However, possibly because of the smaller size of the city overall, and coupled with the isolation of Perth from other major cities in Australia, individual palliative care professionals within Perth are well known to each other. Some of the key players in palliative care have joint appointments to services. Many of the major figures cooperate to organise events such as state conferences, and often attend the same events, such as workshops and lectures from visiting health professionals. Therefore, in the absence of any purposeful attempt to coordinate services within Perth, communication processes are well developed, albeit on an ad hoc basis.

Serving Two Masters: Palliative Care and The Dollar

In each of the areas of fieldwork there were issues regarding appropriate use of resources, often in the guise of the length of patients' stay. These issues were discussed under the premise of the suitability of patients to receive palliative care, or the suitability of patients to receive palliative care at that facility. Again this begs the question, what is palliative care?

At Waratah there were issues associated with patients who were perceived not to require acute palliative care. Perhaps, because of the nature of disease progression, or more precisely the uncertainty of disease progression, some patients in Waratah Palliative Care Ward stay beyond their expected time. Some patients are admitted for treatment, but deteriorate prior to or during the treatment, and are expected to die quite quickly. Staff do not question care for these patients when death is imminent, but when the patients do not die in the expected timeframe, staff are faced with a dilemma. Decisions regarding transfer of a dying patient to another facility, including the consideration that the patient may even die en route, versus unnecessarily use of a costly hospital bed, pose difficulties for the staff. Although perhaps not thinking in terms of the expense associated with use of the bed, consideration is certainly given to services that are not required for these patients. Staff, therefore, while trying to maintain the best care for patients, also consider that some patients are in the ward inappropriately, especially when other patients are in need of admission.

In Melbourne, the situation of private health insurance in relation to the private PCU provides clarity about admissions and length of stay. However, at Heath the situation is not so clear cut. Admissions to Heath can be based on perceptions of care needed, with some staff expressing views that acute care is not appropriate. On one occasion, a planned admission was discussed in one of the wards. It was discovered that

the patient to be admitted had an intravenous infusion of antibiotics, which the referring staff expected to be continued at Heath. The ward staff questioned why this patient was to be admitted to Heath and the appropriateness of this intervention. Although I believe the staff had the skill to care for this patient, there was a perception that this type of treatment was more appropriate in another facility.

Length of stay can also be a contentious issue regarding suitability of patients at Heath. Although patients at Heath have longer lengths of stay than at other facilities (22 days average compared with 11 days at the more acute PCU in this area), the staff do question why some patients are considered for nursing home placement, and others are not. The uncertainty of prognosis creates difficulties when considering transferring patients for more appropriate use of palliative care beds. This is further complicated by the compassion of individuals working in the palliative care settings, such as at Heath, who feel averse to transferring patients because of the disruption to the patient and family.

Similar dilemmas regarding nursing home placements occur at Numbat. During the time of my fieldwork, nursing home beds were difficult to find. It was acknowledged that at least a three month waiting period was required once a patient's name was submitted for placement. There were patients on the ward who, although their conditions appeared to be reasonably stable, were slowly deteriorating. Decisions were made to keep these patients on the ward until they died because it was felt that they would not be well enough for transfer, or would perhaps have died, when a nursing home bed did become available. Making these decision gave the patients security of knowing they were staying at Numbat, and reduced any anxiety associated with an impending transfer for both the patients and their families.

The difficulties in these situations are multifaceted. There are decisions regarding the nature of palliative care, clearly identifying that there are various types of palliative care, and various types of palliative care patients. However, there are also difficulties in anticipating the needs of palliative care patients from one time frame to another, and, therefore, discerning the type of palliative care that they require. Yet another factor is the predicament of championing a supportive, nurturing environment for palliative care patients and their families, while being mindful of the limited resources available and the need to consider financial implications of these decisions.

Summary

In this chapter I have introduced the palliative care services of my study within the context of their parent institutions and geographical locations. I have outlined the development of palliative care within the various Australian states, the demographic profile of the catchment areas of the services, and the overall flavour of the administrations governing these services. I have also provided a preliminary insight into the underlying cultures of the services. All this will help to frame my discussions in the following chapters, where I elucidate the practice of palliative care within those settings.

CHAPTER SIX

THE PLACE

In the previous chapter I outlined the political underpinnings that give context to the palliative care services included for study in this research. In this chapter I am concerned with painting a picture of the physical environments of the palliative care units and their immediate surroundings.

I start the chapter with an introductory description, including my first impressions, of the study sites. Features of the units are discussed, including the underlying meanings that I have attributed to some of these physical features. Interpretations made in regard to my observations of the physical environments are aimed to pave the way to understanding palliative care in the context of these services.

Many of the details of the services given in the following sections are not referenced. The data have been taken from brochures and other documents that would readily identify the services. Although it is most likely possible to identify the services with a little research and local knowledge, I have nonetheless chosen to omit reference to documentation that relates directly to the palliative care services researched in this study.

First Impressions

When entering each of the research sites, I spent the first few days exploring the facilities as fully as possible. It was my intention to capture as much of my initial impressions of the settings before confounding these observations with the overlay of the emerging culture. I made comprehensive records of my observations and reflections in the initial period of entering each site.

Waratah Royal Suburban Hospital, Sydney

Waratah Royal Suburban Hospital is the specialised teaching and tertiary referral hospital in one of the area health services of Sydney. The boundaries of the area served by the hospital are only roughly defined, some of the hospital promotional material stating the target population is up to 1.5 million people and other material quoting about 600,000 people. The hospital is the central facility in a vast medical complex that

extends over several blocks. In addition to the multi-storey hospital, the complex includes a major children's hospital, a dental school, a psychiatric hospital, several research institutes, ancillary services such as coroners' offices, and residential facilities for patients and families, as well as a large complex of staff residential facilities that can accommodate 540 people.

Waratah opened in the 1970s with a capacity of approximately 900 beds. Bed capacity fluctuates, however, with closure of some beds over the summer months when demand is said to be not as great. Staff reported that they were unsure of the capacity at any particular time, but consensus was that it was around 750 beds. Hospital personnel referred to the high demand for beds, even during the warmer months, which was the time when I was conducting fieldwork. Within Waratah, eight beds constitute Palliative Care Ward.

The health area covers several electoral boundaries and it is difficult to accurately map Australian Bureau of Statistics data to the area. One of the publications of the Health Service Area states that the population of the area is relatively young, and that the socioeconomic status for the overall area is slightly above the State average. There is significant variation throughout the area though, and some regions within the area are described as "among the most socioeconomically disadvantaged in NSW."

Impressions of Waratah

Personal Note: The impressions I formed about the hospital and its immediate environment were significantly influenced by my lack of familiarity with Sydney generally. I had previously been a tourist in Sydney on several occasions, but had never lived or worked in the city prior to this experience. I arranged to live in the Waratah residential facility while undertaking the research, which afforded me convenient access to the hospital. However, I was reliant on public transport to move beyond the Waratah area, and felt particularly confined by these circumstances. I had few social contacts beyond those people I was meeting during the course of the research, and little opportunity for social activities with the people I was meeting. This was therefore, quite an isolating experience and no doubt colours my reflections about the cultural aspects of Waratah.

My observations in this area of Sydney were of a cosmopolitan population in which many people did not speak English as a first language, or had difficulty speaking English. Australian Bureau of Statistics, as shown in Table 12 in Chapter 5, indicate that about a third of the population was born in non-English speaking countries, and that almost half the population does not speak English at home. Other than English, the most

common language is Cantonese, spoken by about five percent of the people. Indeed there seemed to be many Chinese people working both in the hospital and in shops around the area. I also noticed a number of women wearing "hijab," the head coverings worn in public by some Muslim women. The statistics record that about seven percent of the population list Islam as their religion, and it is the highest non-Christian religion in the region. These figures pertain to the electoral area in which Waratah is situated, the area in which I was living during the period of the fieldwork in Sydney.

The suburb of Waratah is situated in a lower socio-economic area of Sydney, and the main "industry" in Waratah appears to be health care. Within the Waratah health complex there are several hospitals and research facilities, and around the corner there is a private hospital. Traffic flows constantly past the hospital, although the main arterial roads are a few blocks away, as are the larger shopping malls. A railway station is located a short walk away from the hospital. There are two secondary schools opposite the health complex, and a University campus is situated around the corner. Even without the through-traffic of the main arterial roads, there is still enough movement on the roads around the hospital site to require several sets of traffic lights at the hospital entrances. Pedestrian traffic consists largely of school children and people associated with the numerous healthcare facilities in the area. The bustle on the streets ebbs and flows, and is busiest in the mornings and evenings, as people come and go from work or school.

The atmosphere within the hospital is little different from the bustle found on the streets. The foyer of the hospital is large. People move quickly, although some, probably patients, sit or stand in queues waiting for staff to attend to them. There are several areas where people wait; the inquiry counters, admissions section, and the cashiers' booths. There are also two or three elderly females, I assume hospital volunteers, usually present in the hospital foyer selling raffle tickets. Within the foyer there are also several shops, among them food stalls, newsagents, a florist, a post office, a pharmacy, gift-shops, and a bank. A short distance from the hospital entrance there is a coffee shop with areas of tables and chairs both inside and outdoors, and a little further along there is a "health promotion shop," selling sun-protection items such as sunglasses, turbans for people who have lost their hair, and other similar merchandise.

In these public areas of the hospital, and in the surrounding areas generally, I found that people were not particularly friendly and seldom engaged in conversation. I was accustomed to Perth and the social banter of a smaller population, chats about the

weather or the weekend approaching, a hint of a smile as people passed you in the street or in a corridor. In Sydney, I found people did not often exchange such pleasantries unless you knew them or had been introduced to them by a mutual acquaintance. I was surprised that on several occasions both within the hospital and on the street outside the hospital, people approached me and asked me for directions. This was an ironic situation because I was often quite lost myself. Commenting on these events to some friends who were long-time Sydney residents, they said that it was probably because I looked like I was prepared to answer the person's inquiry. Perhaps by looking at people, making eye contact, even not walking as quickly (often because I was unsure where I was going) I was perceived to be more approachable than others.

Personal Journal 28 September 2001

My general feelings are of panic! This is my first time to this part of Sydney, not a very affluent area, and certainly a far cry from the tourist attractions I've been to on previous occasions. ... The pace of things is so fast. People seem to be in so much of a hurry. They move quickly, and they don't look at you. It's like they're afraid to make eye contact in case you're a mugger. I feel a bit scared too actually. Janet said not to walk back to the residences after dark. There's a dark spot, where the footpath crosses over a creek. She said to get the hospital security transport.

Along with the busy-ness of the place, I also encountered some of the less pleasant habits of people in the area. I recognised that I found some of these encounters confronting. One of these occasions was in the foyer of the Dental Hospital when I was walking through to get to the main hospital. The Dental Hospital and Waratah Hospital were joined by a walkway that was open during weekdays, and I often cut through this way to the hospital. A man was begging a staff member to take out his tooth.

Fieldnote: 10 October, 2001

As I passed through the dental hospital this morning there was a real commotion happening. A man was sitting in the foyer, screaming, well yelling really loudly. The guy with him I had seen before, he was from the reception area, I guess one of the people who makes the appointments. This man was screaming out – "I've got pain now, not next week, not tomorrow, now. I'll give you \$100 now to take the f...g thing out." The other chap was trying to explain to him that the doctors couldn't see him now and he'd have to come back next week. But the man kept arguing, pleading, and abusing.

There were other occasions when there were disputes happening as I walked through this area. Usually the conversations were about people not having valid healthcare cards that would entitle them to the dental services at the hospital. These

disputes could also be volatile and abusive, although I did not witness any physical abuse. It became commonplace to hear these types of exchanges in the public areas around the hospital. Even within the hospital wards such disputes were heard. On another occasion, a patient in the ward adjacent to Palliative Care Ward was being quite vocal about wanting a cigarette and wanting to get out of the ward. His voice carried throughout the floor, so that patients, visitors, and staff of several wards in the vicinity were aware of his plight. The staff in Palliative Care Ward gave his pleas little consideration, and seemed to ignore his language, which was filled with swear words that could have been offensive to some people.

I also noted that, initially, I had difficulty understanding what some of the hospital staff were saying, especially when they were talking with each other. The language was familiar, but I had difficulty deciphering the words because some people spoke very quickly. Again one of the Sydney-siders commented on this fact, and that it often takes people from other parts of Australia some time to get used to this.

There was always noise about; loud voices, the sounds of trolleys clanging, rattling meal trays coming from the cafeteria, and call bells ringing in the wards. The patient call bells would chime every few seconds until they were switched off at the bedside. Sometimes they seemed to go on for a long time, several minutes perhaps, which added to the feeling of urgency that pervaded the place. My overall impression of the hospital was one of a very large facility, with many people going about their business, always in a hurry.

The busy-ness that was apparent in Sydney generally and in Waratah specifically, was also present in Waratah Palliative Care Ward. Entering the unit there was usually an atmosphere of what I would describe as "mild panic". I became accustomed to this over time, but at the beginning of my research when I was still meeting people and introducing myself to gain access to the ward, I felt very much in the way. I was aware as I waited patiently to speak to staff while they finished phone calls, answering patients' call bells, inquiries from other staff or visitors, and generally attending to the business of the unit, that there was a stark contrast between the urgency of the staffs' duties and the luxury I was afforded of assuming a researcher's gaze of the scene.

On reflection, rather than being in a panic, people were probably being highly efficient coping with busy routines. Gill was often talking, reasonably loudly, on the phone or to staff in the unit, sometimes planning ward moves, assessing who would be

leaving the unit, who were the patients who needed to be moved in. Her pager was often beeping, and she would move quickly to answer the call. When I first arrived at Waratah I sought Gill out to talk with about my research and previous work I had done. She was particularly interested, and after a week of trying to find uninterrupted time to talk with me, we agreed to schedule a formal appointment to talk. She was more than willing to meet with me, but without making this appointment she was likely to be called to answer some inquiry, either from within or outside the hospital.

Similarly, the Nurse Unit Manager also had a busy schedule. She was often going on and off the ward to attend meetings. The general nursing staff seemed more relaxed. However, the general perception of busy-ness was pervasive, and the staff rarely perceived that they had enough time to attend to their duties. The ward was small and commonly full of other staff as well; orderlies collecting and returning patients from various appointments, consultant doctors doing ward rounds, allied health staff attending to their duties, kitchen staff, cleaning staff, as well as visitors and patients. The size of the ward added to the feeling of high activity.

Personal Note: I was aware of the limited space within the ward and I also was becoming aware of a difference in personal space generally in Sydney. I noticed this on the streets, in shopping centres, crossing the road. I felt uncomfortable and sometimes angry. Giddens (1993) notes this as being a typical reaction of someone who feels their space is being invaded. Westerners traditionally have a greater need for personal space than people from the Middle East for example, and also from Asia, both of these cultures being well represented in this part of Sydney.

My overall impression of the environment at Waratah was coloured by all these factors. In summary, I found Palliative Care Ward to be busy; crowded, noisy, and a flurry of activity. This reflection is contrary to a common image of palliative care units as being calm and peaceful places of rest.

Platypus Regional Hospital, Sydney

Platypus Regional Hospital is located one of several smaller health regions situated within the health service area serviced by the Royal Waratah Suburban Hospital. Platypus is a 200 bed tertiary facility that opened in the mid 1980s to service a new and growing community. It provides an emergency department, medical, surgical, paediatric, gynaecology, coronary care, and intensive care wards, as well as a 16 bed "state-of-the-art" PCU, which I have named "Kookaburra". Facilities within the regional hospitals have been designed to complement rather than duplicate services.

Patients from Platypus can be referred to Waratah if it is necessary to access some of the more acute services available there.

Impressions of Platypus

Personal Note: I needed to catch the train to get from Waratah to Platypus, and the hospital was then a bus ride or a walk from the station. The first time I went there I caught a cab from the station because I didn't know where I was going. I wasn't used to catching public transport. When I'm at home I drive everywhere. I was scared, and cautious, and certainly didn't stay until dark, although once I knew where the hospital was, I did walk to and from the station. I wonder if I would have formed the same impressions if I hadn't been forewarned?

During my travels from Waratah to Platypus, I often noticed young people hanging around the stations, and overheard language that could be offensive and abusive. I was never personally confronted, but I felt a constant threat of danger, as I probably would in any large city. However, I had been warned about the outer areas, around Platypus in particular, having a high unemployment rate and crime rate. Friends had suggested that I should not wear jewellery or carry a laptop computer when travelling on the trains. I often saw uniformed security guards walking through the carriages on the train. They would ask to see tickets, for people to move their feet off the seats, and generally seemed to be on the lookout for any misbehaviour. On one occasion two youths were in the train, and one yelled out to the other to watch out for the security guards. One of the boys ran through the train, moving from one carriage to another, ducking and weaving to avoid the guards seeing him. Eventually he jumped off the train just as it was pulling out of one of the stations. Although I encountered no problems, I remained cautious when travelling on this route in particular.

On my first visit to Kookaburra I caught a taxi from the railway station to the hospital. I was intrigued as the cab was fitted with a safety shield that completely protected the driver. There was a small flap in the shield through which money could be exchanged. I had not seen this sort of protection anywhere before, including the cabs that I occasionally took around the Waratah area. I deduced that my friends were not the only ones to consider that this area was dangerous.

Platypus Hospital is situated a short way from the railway station, on a large open area of natural bushland. The hospital itself is much smaller than Waratah. Apart from a couple of smaller buildings and sheds surrounding the main building, it stands alone, unlike the huge complex of health facilities at Waratah. Although the reputation

for the area is one of greater crime, the overall impression created by the open spaces and bushland in which the hospital is located is one of calm and tranquillity. Entering the hospital, the contrast was further marked by the absence of the busy-ness of Waratah. Although initially fearful of this area because of the stories I had heard, I was less daunted by the atmosphere here, which seemed a lot calmer and less overwhelming than at Waratah.

Personal Journal: 10 November 2001

It's like a country town. ... Around the shops and around the hospital is very dry and dusty. There's a large town square, with library, medical centre, swimming pool etc. ... There are lots of people but sort of "stuck away in the sticks" [a more rural atmosphere]. Laurie's [Kookaburra's manager] early description of this part of Sydney was that the government shipped a whole lot of low socio-economic people, young single mothers and so on, out here with no connection to the rest of Sydney, and in some ways it feels like that. In some ways I guess I am "scared" of what might happen out here, however, I haven't felt threatened at all, at least in the day light hours, which is all I have known. It's a pleasant walk from the station to the PCU, which is to the side of the hospital. And the atmosphere both walking through the hospital and in the unit itself is far less frenetic than at Waratah.

Kookaburra PCU itself is located in a separate building, joined by a walkway to Platypus, and therefore, is further distanced from any hospital bustle that may occur within the other wards of Platypus. The unit is spacious, clean, and bright. A receptionist greets people at the entrance, the actual ward being off to the side. Therefore, first impressions are devoid of any evidence of hospital equipment or staff directly attending to patient care. This is a major contrast to the initial impressions of entering Waratah Palliative Care Ward. My first meeting with the manager at Kookaburra was a little rushed. He had been in the ward attending to some crisis with a patient and, therefore, was a little late. However, he was reasonably relaxed and welcoming. After chatting for a short time he escorted me around the unit pointing out many of its features.

The staff seem relaxed here. Although there are eight occupied beds, as at Waratah, the patients are accommodated over a larger area. The congestion of Waratah is not evident here at Kookaburra, and of course, being only three years old, the surroundings are clean and fresh. The medical director acknowledged that there was a different atmosphere between the two units, and we talked about that.

Fieldnote: 14 November 2001

Harvey and I talked about this [the difference] for a bit, trying to find the right word. ... Hurried, rushed, urgent. He made the comment that perhaps the urgency of Waratah meant that things sometimes were not fully addressed, but the surface things, the immediacy of things was done and the detail fell off. He actually felt that the things that happened at Waratah were not that much more technical than at Kookaburra, in fact things were much the same in reality. Was it urgency, busy-ness, emergency, intensity?

Heath Church Hospital, Melbourne

Heath Church Hospital, a Catholic facility, is located in a well established suburb of Melbourne that covers an area of 22 square kilometres and has a population of about 70,000 people. Heath Hospital, unlike Waratah, is not a central component of a large health care area. In fact it currently accommodates only about 100 patients in three wards, 44 beds being designated to the two palliative care wards. The demographic data quoted from the Australian Bureau of Statistics (Table 12 in Chapter 5) relate to the immediate vicinity of the hospital, although promotional material about the hospital lists five local council areas within the catchment area.

The hospital is located in an otherwise residential area. The surrounding housing consists of predominantly single residences on large lots with well kept gardens. During the period of research, the streets were quiet, even on the occasions when I was there after dark. The area gives the impression of being middle-class, which is borne out by Australian Bureau of Statistics giving the median weekly individual income as between \$300 and \$399, higher than the National average of \$200 to 299.

The area around Heath is noted for having a large Jewish population. There are several Synagogues in the area, where people congregate on Saturdays, the Jewish Sabbath. It is not uncommon to see males in the street wearing the traditional "yarmulkas" (skull caps). Again, census statistics confirm this observation, showing that 20% of the area's population list Judaism as their religion, the same number as recorded for Catholicism.

Impressions of Heath

Personal Note: I grew up in Melbourne, and have continued to visit on a regular basis as my mother still lives there. I was able to stay with her during the research, and also to use her car, which meant I didn't have to cope with public transport. Many things have changed since I lived there, however, I felt comfortable and "at home" with my surroundings. Although I had never visited Heath Hospital prior to this research study,

being familiar with the general surroundings made this research period much easier than my (later) experiences of Sydney.

The atmosphere in the area of Melbourne surrounding Heath Hospital is not one of a large bustling city, although the population of Melbourne approaches that of Sydney. This area, however, is a residential suburb with several parks nearby and few large buildings other than the hospital. There is no emergency department attached to the hospital, therefore no regular traffic coming to and fro other than the staff and patients' visitors. The hospital complex is not large, the main building being four storeys high. There are, however, many outbuildings, and the hospital administrators have acquired several houses that are now used for offices for some of the community services run from the hospital.

Inside the main building the atmosphere is quiet. There are no wards on the ground floor, where reception, administration offices, and the hospital chapel are located. Maintenance workshops are also on this level, but well hidden at the back of the main building. There is little in the foyer other than the reception desk, a few chairs, two lifts and a stairway, leading to the two palliative care wards. There are several religious artefacts in the foyer and at the top of the stairs of each floor. These vary in size and prominence from large, life-size statues of Jesus and the Virgin Mary, to smaller wall plaques with the symbol of the order of nuns who administer the hospital. The initial impression, with grey vinyl flooring that continues up the stairway, is of a clean, scrubbed, austere atmosphere.

The palliative care wards are located on the first and second floors, and almost identical in layout. Staff pointed out to me that one ward is decorated in pink tones and the other green however, the colours are pale and muted and looked much the same to me, especially on first impressions. Both wards have two large swinging doors at the entrances, frosted glass in the top half. There are signs on these doors in both wards asking that they be kept shut.

At first, venturing into the ward area was daunting for me, and the closed doors formed a significant barrier. One day, early in the research, I had arranged to attend my first handover in Possum ward. I was early to the hospital, and although I had introduced myself to some staff in Honeyeater ward the day before, I was reluctant to enter the ward.

Fieldnote: 18 May 2001

I wandered about the staircase, went up to the second floor. Is that Honeyeater or Possum Ward? I do get them mixed up. ... Feel like a bump on a log. ... I want to go in [to Honeyeater] ... but the doors are closed, frosted glass, can't see in. I should be planning with them to attend there on Monday, 7am handover. ... Guess I need to gird my loins and get on with it. All I want is to get handover over and go home and retreat. ... Lots of staff coming and going in the cafeteria [lunchtime]. At least in here I can have a cup of coffee, write these notes, and look like I'm doing something. I need to have something to do. It's really hard just hanging around.

Black Swan Private Hospital, Perth

Located in an affluent area of Perth, Black Swan Private Hospital is an acute care teaching hospital of approximately 350 beds, situated adjacent to one of the major teaching hospitals in Perth. Black Swan has a long history. Although since 1994 Black Swan has been a private hospital, it originally opened in 1942 as a 500 bed Commonwealth Government hospital, providing acute care for service men and women and later for veterans and war widows/widowers. It has been widely known in the community as the "Repat" Hospital and, even since its takeover in 1994, this reputation continues because of the tender arrangement with the Department of Veterans Affairs (DVA). As mentioned in the previous chapter, it is still the preferred hospital for service veterans in Perth, and about 80% of the current clientele are DVA-entitled patients. Some of the older patients have been admitted to the hospital many times over the years, and for these people the culture of "Repat" remains.

According to the 1996 census statistics (Australian Bureau of Statistics, 2000), unemployment in the area at 4.7% is considerably lower than the Australian average of 9.2%, and the average weekly individual income of \$300-399 is above the Australian average. The area has a high proportion of English speaking people (85%), with only about 14% of people being born in non-English speaking countries. Apart from English, the main language spoken at home is Cantonese (1.8%).

The area around the hospital contains a mixture of health care facilities and residential homes. The major public hospital located adjacent to Black Swan has many clinics and laboratory services associated with it, creating a large complex of medical facilities. There is a large aged care facility also in the vicinity, yet there are many private homes, both single dwelling houses and units, further along the street. The shopping area around the corner boasts several restaurants that are popular with hospital

staff during the day, and also well frequented by people in the area in the evenings. There is generally a significant amount of movement around the hospital during the day.

. There has been a substantial effort to update the hospital since being acquired by the private health group, which boasts an ambience equivalent to, as their web-site mentions, a "five star resort". Many new buildings have been erected in recent times, including private consulting rooms, a psychiatric inpatient and day patient clinic, and radiography services. Some of the hospital areas are yet to be rebuilt or refurbished, including the 22 bed Numbat Palliative Care Unit.

Impressions of Numbat

Personal Note: Numbat PCU is familiar territory for me. I have never worked there, but have been to the unit on many occasions over many years. Meetings with palliative care colleagues are often held here, and I have also been involved in prior research in the unit. I was, however, unfamiliar with the ward areas and many of the hands-on staff working there were only passing acquaintances. I was quite friendly with senior staff of the unit though. I wondered if this would influence my acceptance at the unit. I didn't feel the same trepidation as I experienced in Sydney and Melbourne when I was entering the field.

Although familiar with the offices and meeting rooms at Numbat, I was not at all familiar with the ward areas. Initial impressions were of an old hospital. The unit, however, consists of two wings. One has open, four-bedded rooms, shared bathrooms and vinyl floor-coverings; the other wing has several twin and single occupancy rooms, ensuite bathrooms, and carpeted floors. My impressions concurred with some of the staff's, who describe one side of the ward as "nursing home" style and the other like a hospice.

Being familiar with many of the surroundings, it took me a few days to get into a researcher routine and start to observe the surroundings. I became aware of the activities that were taking place in the unit. In one lounge, the one situated in the "nursing home" wing, there is lots of activity. Two mornings a week the art therapist and several volunteers are there, creating a mosaic. Patients, families and staff are encouraged to join in. It is a busy place.

If the weather is fine these activities spill out into the garden, a rather beautiful area where patients can sit, and even be wheeled out in their beds. The mornings in Numbat seem quite busy, not so much with patients coming and going for treatments,

although that happens also, but patients getting going for the day and coming outside, or into the lounges.

The other lounge, in the carpeted end of the ward, also houses activities but generally seems a quieter area. Recorded music is often playing in here, and on Friday afternoons a crew of volunteers come to offer patients, families and staff comfort therapies such as foot baths and aromatherapy.

Another feature of Numbat is the presence of volunteers. They always seem quite busy, and very cheerful. There are usually two volunteers each shift on the ward, and they attend to flower arrangements, fill out meal menus with the patients, give out meals, make beds, or just sit with patients. There are many different volunteers rotating through the rosters, and they all seem to be bright and enjoy their time in the unit.

My overall impression was that there is a mixture of activities happening at Numbat. There are quiet areas and activities, and other places that are busy. The impression of busy-ness is different from that at Waratah. At Numbat, the activities seem to be less about hospital routines and patient procedures and more about recreational activities that involve patients, families, and staff. It is a lively atmosphere.

These few comments reflect my initial impressions of the PCUs. The following table, Table 13, provides a recapitulation of the major features of the units, a summary of data given in the descriptions above.

Table 13

Major Features of the Study Sites

City	Name of hospital	Size of hospital (beds)	Name of PCU	Number of beds	Payment type
Sydney (1)	Waratah Royal Suburban Hospital	750	Palliative Care Ward	8	Public
Sydney (2)	Platypus Regional Hospital	200	Kookaburra PCU	16	Public
Melbourne	Heath Church Hospital	80	Honeyeater Ward	22	Public / Charitable
			Possum Ward	22	
Perth	Black Swan Private Hospital	350	Numbat Palliative Care Unit	22	Private & DVA

Waratah Palliative Care Ward, Heath Church Hospital - Honeyeater and Possum wards, and Numbat PCU at Black Swan Private Hospital, have certain common features. Each is located within a major metropolitan area of Australia, each has been established for at least 10 years, and each is situated in a hospital ward that has previously been occupied by other health care personnel. Kookaburra PCU, although attached to Platypus General Hospital, differs significantly in these aspects. Kookaburra is a stand-alone facility, opened only three years ago, and has been built specifically for the purpose of housing a palliative care unit.

Selection of Sites

Selection of the study settings was discussed previously in Chapter 5. I again raise selection of the study sites, not in relation to inclusion criteria, but the logistical considerations that framed the choice of these particular services.

Apart from access to services through links with key personnel, the location of the services was a consideration. In addition to having well-established palliative care communities, two of the three cities were selected for convenience. Perth was chosen

because it is where I live; Melbourne, the second largest Australian city, because of my familiarity with the city having grown up there; Sydney, with which I was unfamiliar, was selected because it is the largest city in Australia. Another criterion was to have a selection of service types; private, public, and charitable, which is illustrated in Table 13 above.

The addition of a fourth site was at the suggestion of a colleague who mooted that a "purpose built" facility might provide another view of palliative care. It was expedient to include Kookaburra PCU for this purpose, as this required only a small change to the research protocol that had already been approved by the Sydney area health service ethics committee in relation to the research at Waratah Palliative Care Ward. Only one week was spent at Kookaburra, which did shorten the period of observation at Waratah. However, this data collection time provided an insight into another service model, and allowed some comparison of services within the same geographic area. The substantially reduced observation period at Kookaburra has meant that observations here are not as detailed as at other sites, and no formal interviews were conducted. However, observations were sufficient to allow a broad view of the unit, in particular the impact of the initial impressions made by the physical surroundings, especially when compared with the physical appearance of the other sites in the study.

Physical Features of the Units

To illustrate the comparisons of physical presentations of the different units, the physical attributes of the newer Kookaburra PCU are described first.

The Purpose Built Palliative Care Unit

Kookaburra PCU was designed and built specifically to cater for a palliative care service. The unit commenced operation only three years ago. Prior to this, terminally ill patients were cared for in one of the general medical wards at Platypus Hospital, or at palliative care facilities elsewhere in the region. As yet, only eight of the sixteen beds in the unit are being used. The other eight beds are yet to be funded, although the unit is fully fitted and furnished for the full complement. Platypus Hospital is designated as a public hospital, but it does have a nominal affiliation with the Catholic Church. Throughout Kookaburra the only presence of this was placement of an occasional crucifix in some of the common areas. The manager specifically pointed these out to me, otherwise I may have overlooked them completely.

Initial perceptions of Kookaburra were of a bright, airy place. The floors are carpeted and soft underfoot. There are feature walls painted in colours such as deep burgundy that contrast with the paler colours of the surrounding areas. Black and white prints of early settlers to the area have been framed and hang at eye level along the corridor leading up to the ward area. Within the ward, the main corridor is wide and slightly curved. There is a large picture window at one end, and, as the corridor curves past the patients' rooms, another large window becomes visible at the other end. A further impression of space and light is given. There are splashes of colour along the corridors, decorated in one area with a selection of aboriginal artefacts hung on a feature wall, behind which is a large open area, the television lounge. Further along the corridor is a fish tank, with brightly coloured tropical fish adding further colour to the area. At various points along the corridor there are comfortable aqua-coloured sofas, again giving splashes of colour to the unit. Along one side of the corridor more windows overlook a central courtyard, in which there is a fountain that gently sprays water into the air. The position of the courtyard is such that dappled light filters into the corridor, adding to the feeling of openness, and bringing the "outside in".

Patient rooms are also airy, with generous space around the beds, and with each room opening onto a wooden decking. Beyond the decking there are landscaped gardens, including two gazebos which provide shade to the seating areas underneath. Half the patient rooms in the unit are designed for single occupancy, and have an accompanying ensuite bathroom. The other rooms are two bedded and share a bathroom per room. Because half the beds remain unoccupied, staff often assign only one patient to a room, and occasionally a relative staying overnight with a patient is permitted to use the other bed in a two-bedded room.

I reflected that much thought had gone into the planning and design of this facility. The manager of the unit discussed this with me on my guided tour. He proudly displayed the features to me. There are several small rooms also with comfortable sofas, where families can retreat in privacy, and where staff can speak with them regarding the progress of the patient, or comfort them after the death of a patient. Also within the unit is a large, well-equipped kitchen. Visitors are encouraged to use the facilities, with tea, coffee, and ice being freely available at all times of the day. The kitchen is also used in the preparation of patients' breakfasts, although their other meals are delivered from the hospital kitchen. The general atmosphere of the unit is one of openness and space. There

is little clutter, suggesting that in planning the unit, attention was given to providing adequate storage.

Making Do: From a Five Star Resort to the Transformation of a Cupboard

In stark contrast to Kookaburra, Waratah Palliative Care Ward, Possum and Honeyeater Wards at Heath Hospital, and Numbat PCU at Black Swan are located within building complexes that have been established for at least 25 years, some up to 60 years. In some areas, the units have seen many incarnations over the years, with various attempts at remodelling and refurbishing to suit the needs of the time.

Each of these palliative care services is located with other services. At Heath, although there is only one other inpatient ward, there are many community services based within the hospital grounds. The eight palliative care beds at Waratah represent about one percent of the total hospital beds, plus there are many clinics and other health services within the hospital. Palliative Care Ward's eight beds are situated sandwiched between two other wards, cordoned off by large plastic flap doors that are the only barrier between Palliative Care Ward and the adjacent wards. Even the bed numbers of the unit reflect this, being numbered consecutively from 29 to 38. (Although there are only ever eight beds in the ward, the space allocated for the unit is equivalent to ten beds, utilising two single rooms and two potentially four-bedded rooms.)

Access to the palliative care areas at both Heath and Waratah is past common reception areas that are subject to the hurly-burly of busy hospital routines, particularly at Waratah. Large numbers of staff, patients, and visitors are seen going about their business, and the entrance at Waratah clearly shows the volume of usage over time, with seats that need recovering, threadbare carpets, and a general appearance of grubbiness that is common amongst areas of public utility. Numbat PCU, although part of a larger complex at Black Swan, does have a separate entrance that tends to be used more frequently than the main hospital entrance. Access to Numbat via the main entrance is difficult, involving negotiating several different corridors and paying particular attention to the signs directing the way. Generally, only staff use the internal entrances, usually because they have business in another part of the hospital.

Inside the units some attempts have been made to brighten the wards. For instance, each unit has recently been painted using neutral tones of beige-on-beige, pale green, and occasionally a peach contrast. These colours emulate the utilitarian colours often found within the sterile environments of public hospitals. Carpeted areas are sparse, vinyl-type flooring being favoured, presumably for ease of cleaning. These

surfaces, however, are hard underfoot and amplify footsteps along the corridors. I noticed particularly that rubber-soled shoes, mine and others, made loud squelching noises despite attempts to walk quietly along the corridors. These noises were constant reminders of the business of the wards, and I reflected that this could not be restful or conducive to creating a homelike atmosphere for patients or their families.

Unlike the decorations on the walls of Kookaburra, the pictures on the walls in these other facilities are an eclectic mix of different styles and themes. Some of these styles reflect a preference for muted tones, prints of watercolours featuring flowers, cottage gardens, water scenes, and bush scenes. Many of these appear to be posters of the type that are mass-produced and widely available. However, some of the artworks are apparently original paintings by "known" artists and are quite valuable. There is no evidence of any recognition of these works, no accompanying identification of the artist or description of the work, and these original pieces are interspersed amidst the other pictures. Also on display are quotations and verses that have been printed in calligraphic styles and framed. An example of such a verse is

Some people come into our lives and quietly go.
They leave footprints on our hearts and we are never, ever the same.

Many of these pictures have been given to the wards by families of patients who died in the units, in appreciation of the care given to that person. This could explain the mosaic of styles that is evident. Many of the pieces have a plaque saying that they have been donated by the family of *Patient Name*, in appreciation of the care given by the staff of *Ward, Hospital Name*. They may also have the date of birth and death of the patient, and further inscriptions reminiscent of those found on tombstones.

During the period of observation I saw several families return to the wards with letters and gifts of appreciation. Sometimes the gifts were boxes of chocolates, cakes, and similar edible items. These gifts were accepted graciously and often the staff on duty would ensure that these be shared amongst the staff by putting them aside to be offered later, perhaps at a team meeting. Patients or their families also gave these types of gifts when they were being discharged from the ward.

Other families choose to give more permanent gifts to the ward when a patient had died, such as the pictures previously described. The staff express a degree of ambivalence about accepting these tokens of appreciation. On one occasion, a week or so after the death of a patient, a family returned to the ward with a gift that was obviously very important to them. They had travelled some distance back to the unit to

see the staff, and brought their gift quite proudly to the ward. The staff on duty accepted it graciously, and thanked the family appropriately for their thoughtfulness. They inquired into the health of the family, commented on the sadness they must be feeling, and said that they had been fortunate to have met the now-deceased patient. He had been a kind and gentle man for whom they had enjoyed caring. The wife of the patient kissed two of the nurses, thanked them, and the family left.

After their departure, the staff started talking about the gift, which many of them thought was particularly ugly and tasteless. It seemed that, although the staff were genuine in their concern for the welfare of the family and the comments they had made about caring for the patient, they certainly had not been honest about their appreciation of the gift. However, they clearly felt that support for the family included respect for the sentiment behind this action. In subsequent days the object was quite a talking point within the ward, with many accompanying jokes that reflected the true thoughts about its artistic merit. Over a period of a few weeks the object was relegated from being in pride of place opposite the nurses' station, to a corner of the day room where the television competed for equal exposure.

Further reminders of the patients who have died in these services are in the thank you cards and floral tributes that are found around the nurses' stations, sometimes even pinned up on the x-ray viewing screens at the desk. An example of one of the messages in these cards is given in the following passage.

To all staff of xxx ward. Our sincere thanks to all for care given to H over the last 4 months up to his passing on [date]. We also thank you for the kindness and support given to us during this time. How appreciative we are to have known you and how comforting it was for us to know that H was cared for by such wonderful people. We wish we could have thanked you all personally.

Sometimes the flowers at the desk are sent by the families as thank you tokens to the ward staff. Often they are flowers from the patients' funerals, and are dropped off by funeral directors after the service. In one of the units, one of the duties of the volunteers was to look after the flowers on the ward. They had been briefed that they were to rearrange these funeral sheaths as soon as possible. The reason for this was given as being not to appear as though they were funeral arrangements. I assume the reasoning behind this is to shield patients and visitors to the unit of any association with a funeral. I noted there was contradiction here. This diversionary act of rearranging funeral flowers seemed to perpetuate the attitude of hiding death-related issues, yet the open

display of artwork bearing “In Memoriam” inscriptions, as well as the prominence of verses about life and death and leaving memories, is perplexing and ambiguous.

One of the features of palliative care practice is purported to be an open approach to death and “truth-telling” (Woodruff, 1999), a reaction against the so-called “conspiracies of silence” that were practised within traditional bio-medical models of the past. Open communication about the nature and prognosis of disease is presented as a means of empowering patients, enabling them to make informed choices about their ongoing care, and assisting them to resolve conflicts so that they may approach their deaths peacefully (Saunders, Baines and Dunlop, 1995; Woodruff). Street (1998) challenges the appropriateness of this as an approach in all cases, and suggests that truth-telling of itself may perpetuate a bio-medical model. The tension noted at Numbat between condoning practices of openly acknowledging and remembering the deaths of patients and hiding evidence of recent funerals, is a further example of competing discourses, though different from those to which Street alludes. However, the example illustrates there are some apparent contradictions within palliative care practice.

Patient Facilities: More Creativity and Making Do

Patient facilities are similar within the revamped units with a few single rooms, but mainly shared rooms of up to four patients. Waratah Palliative Care Ward and both Possum and Honeyeater Wards have, however, been creative in their use of bed space.

At Waratah, although only funded for eight beds, they have space for ten. If possible they accommodate only three people in the four-bedded rooms, which gives more space for everyone in the room. Sometimes, however, the mix of male and female patients dictates that there are four same-sex patients to a room. On rare occasions, with patient and family permission, they do mix sexes in the one room. One occasion of this occurred when two patients were particularly restless and confused, and disturbing others in their respective rooms. Moving these patients, one male and one female, into the same four-bedded room gave the other patients in the ward a more restful experience. My initial reaction to this was one of surprise. I had never contemplated doing this in my practice nor had I known of it happening, other than perhaps in intensive care areas. On other occasions the need arose because staff deemed that two particular patients each needed to occupy a single room, leaving a mismatch of males to females among the other six patients at the time. Patients, or when patients were unaware, families, seemed to be very accepting of the arrangements.

At Heath Hospital, there is no mixing of the sexes in the rooms, but they do restrict occupancy to only three patients in the four bedded rooms. This in effect reduces the bed capacity from 22 per ward to 19 per ward. The practice is not only undertaken to provide more room for the patients, it is also a creative way of using the allocated funding, which is in some way related to occupancy rates. The exact administrative rationale behind this creativity was never fully explained to me.

Three rooms at Numbat were four-bedded rooms and often fully occupied. Although staff at Numbat lamented the lack of resources, particularly single room availability in the unit, many of the patients in these shared rooms appeared to greatly enjoy the experience, and some verbally acknowledged this. Often the rooms were occupied by four returned servicemen, who shared many things in common. They were of similar age, had memories of wartime experiences that many other community members had no understanding about, and were again facing adversity (this time terminal illness) together. The camaraderie appeared important to them.

At times, staff became concerned about the relationships some of these men formed, as one by one room-mates would die. Occasionally a patient would be moved to a single room if staff felt that they had witnessed a number of deaths in a short period of time. These considerations by the staff were commonplace, however, I am unaware that the reasons behind moving these patients were ever discussed with the patient themselves.

Within these revamped facilities, one of the major issues is the bathroom facilities. At Numbat in particular, staff identified a major concern about the physical environment is the inadequacy of the bathrooms. Some bathrooms are ensuite, although shared between two or four patients, however, patients in the four-bedded rooms may have to share one bathroom amongst eight patients. Family members staying overnight have also complained about the lack of bathroom facilities.

One of the patients, Mary, was able to disclose to me her very personal reasons for concern about sharing a bathroom.

Fieldnote: 8 January 2002

Following our talk last week, Mary had rung and left a message on my answering machine that she wanted to add something regarding differences between the palliative care unit and the other hospital ward where she had been. ... What she wanted to tell me was about the disgust and betrayal she felt about her body. How it was letting her down. That control was very important to her. She said she's always been bossy and now her body is letting her down. ... The part she wanted to tell me was

that as a patient it was very important to her to have a private bathroom. She wanted to shower when she felt like it. And the smells, her smells. She was embarrassed about her insides reacting, making noises, having pain, from eating three meals a day after she hadn't eaten for so long. She felt embarrassed talking to me about it, she said. But she thought it was worth passing on because patients in the future might benefit. "It might do some good." I explored what she meant by "good" and she said she meant that it might do others some good to know how patients felt.

Prior to coming to the PCU, Mary had been in another ward within the hospital. That area has recently been refurbished and having visited these other areas of the hospital, I could envisage the differences, with brighter surroundings, new carpet on the floors, and matching décor. Mary was unconcerned about those aspects of Numbat. It was sharing a bathroom that worried her, and the meaning for her about the loss of control and feelings of "disgust and betrayal" she felt about her body. She valued and missed the sanctity of her own bathroom that could provide her with the privacy to hide some of the disgrace she felt about her body.

I doubt that Mary shared her feelings with the staff in the unit. It was only that I had specifically asked her about her experiences and the comparison between different parts of Black Swan. Even had she told staff, there was little that could be done to accommodate her privacy any further. Staff in the PCUs display creativity to meet the perceived needs of the patients, and families, however, much of the time in these older facilities they are merely "making do."

Staff Facilities: Backspace and Making Do

Within each of the units, the focal point of the wards is the nurses' station, as in most hospital wards. This area seems to be the place where staff congregate, where visitors seek direction to patients' rooms or come to ask a question of the staff, where telephones and patients' notes and resource manuals are located. The terminology, however, is not quite accurate. It is not only nurses who congregate here, but all staff disciplines tend to avail themselves of this area, certainly in the four sites observed in this study. Another common feature of this area is that, although sometimes referred to as a desk, such as in the phrase "it's up at the desk," this area is usually a raised counter behind which the staff sit or stand. It is uncommon to see anyone other than staff behind this counter, although there is no physical barrier to prevent patients or visitors from entering the space. The counter, however, acts as a barrier, providing almost a sanctuary to the staff, a reminder of the delineation between those who "belong" and those who

are merely "guests." This division occurs despite the home-like atmospheres and attitudes of inclusion in the units.

Goffman (1959) talks about the front and back regions of social life, using the analogy of the theatre. The front region is where the stage performance occurs, or in the context of the ward, where professionals interact with patients or families in their various health roles. The back region, in this example the space behind the nurses' desk, is where behind-the-scenes activities occur, which can range from talking *about* patients and families, writing confidential reports, or interacting socially with colleagues. The following incident gives an example of an audience member (me) being caught backstage, and the reaction to that intrusion.

Personal Note: During my research I was personally reminded of the invisible barrier the nurses' desk creates.

Fieldnote: Saturday October 20

I made a faux pas this afternoon. It's Saturday. I've been feeling quite comfortable in the ward after several weeks here. I walked into the ward and started reading the message book, which was on the desk. [This is a communications book that staff use to record various non-clinical information about the ward, and which I like to read when commencing my observations for the day, to gain a picture of things that might have happened in my absence. This was a common practice and one that I had clarified with the Nurse Unit Manager was acceptable for me to do.]

Dorothy came up and wanted to know who I was and what I was doing. I realised immediately who she was and that she was back from holidays. I'd heard about her, because she's the other senior nurse on the ward and people have been talking about her since I arrived. But, we hadn't met until this moment. Of course, I'd forgotten to wear my hospital badge. I quickly explained who I was and what I was doing in the ward but, for the first few minutes of our conversation there was a difficult exchange. I felt very uncomfortable.

Personal Note: I was aware that the relationship between Dorothy and me remained strained for the duration of my fieldwork. As a stranger, an outsider, I had crossed the invisible barrier into insider space. I also became aware that some of my prior comfort was being allowed/accepted into this backspace, including being privy to reading the message book. Dorothy had challenged this.

The nurses' station at Kookaburra had again been designed with attention to creating a spacious and functional area. The counter area, which has a highly polished dark woodgrain finish, is L-shaped and the desk area behind it is large enough for

several people to sit and write or use the telephones. In addition to this there is a niche with a writing area behind the main desk. Staff also utilise this area to read and write their notes. There are two computer terminals here, used for checking patient information such as laboratory results, and space for at least five people to be seated. There are also several rooms that staff use where they are able to shut the door. These areas are used for handing over from one shift to another, for preparing medications and equipment for the patients, and also there is a "dirty" area used for storing dirty linen and emptying and cleaning of soiled equipment such as bedpans.

Similar working areas are found in the revamped facilities, as they would likely be found in any inpatient health care facility. The thought behind the design of the purpose built unit was again obvious. There has been attention to space for staff to undertake the duties they are required to perform in these areas, and storage space is available. In the older units some of these areas are very cramped. This is especially obvious in the dispensing of medications.

Hospital regulations require that opiates, which are commonly used in palliative care, require two authorised staff members to check and dispense to the patient. There is also a need to undertake this task with consideration to the security of the drugs and mental concentration by the staff as they may be required to calculate the appropriate dosage for the patient. Some of the areas used for this purpose are extremely small, but in frequent use because of the demand for medications of this type in these units.

In the older facilities, modification has been made to other areas, such as the placement of shelves to accommodate patient case notes and x-rays. These have been added into the offices rather than being part of the original design. Such additions further decrease the space in these rooms, and staff squeeze past others in order to get to the items they need. It is not uncommon to see staff standing, resting papers on the counter of the nurses' station, to write in patient notes or order patients' tests.

In each of the units there are also offices located at a distance from the ward, in which staff with managerial and coordinating positions are located. In Kookaburra these offices are located in another wing of the building. At Waratah, the most cramped of the PCUs studied, offices are scattered throughout the larger hospital. One is at the back of the Palliative Care Ward, another across the corridor, and yet another is several floors away from the unit. It seems that space is at a premium within the hospital and people avail themselves of whatever office space is available.

At Waratah Palliative Care Ward a great deal of creativity has gone into the use of space, in particular the creation of a staff room. The manager here was able to convert a cupboard into a staff room. With limited funds she arranged that this room and two of the offices were painted in bright colours, and that the "cupboard" become a staff room. Equipped with a two-seater sofa and two other small yet comfortable chairs, I was told that the room is only one and a half meters square. Even though it is small it is a space where staff go for their tea breaks, shut the door, and flick through one of the dated women's magazines that have been left there. Throughout my period of observation at Waratah, there was a sign on the door reading "Staff Only," and this restriction was heeded by patients and families.

At Numbat, the "backspace" activities occurring in the staff room are a major part of the ward routine. This room is significantly larger than the cupboard conversion at Waratah. In fact, at Numbat there is a large meeting table in the centre of the room that will comfortably seat 12 or more people. Rather than going to other areas of the hospital for tea breaks or meal breaks, staff congregate here. Meetings and seminars are also conducted in this room. Sometimes social events, such as a farewell afternoon tea, or while I was there, a baby shower (for one of the nurses), are held in this room. People tend to come and go, fetching a cup of coffee to take back to their office, or sitting and chatting at the table.

In my early days at Numbat, I too sat with the staff at meal times and on their breaks. Some staff would discuss the research with me and I was often tempted to ask them about aspects I had seen in the ward. These exchanges were initially tolerated, however, over time I noted that several staff members made a point of saying that there was "no shop talk" during these breaks. These comments may not have been directed specifically at me, however, I did subsequently refrain from discussing too much of the ward activities during these times.

At Heath and at Kookaburra there are no designated staff areas. The lounges within the unit are available for all to use, however, if staff wish to retreat from the ward environment or the possibility of being engaged in conversation with a patient or relative, they need to physically leave the ward. Many of the staff do this, both at tea times and meal breaks. At Heath, the cafeteria becomes almost exclusively a staff province, although patients and families do occasionally venture into the area, and there are no restrictions on who uses the facilities. In the cafeteria staff sit together with their colleagues from the ward, or occasionally, weather permitting, they venture outdoors.

and sit in the garden. Some staff do not bother to leave the ward at all, and have a cup of tea or coffee at the desk. This occurs at all the units, despite that fact that at Waratah in particular, the hospital management do not condone the practice of having food or drinks at the desk.

Overall, staff facilities do not appear to be major considerations in planning for any of the units. Rather, staff tend to "create" spaces to call their own, and are skilled at clearly delineating these spaces. I was interested that, even within palliative care, where I suspected staff may be less concerned with separating patients and families from themselves, backspaces were important and protectively maintained.

Family Facilities: The Unit of Care and Making Do

Each of the units have either planned or created space for family members to use within the facility. At Kookaburra three areas for family use are provided. One of these is the large television lounge, where there were several sofas and easy chairs, a large-screen television, a stereo system, some popular novels, and a children's table and chair set as well as some toys. This is a comfortable and attractive area, with floor to ceiling windows looking out onto the landscaped gardens. It is a common area, available for all to use, although in the week of my observation at Kookaburra I did not see any of the inpatients utilising this area. The other two lounges are much smaller, yet equally comfortable. These smaller lounges offer more privacy. I saw one family congregated in a small lounge over a period of several days, keeping vigil as their loved one gradually deteriorated and eventually died. These lounge areas are also used by staff to meet with families and discuss patient management, and for staff to meet with each other, although I witnessed little of that occurring.

Similar facilities are made available at the other units. Even in Palliative Care Ward where space is at a premium, a family lounge slightly larger than the staff lounge has been made available to offer some sanctuary to family members. Generally, I observed only one family group using this space at a time. This meant that other visitors were sometimes seen outside the ward, sitting on vinyl-covered chairs located opposite the lifts in a very public area of the hospital. It was common to see people sitting here, waiting to visit a patient, or waiting for other family members to come out of the ward. Some families would be waiting to be with a patient who was dying. I saw several family members eating their meals in this area, a food tray balanced precariously on top of a rubbish bin.

Each of the units makes provision for family members to stay overnight, a practice that is often encouraged when a patient is close to death. As previously described, there are several spare beds at Kookaburra, and accommodating family members overnight is comparatively easy. Most of the units have large armchairs, either recliner rockers or large vinyl hospital-type chairs, in which visitors can rest, and often sleep or doze overnight. Sofas at Numbat pull out to beds specifically for family members' use in these situations. At Waratah, camp beds are provided and can be placed in the patient's room. In a single room it is possible to accommodate two of these, one either side of the patient, and they were often utilised in this way during my time there. There is an on-site flat at Heath, a suite with a television, tea and coffee making facilities, and a bathroom. However, few family members choose to use this facility, preferring to remain close to the patient, usually at the bedside.

It is usual practice at each of the facilities to welcome families as well as the patient, to the unit. The visitors are shown around, amenities pointed out, and they are encouraged to help themselves to cups of tea and coffee. All the units made overt attempts to welcome family members and provide them with some comfort, again physical limitations of the particular settings creating a need to "make do" with available resources.

Special Features of the Units

Some physical features of the units appear to have particular relevance for the staff working there. These are not staff facilities, rather patient facilities that staff appear to promote, even take pride in being able to offer to their patients.

Kookaburra in its entirety engendered this response from staff. Indeed, many of the facilities at the unit are noteworthy. The garden is a particular source of pride. There were several photographs on a pinboard in the unit of the opening ceremony where local dignitaries mixed with staff members. I understood that money for the establishment of the garden had been raised by the local community, and added to the significance of setting up the garden.

The garden area at Numbat is also an area in which staff express pride. This area has been recently landscaped, and includes rockery, trees, gazebo sitting areas, water features, as well as an area specifically modelled to accommodate several hospital beds. When I first began the fieldwork at Numbat, the Nurse Manager was still deciding on the final plan for the flower and shrub beds. She told me that all staff members of the unit had been encouraged to have input into the garden, and those who wished to were

asked to contribute a plant, perhaps a cutting from a favourite in their own garden. At Kookaburra, patient rooms overlook the garden, but this is not the case at Numbat. However, weather permitting, staff encourage as many patients as possible out into the garden, many of whom will stay there from mid-morning until well after lunch.

Possum and Honeyeater Wards at Heath are located above the ground floor and therefore access to a garden is not possible. The features in both these wards are the “balconies”. In each ward the balcony is an area that provides a view to the bay, including Melbourne’s port and across to the high rise buildings of the city. Most people agree that it is a spectacular view, especially on a clear day. In the evenings the sun setting through the clouds creates a warm orange glow to the surrounding areas. The balconies were once open to the elements and have now been enclosed, but there are some major design flaws with this renovation that make it less than ideal to accommodate patients. A reasonably narrow space, it is not quite wide enough to accommodate a hospital bed and, therefore, patients who are confined to bed cannot access the balcony. Viewing from chair height is restricted as most of the windows are too high. As well, despite the renovations, it can be very drafty and cold in these areas during winter, and far too hot to sit here in summer.

Perhaps the biggest drawback about using the balcony is that access is only via doors leading off patient’s rooms, about six along this particular corridor. This means that both patients and visitors as well as staff pass through another person’s room. Sometimes these patients are unconscious and close to death. I felt this was perhaps inappropriate, both for the intrusion to the patient, and for those passing through. However, staff at Heath acted as if this was an acceptable practice. Despite the problems that I perceived existed with the “balcony”, staff referred to it as something special. Heath has undergone so many modifications, I reflected that the balcony area was accepted as a compromise, another example of making do in less than ideal surroundings.

Summary

This chapter has provided an overview of the physical aspects of the units. In providing these descriptions, I have also given interpretations of my observations that provide an insight into the palliative care cultures within these services. I have also provided the reader with my first impressions and reflexive analyses to enable them to make their interpretations of my conclusions.

Examination of the study sites revealed settings that, with the exception of the purpose built Kookaburra PCU, are "Making Do" to provide the facilities that people consider appropriate in these environments. These efforts indicate concern for meeting patients' needs in terms of providing home-like environments, and inclusion of the family within the environments. Some concern is shown to protect people within the units from overt expressions of dying and death, although there is also overt acknowledgment of people who have been cared for and died within the units, as noted in the remembrances displayed about the units.

Particularly interesting are the efforts by staff to maintain some degree of separation from patients and families, despite being closely involved with them and striving to provide welcoming atmospheres within the units. Further examination of relationships between staff, patients, and families is explored in the next chapter, "The People."

CHAPTER SEVEN

THE PEOPLE

In this chapter I discuss the people whom I observed, interacted with, and whose behaviours I interpreted throughout this study, the "actors on my stage." As I alluded to earlier, although some of the actors performed knowingly and willingly, others were oblivious to their roles in this unfolding drama.

Where possible, I provide demographic profiles of my actors. Demographic data were collected from participants who were purposively recruited for interview as key informants. Other participants' profiles are composite impressions of the people I met in the research sites. Many participants who were naive to the research remain anonymous and undescribed, although their contribution to the observations in the research environments was vital to making interpretations of the interactions I witnessed.

Also in this chapter I discuss relationships between participants in the study. Of particular interest are team relationships. Here I describe four different models of palliative care teams that I encountered in this research. Examination of relationships among staff members leads to a discussion about staff support and relationships of staff with patients. The concept of "loving care" is introduced, and consideration is given to this concept as a core component of palliative care practice.

Everyone a Participant

All persons who were present in the palliative care settings during the period of observational fieldwork were potential participants in this study. The number of people within the field sites is particularly difficult to estimate, with constant movement in and out of the units. However, the number of Information Sheets (Appendix 4) distributed while in the field was in excess of 300, and this figure provides a crude estimate of the number of people directly involved in the fieldwork.

In addition, I have been in contact with people from each of the study sites who may or may not have been present during periods of my fieldwork. These people have subsequently provided clarification, refutation, and confirmation of my interpretations of observations from the field. Palliative care colleagues, acquaintances, conference

participants, fellow students, lecturers, supervisors, and friends have, in various ways, become participants in the study by their contributions and feedback to the emerging analyses throughout the research process. Every interaction with persons in the field sites and each peripheral observation has in some way contributed to the overall research and understanding of the culture.

Specific demographic characteristics were not collected on all these people, however, participant profiles are available for people who took part in formal tape recorded interviews. These profiles are shown in Tables 14 and 15.

Table 14

Demographic Data of Staff Participating in Formal Interviews

Pseudonym (age in years)	Involvement with palliative care (pc)	Relevant palliative care (pc) education
Andrew (50)	Manager Pastoral Care & Bereavement Services Five months pc experience	No formal pc education
Betty (63)	Manager Volunteer Department 13 years pc experience	Palliative care short courses and seminars
Chris (33)	Social Worker 10 years pc experience	No formal pc education
Karen (58)	Occupational Therapist Five years pc experience	Palliative care nursing course, Advanced Counselling Skills for pc workers
Quentin (49)	Chaplain 15 years pc experience	No formal pc education
Frank (55)	Clinical Nurse Consultant Mental Health 18 years pc experience	No formal pc education
Gill (43)	Clinical Nurse Consultant Palliative Care 10 years pc experience	Post-graduate diploma pc nursing
Lionel (31)	Clinical Nurse Consultant, Clinical Nurse Manager Nine years pc experience	Post-graduate diploma pc nursing Masters student, pc nursing
David (60)	Palliative Care Physician 17 years pc experience	Post-graduate diploma pc
Harvey (50)	Doctor, Medical Director of Palliative Care 14 years pc experience	No formal pc education

All staff members who participated in formal interviews were educated to university level although not all had formal qualifications in palliative care. This is despite the fact that they held senior positions in the area. Andrew had only worked in the area for five months, while all others had between five and 18 years experience. I purposively selected these participants because of my perception that they held key positions and would, therefore, answer key questions about the services. It was

nonetheless interesting to note the lack of formal training in palliative care of some of the senior palliative care professionals.

As previously discussed, the majority of data obtained for this study was through observation and informal interviews. Several patients and family members did, however, participate in formal tape recorded interviews, and their demographic details are given in Table 15 below.

Table 15

Demographic Data of Patients and Family Members Participating in Formal Interviews

Pseudonym (age in years)	Involvement with palliative care (pc)	Highest level of education
Evelyn (74)	Patient diagnosed with breast cancer six years prior. First pc experience; several weeks in the PCU.	University
Pat (76)	Patient diagnosed with leukaemia a few months prior. About six months with the pc service; home care and several admissions to the PCU.	Completed some high school
Mary (62)	Patient diagnosed with breast cancer about six years prior. First pc experience; two weeks admission.	University
Olive (55)	Daughter of patient. Several months of pc experience in relation to mother; no other experience of pc.	Completed high school
Neal (65)	Husband of patient. Mother died in a nursing home, but no experience of palliative care as such, until wife's involvement (about two weeks).	University

Selection of patients for these formal interviews was opportunistic. I developed comfortable relationships with Evelyn, Pat, and Mary, each of whom was willing to share their stories. By no means were they the only patients with whom this occurred. However, I chose to formalise these interviews and tape record them. Olive and Neal were family members of Pat and Mary respectively. They were also willing to participate, and I interviewed them to expand and triangulate the unfolding stories. The contributions from these participants are interwoven throughout the thesis, their stories adding to the overall understanding of palliative care.

I have chosen to discuss the people involved in this study in three general categories. *Patients* are those people who were admitted to the units, or were being seen as outpatients at the services, during the period of the fieldwork. *Family* I use in a broad sense to include family and friends of patients who were visitors to the units, attending because of some social connection with a patient. *Staff* members are those people who were employed by the facility, including volunteers recruited to the service, as well as people such as medical consultants and community nurses who visited the ward in a professional capacity.

Patients

The majority of patients in all four units were aged over 60 years, the oldest during the period of observation was a 92 year old woman and the youngest, a 39 year old woman. Most patients had been diagnosed with a malignancy, which in some way was the contributing cause of their admission to the palliative care unit. Those patients who did not have cancer had a variety of medical problems. For example, an elderly lady, who had previously had several strokes, subsequently had a fall and fractured her leg, after which she suffered another stroke. She was admitted to the general part of the hospital initially, and after review over several days, transferred to the palliative care unit for terminal care. On admission to the unit she was semiconscious and died about 36 hours later.

No patients during my period of observation had an HIV/AIDS diagnosis. Within some of the regions there are other facilities that specifically treat patients with HIV/AIDS, which may account for the absence of these patients. However, none of the units specifically exclude HIV/AIDS patients. It may be that generic palliative care units, such as included in this study, are not appropriate for these patients. People with HIV/AIDS are not only likely to have distinct socio-political issues associated with their illness, but are also likely to be younger, and receiving complex and often experimental polypharmaceutical regimens. Current trends in this area of health care indicate that, with advances in treatments, people with HIV/AIDS are living longer and more fully than patients typically cared for in palliative care units (Parsons, 1998).

Within one of the geographical areas, a well-established neurological service is available for patients with diseases such as Motor Neurone Disease and multiple sclerosis. Patients with these diagnoses, therefore, tend not to use the palliative care services in this area. Nonetheless, in all areas of my study, only one patient with a neurological condition was admitted during my period of observation. This woman had

a diagnosis of Motor Neurone Disease, and was admitted for respite care during the final days of my research at that facility. The majority of observations made in this study, therefore, relate to palliative care provided to patients with a cancer diagnosis.

Non-English speaking patients were excluded from the study by the criteria established at the outset. However, although these people were not directly approached, it was not possible to be in the wards without interacting with them. Often some of the patients' relatives spoke English and the research was explained to these relatives. Whether they then informed the patients is unknown; there was no assumption that the patients were informed. My interactions between these patients were superficial and included friendly greetings or assistance with fetching a blanket or taking a meal tray. Similarly, my interactions with patients who appeared to be confused were limited, and the research was explained to them within the bounds of what I perceived was their understanding and interest.

Family

Throughout the thesis the term "family" is used to denote any person who has a significant relationship with a patient, and does not necessarily refer to a legal or biological relationship with that patient. One of the basic tenets of palliative care practice is purported to be that the people requiring palliative care are both the patient and the family, the latter in terms of the support needed to cope with the illness and death of the patient. A common catch phrase instilled in palliative care principles is "the patient and family is the unit of care", which notably was stated as the first standard in the original edition of the Australian Standards for Hospice and Palliative Care Provision (AAHPC, 1994). Inclusion of the family within the palliative care units is demonstrated in the following observations.

In each of the units visitors are free to come and go at any time of the day. There are no imposed visiting hours, even if adjacent wards do adhere to strict visiting hours. There are no restrictions on children visiting in the ward, or on the number of visitors at any one time. During my fieldwork I saw visitors with babies in prams, toddlers, and older children. The study criteria specified that people under 18 years of age would be excluded from the research and these children, therefore, were not interviewed or approached to be involved in the research. However, it was impossible to ignore their presence on the wards.

The absence of regimented visiting hours is stressed to the families as part of their orientation to the ward. They are often given direct phone numbers to the ward and

encouraged to ring at any time. Staff appear to recognise the need for family members to remain in touch with the progress of the patient, especially if the patient is deteriorating and approaching death. The following excerpt indicates a response to the deterioration of a patient recently admitted to the ward.

Fieldnote: 22 June 2001

A new patient died within a few hours of coming to the ward. I first heard a staff member on the phone to the relatives saying that she thought it would be a matter of hours. Then the lady died. Quite suddenly apparently. The relative was rung back and told. He [the relative, a son] was concerned about his brother who was on his way in [to the hospital] and didn't know that his mother was deteriorating, let alone had died. The ward [staff] were concerned about this, and phoned for the pastoral carer to be there.

The staff's response demonstrates concern for informing the relatives of events as they are occurring. Staff members also show a sense of anticipation of the possible grief reactions that family members may experience, hence the pastoral carer was called to await the arrival of this relative. The changeable nature of patients' conditions necessitates an awareness and rapid response to communicate the changes to families. There is also an awareness of relatives' concern and their need for ongoing involvement in patient care. Another example of this concern was noted in the following situation.

One elderly man had been a patient in the unit for several weeks. He was visited frequently by his son, but his wife was unable to visit because of her frailty. The patient was almost blind, and had difficulty using the phone beside his bed. Each day, the nurse coordinating the ward activities incorporated a phone call to this man's wife into her routine of duties. The phone call was made at a regular time each morning, and the nurse gave an update to the man's wife about how the patient had slept, if he was comfortable, how he was eating, and what procedures were planned for him that day. The phone call was not seen as an "add on" to a busy ward routine but rather, viewed as a necessary and integral part of the day's activities.

Lack of visiting restrictions can be problematic. The following account of a situation that occurred with an Asian family illustrates some of the dilemmas that staff may experience about imposing restrictions on visitors.

Fieldnote: 2 November, 2001

The man who has so many visitors. I think they are performing some sort of Reiki. Something to do with their church I heard (from one of the nurses). His wife is so upset, and she wanted to remove some of them. This was an issue today. His wife is really tired and overwhelmed with

the number of people surrounding her husband. It seems to be a cultural thing? She is polite and greets each one respectfully, bowing and talking to them. However, there must have been about 16 people in there this afternoon. This is in a four-bed room, with two other occupied beds on the opposite side of the room. The wife asked one of the nurses could she ask some of them to leave. I guess this was saving face from the wife's point of view. The nurse asked Amy, a more senior nurse, who said that she really couldn't insist, or say that there's restricted numbers, because there isn't any restriction. She seemed reluctant, hesitant. She did go in and suggest that he needed to sleep and perhaps so many people were keeping him from resting. Quite a few people did make an exodus after this. I guess this was a case of the leniency of palliative care in the inpatient setting actually being an obstacle, at least for the wife. Especially when meeting the cultural norms that she felt she needed to maintain. Yet if the hospital system had been more rigid and old-fashioned, perhaps it would have better matched her needs and perhaps the patient's. Perhaps.

I was surprised at the approach taken by Amy and her hesitation in setting boundaries in this situation. With knowledge of the "open door policy" of the palliative care unit, and that the regular hospital policy regarding visitor restrictions did not apply, she seemed to be left in a dilemma about whose needs to meet. She was unable to directly ask the patient's friends to leave, but obviously wanted to support his wife. By suggesting that the patient needed to rest, she gave the appearance of acting in the patient's best interests. The patient was at this time unconscious, and from my observation seemed to be unaware of his surroundings and the people surrounding his bed. I concluded that Amy was required to make decisions about whom of his family to support, his wife or his close friends, hence her hesitation about handling this situation.

I also witnessed staff actively encouraging family visits for specific occasions. Stories from many palliative care units talk of fulfilling patients' wishes, chaplains performing simple wedding services for patients wishing to be married before they die, and families coming to the PCU for the ceremonies. Birthdays are often special occasions. In one unit for example, ward staff organise with the kitchen staff to supply a birthday cake for patients and have some type of celebration in the ward. Sometimes arrangements are made for the families to have special birthday celebrations, and family members bring food and decorations for the event with staff making special efforts to accommodate their needs.

Patients are encouraged to attend family functions outside the wards. Staff will make special efforts to support the patients to attend these, rearranging schedules to get patients ready at specific times, altering their medication regimens to optimise their

physical condition for an event, arranging hair appointments and assisting with make-up. If the patients are not well enough to attend an outside family function, sometimes the function comes to the unit.

One enterprising chaplain arranged for a patient's grand-daughter to visit the unit following her wedding ceremony and prior to the reception. After much anticipation, the bride arrived dressed in a brocade and satin wedding gown, accompanied by her new husband and their attendants. The patient, Mavis, had hoped to attend the wedding but felt that she was not well enough and did not wish to cause any disruption to the service should she be unwell at the church. She decided to stay within the care of the unit. The hospital chaplain was a member of the congregation at Mavis' church, and arranged this visit. This caused a degree of excitement for both staff and the other patients. Staff assisted Mavis to prepare for the visit, helping her dress neatly for the occasion, although still in her nightie, but with her hair done and wearing a little lipstick. Further, the staff had planned Mavis' care around the time scheduled for the visit. Medications had been given to ensure maximum comfort and minimal sedation for the estimated time of the event. Mavis was delighted. So too was the bride. She was happy and laughing when I saw her getting into the lift as she and the wedding party left the hospital.

Susie, a student nurse on placement in the unit at the time, was amazed that this visitation was "allowed" to happen in the ward, especially with such enthusiastic encouragement from the staff. While this was an unusual event and caused considerable disruption in terms of work schedules, it appeared to be well accepted and considered by the staff to be highly appropriate. There was an understanding that this was an important life event for the patient, and perhaps for the grand-daughter also, and that facilitating this visit was a natural thing to do in this environment. Susie's reaction of surprise contrasted the matter-of-fact acceptance of the staff in the unit. I reflected that an event such as this seemed to echo the notion of "living until you die", the staff thinking creatively to facilitate the patient's living. This notion comes from the foundations of modern palliative care thinking, given in the following quote from Dame Cicely Saunders (1975).

You matter because you are you. You matter to the last moment of your life and we will do all we can to help you die peacefully, but also to live until you die.

In the main, family members themselves appear to quickly embrace the hospitality afforded them, making themselves at home in the units. In each of the research sites part of the patient admission procedure appears to include family orientation. Staff members greet family members enthusiastically, orienting them to the layout of the ward, ensuring they are shown where to make themselves a cup of tea or coffee, and where other amenities are located.

In all units except Waratah Palliative Care Ward, membership of family included pets. Throughout my fieldwork I observed several patients enjoying visits from their pet dogs. Staff members not only permit this practice, they actively encourage it. In one unit staff bring their own pets to share with the patients.

The inclusion of family, however interpreted, appears to be an important factor in encouraging patients to participate in life activities, the notion of "living until you die". In each of the palliative care units the hospitality extended to family members, while the norm to those involved in the process, seemed to exceed expectations to people such as student nurse Susie.

Staff

Staff within each of the units spoke of the entity "The Team" in reference to the people working within the palliative care unit. Teams are commonly referred to in palliative care literature (for example see Maddocks, 1993; Saunders, 1990; Twycross, 1999; Zollo, 1999). Some palliative care definitions, such as the 1994 version from the AAHPC given below, attempt to explicate the members of the team who may be involved in providing palliative care.

"Hospice and Palliative Care" is defined as a concept of care which provides coordinated medical, nursing and allied services for people who are terminally ill, delivered where possible in the environment of the person's choice, and which provides physical, psychological, emotional and spiritual support for patients and for patients' families and friends. The provision of hospice and palliative care services includes grief and bereavement support for the family and other carers during the life of the patient, and continuing after death. (AAHPC, 1994.)

Palliative care aims to provide holistic care, addressing not only physical issues but also emotional, social and spiritual aspects of caring. Therefore, it is likely that more than one individual or one individual discipline is needed to meet the care needs. Twycross (1999) notes, however, that in practice only doctor/s and nurses may be "the essential core clinical team" (p. 3) and that various other disciplines may or may not be

involved. Indeed, the teams within the units included in the research varied considerably in composition.

Literature about palliative care teams refers to multidisciplinary and interdisciplinary teams. These terms are sometimes used synonymously, although some authors also make important distinctions between the two. Cummings (1998), for example, suggests that the difference between a multidisciplinary and an interdisciplinary team is in the *vehicle of action*. She describes a traditional multidisciplinary team as functioning primarily within their discipline, sharing information with other team members via the vehicle of the medical record. The leader in a multidisciplinary team is the member with the highest rank. In contrast, members of an interdisciplinary team subsume the roles of their individual disciplines for the team. They work interdependently, sharing information and developing care goals together, which will involve different leadership on different occasions, depending on the goal at the time. In this situation, the vehicle of action is the team itself, with the success of the team related to the process of interaction.

I also consider that an interdisciplinary team is different from a multidisciplinary team. I view the latter as simply a group of people from different disciplines. My construction of an interdisciplinary team however, is of a group of people working together with knowledge and appreciation of each other's areas of expertise as well as areas of weakness. They work together, using contributions from team members to complement each other. The composite skills of this team are applied to achieve the best possible outcomes to meet the holistic needs of each patient and family unit.

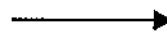
Personal Note: I'm aware that I have a strong conviction about these differences, and a particular interest in how teams function. Therefore I was mindful to reflect on my constructs and examine observations carefully before labelling the teams in the study sites interdisciplinary or multidisciplinary. Construction of the diagrams that follow allowed further reflection about the teams' structures and relationships.

Within the research sites, the multiple disciplines involved in direct care included doctors, nurses, volunteers, chaplains, pastoral care workers, social workers, occupational therapists, pharmacists, physiotherapists, music therapists, art therapists, diversion therapists, and clerical support staff. None of the palliative care teams had representatives from all of these disciplines. Membership varied from Twycross' essential clinical core of doctors and nurses as seen at Waratah Palliative Care Ward, to an extensive mix of disciplines represented in the two palliative care wards at Heath,

and at Kookaburra and Numbat palliative care units. Diagrammatic representations of the teams are shown in Figures 5 to 8. These models not only show the composition of the teams, but also show lines of reporting, and relationships to facilities outside the palliative care service that also differed between the research sites.

Legend for Figures 5 to 8: Models of Teams at the Four Study Sites

Reporting relationships



Health facility in which Palliative Care Service is situated



Palliative Care Unit



Palliative Care Staff



Hospital staff or services that have a significant relationship with the palliative care unit



Overlapping indicates collaboration with other staff or services in caring for palliative care patients and their families.



Abbreviations:

PCW	Palliative Care Ward
PCU	Palliative Care Unit
Chap	Chaplain
Phar	Pharmacist
Sec	Ward Secretary/Ward Clerk
Vol	Volunteer/s
Vol Coord	Volunteer Coordinator
SW	Social Worker
OT	Occupational Therapist
Berv't Coord	Bereavement Coordinator

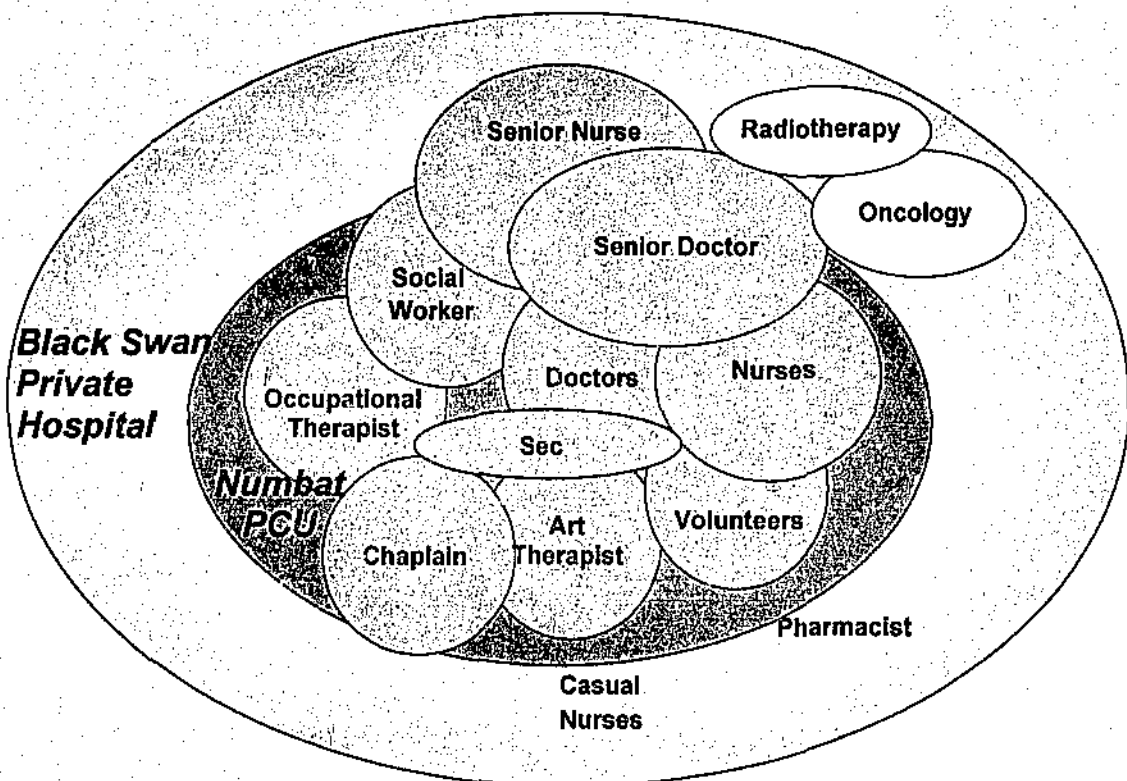


Figure 5. Numbat Palliative Care Unit: an interdisciplinary team model.

The model of Numbat Palliative Care Unit at Black Swan Hospital, depicted in Figure 5, approaches my ideal construct of an interdisciplinary team. The absence of any reporting relationships between specific disciplines and the overlaying of the disciplines represented in this team depicts the notion of communication processes being inclusive rather than hierarchical. The roles of the Pharmacist and Casual Nurses in this model, although working from time to time within Numbat, are more appropriately assigned to a model of multidisciplinary teamwork within Black Swan Hospital. These staff work within the entire hospital and do not often have a palliative care focus. Talking with staff who worked across the hospital afforded some insight into the differences found in the palliative care unit.

Early in the fieldwork I was chatting with one of the casual nurses who was working her second shift in the unit. I was interested in hearing her perceptions of any differences between working in Numbat and other wards. Her response was not as I had expected.

Fieldnote: 5 March 2001

Anna worked here yesterday for the first time and then again today. I asked her what comments she could make about the difference between here and other wards. She said there's a different mind-set. And then she went on to talk about prioritising care. For instance, pressure care had far more of a priority here, it's far more needed than for people in the orthopaedic ward.

These comments from Anna regarding her perception of the differences in the ward were interesting. When she started talking about "a different mind-set" I expected to hear something about the philosophy of care between different paradigms, or about the number of people dying at any one time. I thought she might be referring to the family members who were upset and needed comforting, or even perhaps the staff's approach to care and talking with patients about how they were coping with their impending death. Anna's comments about the aspect of pressure care that was required for palliative care patients seemed to me to be trivialising the attention to comfort that these patients required. However, Anna was not alone in expressing such a comparison. Later in the study I encountered a similar response from another casual nurse at another research site.

Fieldnote: 3 October 2001

I talked to a couple of the nurses who were at the desk and asking me about what I was doing. I questioned them about what they thought palliative care was. They had some ideas. The enrolled nurse who was from the pool [of casual staff] and often works in the ward said that it was about pressure care and pain control, and lots of drugs. "They give them lots of drugs and bomb them out." The other nurse, Julia, has recently graduated. She made the comment that she had been working in the ward for about a week and thought she was doing OK. Then yesterday she went to Gill's lecture about palliative care and she realised that she hadn't known at all what it was about.

Gill is the Clinical Nurse Consultant for palliative care at Waratah Hospital. Although I did not attend her lecture, I understood that it was about the basic approach to palliative care, providing good symptom control, holistic care for patients, and providing support for their families. There was not the opportunity to question Julia further about her impressions, as she was required to attend to her duties. However, I reflected that the response from the enrolled nurse was similar to Anna's, and focussed on the physical aspects of care that perhaps are the most obvious to staff who are sent to work on the palliative care wards and are only there intermittently. I reflected that perhaps only a casual acquaintance with palliative care practice may not convey the full

intent of care, and this may have also been Julia's perception before attending the lecture.

Palliative care nurses, however, were able to express that palliative care was about more than providing the physical care, although sometimes busy ward routines interfered with this. Ellen's comments illustrate this idea.

Fieldnote: 18 March 2001

Sunday, nearly 3pm. Very quiet. A couple of deaths since I was here on Friday, a lady and a gent. So there are a couple of empty beds still, although they probably won't stay empty for long. When I was leaving on Friday, Ellen said, "Oh yeah, come in at the weekend, that's when we really do palliative care." I asked her about that today and she said what she meant by that was without x-rays and procedures and things going on, there's time to actually spend with the patients. You're not rushing around getting them ready to go off somewhere. And to be with them, and do good palliative care.

Palliative care practice for Ellen was to *be with* patients, and even in a palliative care unit it was not always possible to do this, or to do it well. It may have been this notion that Julia gained awareness of from Gill's lecture, and that was absent from Anna and the enrolled casual nurse's focus on physical care. Indeed, if busy ward routines can interfere with "being with" patients, it may not always be present to observe in a palliative care unit.

It was often from interacting with people like Anna, a staff member at the hospital but an outsider to the unit, that I gained most insight into the culture of the palliative care units. However, not only did people from the hospital come to the palliative care unit at Black Swan, Numbat staff were also actively reaching out to establish links with other departments at Black Swan.

Returning to the model of Numbat depicted in Figure 5, relationships with Radiology and Oncology services from within the hospital are shown. These links are in a fledgling state, and a shared approach to care planning is being encouraged. Through these collaborations, there are attempts being made to encourage interdependent care decisions, in line with the interdisciplinary approach. The medical director of Numbat, Sam, talked about some new projects. He is encouraging the idea of "one-stop cancer shopping" where a patient, once linked to the Black Swan cancer service, has the whole range of care available to him or her.

Fieldnote: 7 June 2002

From the informal interview with Sam, sort of a member check, he was talking about some of the new programs that are happening. ... The idea is to link haematology, oncology, and palliative care. People being seen have access to one-stop cancer shopping, including the chaplain, occupational therapist, social worker, pharmacist, dietician. ... Also, complementary therapies, medical hypnosis for pain. Sam told me that the oncologist told the complementary therapist that she was welcome to talk to the oncology patients about her therapies.

This comment about the oncologist welcoming the complementary therapist was significant. Sam and I shared the belief that traditionally, oncologists are very medically focussed and disapproving of complementary therapies, viewing them as interfering with their patient treatment. Sam was making the point that, in developing the program for a non-stop cancer shop, some of the traditional barriers were being eroded. The model that Sam was encouraging for the new venture mirrored that of the palliative care unit, an interdisciplinary team model.

In contrast to this, in both Honeyeater and Possum Wards at Heath Hospital (Figure 6), lines of communication follow a top-down hierarchy and are largely through the Nurse Unit Manager. Although many disciplines are represented at Heath, the majority function outside the palliative care wards, and bring their expertise to the wards as required. Music Therapists, Pastoral Care Workers, Occupational Therapists, and Physiotherapists among others, share their expertise throughout the hospital. They communicate largely through the Nurse Unit Manager as the primary point of contact for both requesting input and reporting outcomes of their interventions. Among these disciplines there is acceptance that liaison with the Nurse Unit Manager is the appropriate communication channel. Support for the individual staff members occurs within the discipline rather than between the individual and the palliative care team.

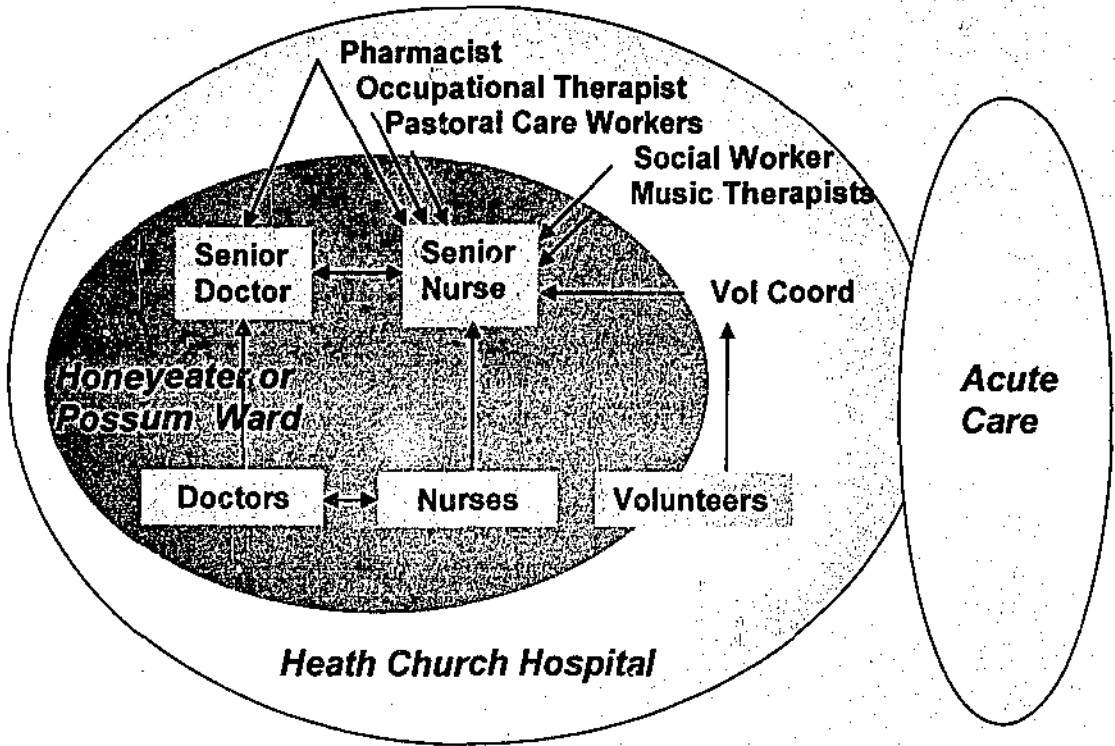


Figure 6. Honeyeater or Possum Ward, Heath Hospital: multidisciplinary team models.

Although reporting lines of communication at Heath Hospital are hierarchical, staff members express a strong sense of Team. *The Team*, however, comprises members of the same discipline. Chris, a social worker at Heath Hospital, gave the following response to a question from me about staff support.

Chris: I think we [social workers] have, informally, we have a great department. You know we're really, just really fortunate and have been for a few years now. But even though people have come and gone the people that have come have been just replaced people. And it's a very supportive sort of nurturing sort of department. And people have commented. ... But what gets them through is they are coming back to the department... and that's not me, that's everyone, that's real, everyone sort of is just here for each other.

Although in the model of Honeyeater/Possum Wards, depicted in Figure 6, doctors and nurses appear to be the staff present in the palliative care units, most of the care decisions for patients in the ward require input from members representing the multiple disciplines at Heath. Heath Hospital consists of one other ward, as well as home care services, and the allied health staff members have duties in these areas also.

However, a significant proportion of their time is spent in providing care to patients in either or both Honeyeater and Possum. I have, therefore, labelled this model as a multidisciplinary palliative care team.

By comparison, the decision-making team at Waratah Palliative Care Ward (Figure 7) consists primarily of doctors and nurses. Working with the doctors and nurses are one volunteer and a ward clerk. This team exists within a large multidisciplinary hospital, which provides additional expertise from staff of various disciplines. Some of the incumbents in these positions are coming to know more about palliative care. This is the case with the Chaplains, Bereavement Coordinator, and Social Worker supporting Palliative Care Ward. Certainly, when discussing the palliative care team with these individuals, they consider themselves to be part of The Team, although the palliative care staff do not see this in the same light.

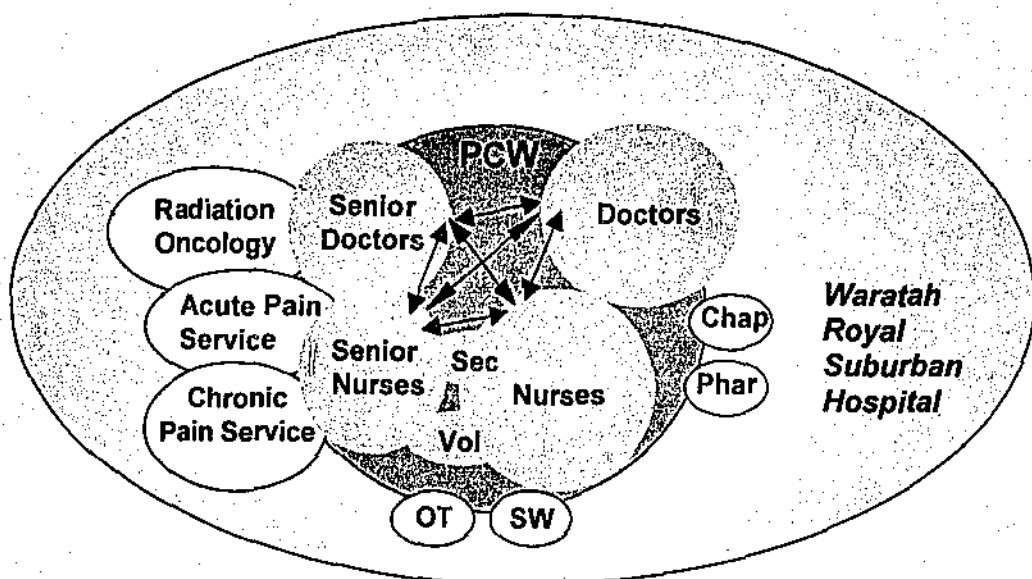


Figure 7. Waratah Palliative Care Ward: essential clinical core of doctors and nurses.

Communication channels between the doctors and nurses of Palliative Care Ward appear to be open and supportive, even though the potential for the hierarchical medical model that traditionally exists within large tertiary institutions is quite high. Strong links have been forged between acute care services, such as the pain teams and Radiation Oncology. Some of the members of these teams have open relationships with Palliative Care Ward team, and work cooperatively in a manner that approximates an

interdisciplinary team. However, working within such a large institution, not everyone shares this attitude and conflicts do occur.

Fieldnote: 11 October 2001

In the ward. A few dramas were going on. One patient's referring doctor had been challenging Janet, the Nurse Unit Manager, regarding palliative management. By this she [the doctor] meant that they [palliative care] weren't treating the patient, not using IVs [intravenous infusions] etc. It seemed that the doctor had handed over the patient, but was still expecting to be involved in the treatment and when she wasn't, was accusing palliative care of not doing anything "active". Richard [the palliative care doctor] said to Janet "you should have put her straight onto me, not taken that". Janet was OK with dealing with it, and thanked Richard for the support. However, I think she felt that she was on the spot and couldn't just say "talk to the doctor", not as the senior nurse.

The implication of this situation was that the referring doctor would have been likely to accept the plan of treatment for the patient if she had been dealing with the palliative care doctor rather than the nurse. Although Richard appeared to work cooperatively with Janet, and his offer of support showed consideration for Janet, he was also acknowledging the hierarchical medical model that operated outside the bounds of Palliative Care Ward.

A different model again was seen at Kookaburra Palliative Care Unit and its relationship to Platypus Hospital. This is shown in Figure 8. Although Kookaburra is administered overall by Platypus, being physically separated from the main hospital seems to provide a greater acceptance of differences in team structures. However, Kookaburra is a developing team and, although there is no obvious hierarchy apparent within the team, there does not appear to be strong professional relationships among team members at this time. This is depicted in the figure by the broken lines linking team members.

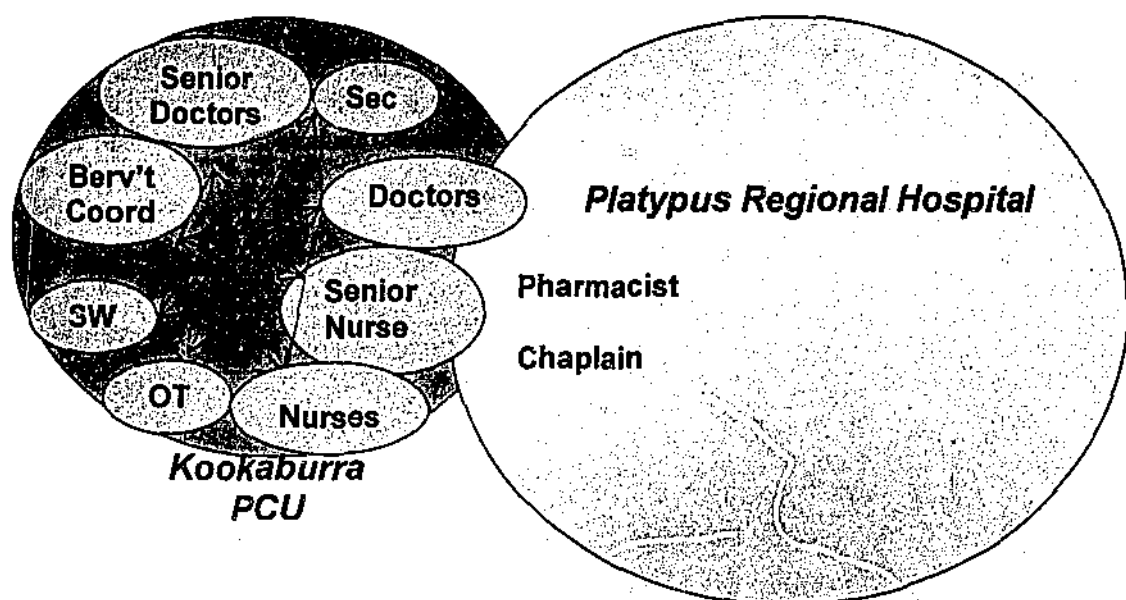


Figure 8. Kookaburra: model of a developing team.

There are strong friendships within the team, some of the staff socialising with each other outside of the unit. Again, with limited time at this site, only superficial observations could be made. The following observations were made in Kookaburra one afternoon, having attended a hospital fete at Platypus in the morning.

Fieldnote: 10 November 2001

It seems like the staff know each other quite well. And their families. Later in the day, the kids at the stall [from the fete] came into the unit. The nurses on duty knew them and called them by name. One of the nurses going off duty said to one of the teenagers that she'd see her tomorrow at church. It was a very comfortable atmosphere. The girl's mother was also going off duty. They were all interested to know how the stall had gone.

A further notable difference between the teams is in the use of volunteers. The newly established team at Kookaburra are yet to undertake any volunteer training, the manager explaining that this was the one area that was not funded in the initial set-up application. He does, however, hope that a Volunteer Coordinator position will be funded in the future. Similarly at Waratah Palliative Care Ward no formal palliative care volunteer program exists, although there is a program for volunteers within the general hospital. One volunteer assists in Palliative Care Ward. She was a member of the general volunteer group but did not enjoy the usual activities volunteers were engaged in, such as running stalls and providing information to visitors to the hospital. She was

able to negotiate access to the palliative care area and works most weekday mornings with the nurses in the unit, assisting with activities such as making beds, and general ward tidying. She also on occasion will prepare morning tea for the staff.

In contrast, the volunteer group at Heath Hospital consists of about 70 people, each of whom have gone through a training program and been assessed as suitable to work on the wards. The Volunteer Coordinator explained some of the duties.

Betty: The main jobs that the volunteers do would be feeding the patients, reading, reading maybe a newspaper, getting the newspaper for them or getting a magazine for them or even a library book. The most popular thing that they do is the gentle foot massage – I can't call it massage, it's the gentle handling by having a foot massage and a hand massage and those ladies who like doing it often do a manicure. They are not trained manicurists so we maybe have about three or four. They often do a manicure, put the nail polish on and we've got two beauticians. They will do things, it's surprising how the ladies like it, you know a bit of relaxing on the face and things like that. Those would be the main things that they do. Most of it is just being there you know because we have found patients will often talk to a volunteer or say things to a volunteer when they won't say it to a nurse or a doctor because they are not an official. You know, they are not going to come in with medications and injections and all the rest of it. And they often have a bit of a whinge to a volunteer that they won't you know if the doctor comes they say, "No I'm fine." You know, that sort of thing. We do stress time and time again both in the course and throughout the year anything that is said is of course strictly confidential.

At Numbat too, volunteers are prevalent. On each morning shift there are two volunteers rostered on duty. Their main tasks are to take the patients' meal orders, and then at meal times to distribute the meals to the patients and to assist with feeding. In between, they make beds, and sit with patients, often those who are unconscious and close to death. At Numbat more than at Heath, the volunteers work with and alongside the nurses during the course of the day.

The different models of palliative care teams encountered in the different sites further serves to indicate the difficulty in describing and understanding palliative care. In each of the sites a multidisciplinary group of people is engaged in caring for the patient and family units. Some teams approximate the concept of an interdisciplinary team. In some teams health professionals outside palliative care are included in team decisions regarding treatment plans, and relationships with these staff in some instances may be developing along the lines of an interdisciplinary approach to care.

Staff Relationships

My observations of the various relationships between participants in the research are discussed throughout this thesis. For example, relationships between staff of the palliative care units and health care professionals in the parent facilities were mentioned in Chapter 5, and further relationships will be evident in the following chapter relating to the practice of palliative care. In this section I discuss relationships on a more micro-level, relationships between members of the palliative care teams. In the next section I discuss relationships between staff and patients.

The Senior Nurse

Formal and informal relationships in the various units differ. Not surprisingly, the major component of the palliative care staff is comprised of nurses. However, nursing structures and conditions vary from state to state. Some of the differences noted can be attributed to the formal structure, others are more likely associated with individual personalities. The senior nurse in the ward seems to have significant influence on the climate of the setting.

In the Victorian and NSW services of my study, the Nurse Unit Manager is the senior nurse on the ward. In NSW the Clinical Nurse Consultant position is at an equivalent level, however, the incumbent appears to have greater control than the Nurse Unit Manager, having significant influence within the ward, throughout the hospital, and to some extent, throughout the health care region.

In WA, the most senior nurse of the palliative care unit is the Clinical Nurse Manager. This position appears to be more senior than the Nurse Unit Managers in the other states, with the Clinical Nurse Manager having considerable responsibilities within the hospital's nurse management team. During my fieldwork the Clinical Nurse Manager changed, and I noted some differences in management style between the two. One of the major differences has been in the ratio of clinical to management input. The new Clinical Nurse Manager seems to prefer greater input into the clinical component of the role.

Personal Journal: 10 December 2001.

It's early days for Tania in her new role. It's interesting to see how she's approaching it. I suspect she's getting involved in the patients' care because that's her comfort zone. I can really relate to that – felt the same when I was in a clinical/management position and not too sure of the management role. I wonder how long before she'll have to give that up and get into the management stuff. Or was it Sally's preference to do

more management? Time will tell. But the ward dynamic has changed. Inevitable really.

The change of Clinical Nurse Manager at Numbat added to the interpretations I was making of the impact that the senior nurses have in each of the sites. From my observations it appeared that the less involved in the clinical role, the less the power rested with the senior nurses. Although it could be assumed that a strong management role would afford significant influence over the working conditions of subordinates, paradoxically, it was apparent that it was *clinical* control that influenced the power relationships with more junior nurses. The most striking example of this occurred at Heath, where all reporting relationships regarding patient care were centred in the Nurse Unit Managers of Possum and Honeyeater, although one Nurse Unit Manager in particular was more involved in clinical decision-making than the other.

Senior nurses who assumed clinical responsibilities were likely to confer more often with the medical staff and less likely to delegate responsibilities for patient care to the other nurses. Medical staff in turn sought out the Nurse Unit Manager to convey treatment decisions. Whether medical staff encouraged this practice and perceived that it was appropriate to confer with the senior nurse, or whether they followed the example of the senior nurse by not involving other nurses in decision-making was not clear. However, in areas where the senior nurse maintained less clinical control, I observed that the medical staff members were more likely to seek out the nurse caring for the patient at the time, and confer with him or her directly about ongoing patient management.

The power relationships existing within the units are, to some extent, represented by the reporting relationships sketched in Figures 5 to 8 showing the different team structures. Informal power relationships also exist. Within the interdisciplinary team, one of the allied health workers shared her experiences with me. She expressed some frustration that the nurses could be particularly obstructive in assisting allied health staff to access patients in the ward. She perceived that the nurses as a group, excluding the senior nurse, held the informal power for the unit.

Discussing the issues of power with the nursing staff in the same unit, however, revealed different perceptions. Nurses felt that the doctors on the unit held the power, and they were often frustrated that they needed to wait for the doctors' orders to carry out care. They implied that the medical staff did not acknowledge their knowledge and

skills. Talking with the senior nurse about this perception, it was suggested that the doctors were more than happy to defer to the experienced nursing staff, but they perceived the nurses were not prepared to accept that responsibility.

Despite the various perceptions of power within the teams, staff members generally relate well to each other and interact in a casual way. Most often first names are used, regardless of discipline or seniority. At Waratah, I observed some staff using formal addresses when speaking of or to senior medical staff. This was more prevalent among junior members of each of the professions and junior medical officers in particular. As well as being a traditional hierarchical approach, this observation may be a reflection of the length of time people have known each other and have been involved in health care settings generally.

Staff Support

Staff support is discussed in much of the palliative care literature, acknowledging the potential for stress associated with working with dying patients (for example, Twycross, 1999; Wilkes, 1999; Woodruff, 1993). It is also noted that staff stress in palliative care is likely to be less than in other areas because of early recognition and intervention, having appropriate staff support mechanisms in place (Vachon, 1997; Woodruff, 1999). It could be assumed that appropriate mechanisms would be regular formal counselling and use of external employee assistance programs. However, staff with whom I spoke stated that they did not use the formal mechanisms, and indicated a preference for informal networks of support, such as talking to colleagues or family, rather than the formal channels offered by the management.

On occasions, group counselling or debriefing sessions are organised by senior members of the units. On Possum ward for instance, after one extremely long-term (over 12 months) patient died, the Nurse Unit Manager arranged a "debriefing meeting" to allow opportunities for staff to review the difficulties of managing this patient's physical condition, as well as the perceived stress of supporting his family. I learned about a similar meeting that had been held at Waratah Palliative Care Ward prior to my arrival, at which the chaplain facilitated opportunities for each of the staff members to reflect on the emotional difficulties of caring for a particular patient. These formalised sessions are not routinely organised, but will be arranged if staff members perceive that a specific incident or patient or family situation precipitates the need.

On a regular basis, staff support occurs within the interactions of staff with each other. The shift handovers are a principal source of communication between staff, and I observed that these were often times of informal sharing and support.

Communication and Handovers

Measures to convey information about patients and provide continuity of care are necessary in any health setting that involves more than a single practitioner. This communication can be provided through written records and verbal accounts. Inpatient settings require that information is provided in a timely and efficient manner as patients in these settings require ongoing care that cannot be paused waiting for staff to update about their conditions. Verbal handovers are commonly used for instant communication of this information, and a varying amount of overlap time between the shifts allows for this handover of care.

Each nursing shift in the palliative care units of the study starts with a handover. In three of the four settings this is done face-to-face, and in the fourth, using tape recorded messages. Tape recorded handovers were a contentious issue among the nurses with whom I spoke. Those who participate in face-to-face handovers believe that tape recorded messages are inadequate, do not allow for clarification, and are likely to be out of date if the recording has been made some time before the next shift comes on duty. Those who advocate for taped handovers voice their appreciation that a lot of idle "chit-chat" is eliminated, and these nurses are happy to confine the exchange to receiving patient information necessary to ensure continuity of patient care, and to get on with their duties.

Not only nurses participate in daily ward handovers. Each morning in the units, after the majority of nurses have started their shifts, one of the nurses provides a handover to the doctors. At both Waratah Palliative Care Ward and Possum Ward at Heath I witnessed that, on occasion, the pharmacist was included in this routine. At Numbat the social worker, occupational therapist, chaplains and the ward secretary as well as the doctors often attend the morning handover.

Apart from updating regarding patient care, handover is also a time when interaction between staff can occur. Often there are inquiries regarding the details of a recent death, what happened, what treatment was given, whether the family was there, and how the family members were coping. There is genuine interest for the welfare of the patient and family during these times. There seems to be a need to provide a type of "closure" for staff who have known and cared for that family unit.

Handovers can serve a further need however. Napthine (1993/94) comments that handovers are actually a method of providing "professional socialisation" (p. 30). These times can be used for sharing feelings of frustration, personality issues with patients, families, or even other staff. Conversations can also be on a more personal level about social aspects not related to the workplace at all. More recently, Hopkinson (2002) found that nurses caring for dying people in the acute hospital held similar views about the purpose of handovers; handovers offered support for "emotional labour as well as physical labour" (p. 173).

Discussion at handovers did sometimes digress to talking about social matters, and the senior nurses present seemed to condone if not participate in these conversations. In one of the units the "professional socialisation" went even further. Arriving just prior to the afternoon handover, I settled into a chair with pen poised, ready to hear about the morning's activities. There was a quick run down of the patients and then some papers with some type of grid printed on them were passed around, and I was asked if I wanted to play Bingo.

Fieldnote: 9 November 2001

Handover started again a bit late. They said they were going to have bingo today. I didn't quite understand. However, they quickly went through the patients, and then got out a plastic bingo cage, and handed out sheets to the nurses there. One of the day staff wasn't able to come in, but wanted to be included, so one girl played two cards. They offered me a go, however, I declined. I wasn't sure what was happening. However, they played a game of bingo! The winner was given the choice of several "prizes" that were there - small things brought in by the staff who participate in the game. Things like a body lotion/soap pack, a bottle of wine, packet of stationery etc. They say it's their "de-stressing" activity.

Bingo did not occur at every handover, and not every day. However, it is apparently a regular activity at nurses' handovers, and on this day the staff felt that they had been having a stressful time, so it was time for Bingo. The manager of the unit supports the practice; in fact I assumed that had he been around, he would have also participated. Playing Bingo is indicative of the generally relaxed attitudes of staff at Kookaburra, especially in comparison to those at Waratah Palliative Care Ward, which operates within the same Sydney health care region.

Sources of Stress

Twycross (1999) lists repeated exposure to death and absorption of patient and family anger and grief as being two sources of stress experienced by palliative care

staff. The accounts that follow are my observations of situations that I perceived as stressful to staff. Many other factors are likely to be sources of stress in the palliative care units. These accounts are only examples, and relate to observations about patients' deaths and conflicts with patients and family members.

Deaths.

In general, staff members seek to know details about patients' deaths and families' coping even if they have not cared for the patient for several days. Returning from time off duty, staff members want to know what happened. At one of the palliative care units during my period of fieldwork, a simple procedure was implemented to address some of this need. At the request of several staff members, the ward clerk collated a list of names of patients who had died and those who had been discharged from the unit (and where they had gone), along with dates of the death or discharge, and posted it in the staff office. The list was updated on a regular basis. Prior to this occurring staff returning from time off, when inquiring about people who had died in their absence, would rely on people's memories or were required to search through various files to find when patients had died.

Although no details were supplied regarding the circumstances of the death, at least staff members had some sense of outcome about particular patients they had known, and could seek to find out further details if they chose to. I also found this list helpful and it was one of the first things I checked each day when coming onto the ward. I would also seek out staff who had cared for a particular patient to inquire about specific details of the patient's death and reactions of their families.

Learning about the death of a patient, even when death is expected, can be difficult for staff, and at times was for me, as the following journal reflection suggests.

Journal Note: 16 March 2001

I arrived later today, about lunchtime. One of the first things I noticed was a couple of empty beds on the ward. Two deaths overnight. One man I didn't know very well. But the other, Mr T, I did. I was sad about that. It was a bit of a shock I suppose. I kind of felt the need to talk about it. ... The patient was somebody I'd known and he'd come to know me. ... And I went to Quentin, the chaplain, because I guess I was looking for a bit of support. This man had died and I knew him and I knew that Quentin had known him quite well, and I wanted to just talk about the man, share thoughts about him. ... And Quentin had only been told ten minutes earlier himself, half way through the day. He was a bit upset about that. There doesn't seem to be a process in place for passing on this information. So Quentin and I didn't talk about the chap. We were both dealing with the shock I suppose, and not knowing who to talk to

because it seemed like old news in the ward. Now I'm making judgements, thinking that they need some process to deal with these feelings, based really on how I'm feeling but also on how I think Quentin is feeling about it. So that's a personal comment, a personal reflection. I don't know how the others [the staff] cope with these things. ... My perceptions are that you need to debrief, you need to understand what's happened to people, and how it's happened too. Just be able to spend a minute or two reflecting about someone.

Both Quentin and I had missed handover this day. Perhaps if we had been part of that there would have been some opportunity to talk about the circumstances of Mr T's death, and reflect about his life, as we had known it.

Personal Note: I didn't really expect that the ward staff would make a point of updating me about particular patients deaths, but I had expected that they would be aware that Quentin would like to know sooner rather than later, knowing how involved he'd been with Mr T.

Patient and Family Conflicts

Not all patients or family members, even when dying or supporting someone who is dying, engender positive feelings in staff members. Of course there are individual personality traits that can impact on this, and interpersonal carer-patient relationships are varied. There are, however, significant negative relationships that can cause great concern for the staff involved, who appear to experience conflict between wanting to show compassion and care, and dealing appropriately with abusive situations.

Conflicts and caring.

During the course of the fieldwork, several patients became abusive towards the staff, and on two occasions, in separate facilities, even punched members of the female nursing staff. Physiological causes may underlie some of the abusive behaviour seen in palliative care patients, altering people's cognition and behaviour. Possible causes include presence of brain tumours (primary or metastatic), drug psychoses, dehydration leading to confusion, hypercalcaemia, and progression of general dementia (Woodruff, 1999). Confusion is likely to be common in palliative care wards, however, abusive incidents cause consternation for many of the staff.

One man who caused great concern became quite disoriented and physically aggressive over a short period of time. Significant investigations were carried out to ascertain the cause of this rapid change in mental condition, including review by the psychiatric team, who could not pinpoint the problem. He required around the clock

“special” nursing, which meant a nurse was assigned to sit with him at all times. The rationale behind this management was to ensure that he did no harm to himself by trying to get out of bed, and also that someone could supervise that he did not pull out his intravenous tube or his urinary catheter. I assumed that it was believed the nurse specialising would be able to call for assistance in time to also prevent the patient from doing any harm to her.

This became an extremely expensive exercise as the situation went on for several days, requiring round the clock one-to-one nursing. Until the cause of his change in condition could be ascertained, the medical staff would not prescribe any drugs to sedate him, in fact they suspected that his condition may have been an adverse drug reaction and so were gradually withdrawing medications to see if they could reverse his condition. Not only was his care physically difficult, it was emotionally challenging for some of the staff who had known the patient prior to this episode and who felt that nothing was being done to help this man.

Fieldnote: Sat Nov 10

One of the nurses, an enrolled nurse, Elly, was upset about the man with the dementia. Yesterday he had been sent over to Waratah for a CT brain scan to see what might be happening. He had to be accompanied by a nurse from the unit, and at handover time another nurse went over in a taxi to relieve the day shift one. The results were not in, but it appeared there was nothing found, no stroke or lesion. The thinking was that the problem may have been a drug reaction and they were reducing some of the chap's present medication. Elly was really concerned because she had been looking after this man for several days now, and commented that she saw him progressively deteriorating. She was concerned that “they” (the doctors) didn't know what was going on, and were making things worse. A Registered Nurse tried to reason with her that they (the doctors) were doing their best to find out the cause of his problems. However, she was quite scathing about the medical management.

Perhaps Elly was upset because she had known the patient before his aggression occurred. The staff viewed these rapid changes as unusual, and were all concerned. There was an obvious tension between wanting to help this man, and the physical danger associated with nursing him. Although staff such as Elly held positive views of this man, others directly experienced his outbursts were less tolerant. There were therefore tensions also between staff.

In other situations I observed, aggression or abusive behaviour did not occur so acutely. Often the abusive behaviour was considered to be part of the patient's personality, and staff members seemed to relate poorly to these patients. Sometimes

there were conflicts about who was to look after these patients for the shift. I noted these staff behaviours to some degree in each of the units.

The dilemmas that these situations pose for staff are multi-faceted. In small units, where there may only be two or three staff on a shift, the workload of caring for an abusive, demented, or aggressive patient is significantly increased. Often it requires that an additional staff member is assigned to care for the patient, and an appropriate person may not be available. It is also a financial burden for the unit, and can very quickly run into thousands of dollars. Ethical questions of how to treat the person arise, how to assess if they are suffering, if they are in pain. This becomes extremely difficult when assessment is hampered by irrational behaviour.

I observed that the staff who cared for these patients grew weary and less enthusiastic about their work, especially if they were continually assigned to these patients. Again in small units it was difficult to rotate the staff to avoid this. Male nurses sometimes seemed the appropriate choice for patients who were aggressive towards females. It was exhausting for the male nurses also. Perhaps the greatest concern to staff in each of these situations is the tension between wanting to provide supportive care to the patient while experiencing the personal burden of providing that care.

The outcomes of these various situations were varied. In one instance the patient was found to have an unusual analgaesic drug reaction and his mental condition improved once the drug was flushed from his system and an alternative used for his pain control. Another man was diagnosed with a psychiatric condition, and appropriate medication was prescribed with effect. Another man's reactions were in response to extremes of pain that he experienced spasmodically. Despite many attempts to treat this pain, these spasms continued until he died. The outbursts of aggression and violence became less problematic for staff as he became weaker due to his general deterioration.

Complaints and caring.

I observed some of the staff responding to complaints about incidents at the hospitals. I do not believe that the reactions of staff to these events were any different in the palliative care setting than they would be in other health care settings. Perhaps, because of the emotional nature of experiencing the death of a loved one, some people were more likely to perceive faults in the care and to threaten action against the hospital. I witnessed only one instance where a bereaved relative rang a staff member with a complaint. The staff member merely listened to the person and clarified her questions about the death, which appeared to resolve the issue.

Complaints, even the threat of a formal complaint, caused concern in the units. I believe that staff generally felt the complaints were unwarranted, and did not consider that they had been negligent in their practice. Complaints, however, are likely to be both personally and professionally threatening. In palliative care in particular, staff appear to take personal pride in their attention to quality care, to inclusion of the family in the care, and indeed staff may have high personal expectations of meeting the needs and alleviating suffering of patients and families in their care. A complaint about that care, therefore, can be personally threatening even without considering the professional threat of possible litigation. Again, the tension between wanting to provide appropriate care and support to a family who is losing or has lost a family member and experiencing anger or lack of appreciation from the family places a burden on the staff.

Not all relationships between family members are ideal. Fisher (2003) has identified abuse in palliative care families as being an "invisible dimension". She suggests that the notion of the functional and loving family that is portrayed in palliative care literature is a highly sanitised view of family life that disallows the reality of some of the abusive relationships that occur. One dilemma for palliative care professionals is coping with the gap that exists between the reality and philosophy of palliative care. Certainly, the philosophy of caring for the patient and family as the unit of care assumes a cohesive unit. The product of dysfunctional families can make care-giving difficult, especially when staff seek to involve family members more in care planning as the patients become less capable of making decisions for themselves. Families may in fact be absent, disinterested, or have divergent views from the patient or indeed other members of the family.

These tensions impact on the burden of health professionals in providing good palliative care. Although some tensions were present during my observation periods, I did not focus on these situations in particular and have little specific data to contribute to this work. Positive relationships of staff with patients were more readily found, and some are reported in the following section.

Staff-Patient Relationships

Relationships between the professional carers (the staff) and the patients and families within the study sites were of particular interest to me because instinctively I feel it is elements of these relationships that identifies palliative care from other health care relationships. Nurse-patient/family relationships have been described by Aranda and Kelso (1997), Byrne and McMurray (1997), and Trygstad (1986), among others.

One of the concepts arising from this literature is that of "professional friendship", described as a "relationship that goes beyond what is generally thought of as professional" while maintaining professional goals of care and boundaries of place and time of the relationship (Aranda and Kelso, p.121). The examples of professional friendships given in this literature describe relationships that include emotional interactions between patients/families and caregivers. During my fieldwork there were some examples of relationships that exceeded patients' expectations, and were perhaps examples of professional friendships.

Most interactions I observed were warm and friendly. First names were commonly used, both for staff and patients and their family members. One patient, Mary, commented on this. Although Mary felt that such informality was generally inappropriate, within the unit she felt that this was a symbol of inclusion, of being part of a family.

Mary: The doctors ... and ... [names]. Both delightful people ... When I first came to Australia one of the things I objected to was everybody called you by your Christian name. Now being English, it was sort of - you're coming too close, no? But here it was wonderful. It made you feel that you were all part of this huge family that was striving together and their one aim was to make you well. And I honestly felt that, you know, this reaction was, as I said before, it had sort of made me back away. But it had the opposite effect.

Loving Care

Several days prior to this interview with Mary, I had asked her and some others on the ward what palliative care meant from their perspectives. Mary's response at the time was "Loving care. They anticipate your needs". Coincidentally, the next person I spoke with on that day also used the phrase: "Palliative care is about loving care." Harry's response was from quite a different perspective.

Harry was an older man, about 80. His wife was dying at this time. He had been sitting with her since early in the morning that day, as had some of his children, taking it in turns to be with him. This was the third day of the family's vigil, the third day that his wife had been unconscious. Harry had visited often before that, when his wife had been more alert and together they were able to observe and participate in the activities of the ward. However, over these three days Harry sat and watched and waited as staff attended to his wife. His response about loving care was in reference to his observations over these last few days.

Four patients shared this room. (Mary was not one of them.) Harry talked about the other women and their families and the things that went on with them, as well as the way in which the staff attended his wife. His observation was that the care given to them all was "loving care". A nurse came by to check briefly on his wife, and smiled fleetingly at Harry. As she left the bedside, he turned to me and said "She's OK", as if to emphasise the care he felt was being given.

The patient, Mary, described herself as a very private person and requested to occupy a single room. I talked with her on several occasions over two or three weeks. She often referred to her body as having let her down, betrayed her. Her appreciation of the care given was often about helping her cope with that discomfort, both physically and emotionally. She talked about the comfort she found in the palliative care unit that she had not been able to achieve at home.

Mary: I had special bedding, which was amazing. I had these sheepskin rugs for the first time. Because I had been using a ring cushion because of this pressure sore, and they told me that was very dangerous. So they introduced me to sheepskin rugs which I found I was so comfortable. ... I'm very comfortable in the bed, felt more comfortable than I ever was in my bed at home and those little things you know, like that. That they thought of that. I would have been totally unaware of but they are always a jump ahead. They know exactly what will

Judi: You were saying that the other day that people anticipate your needs before you realise you have them.

Mary: Yes, they do. Exactly and another wonderful thing are the bed baths because one of the things that terrified me was having a shower. In fact I used not to have showers. I just used to wash myself because going in the shower I'd get terribly claustrophobic and very, very panicky and also the spray from the shower used to hurt me, hurt my skin and I couldn't understand how I was going to get over this. They introduced me to a hot towel bed bath, which I think are the most wonderful things in the world ... They use aromatherapy and then they put ... they massage you very, very gently with the aromatherapy ... made you think you weren't in a hospital, you were in a very expensive rest home or hotel or

Judi: Health spa or something?

Mary: Exactly, yes. Amazing. ... So it wasn't just, they are not just things to make you feel better physically, they are things to make you feel good about yourself. That you didn't stink any more. That you didn't put people off because you weren't clean because that used to ... So all

the things that had beset me at home and I hadn't had any one to talk about. I mean I had my family but I didn't want to worry them with my dirty little things when they were worrying about bigger things and as I said, they anticipated them. So I didn't even have to say to them, look this is worrying me. They will say would you like to do this? Would you like to do that? And they made me feel like I wasn't a nuisance. Because you do get to feel you're a bloody nuisance when you've been ill for months no matter how much you and the family love each other. No matter how good they are. No matter how smiling they are all the time. Only too willing to help you. You do feel I'm being a nuisance but I've never felt that here and whenever I've said to somebody, this is so wonderful, thank you so much for doing this. They look at me and say, "It's our job. That's what we're here for. This is what we want to do." Making you feel that you're doing wonderfully.

Judi: That's nice.

Mary: It is. It's wonderful that they pass everything over to you. They pass the gratitude over even. And they are always smiling. Everybody's always smiling. People are always laughing. This place is full of laughter.

Harry and Mary were both able to articulate that they experienced loving care from the staff. Mary's comments about staff responding that they are just doing their jobs indicates that for her, this care may well exceed her expectations. Whether these interactions would be considered professional friendships is perhaps debatable, however, staff generally consider that their job is to provide care that in fact more than satisfies the care recipients.

Part of The Job

Principles of palliative care emphasise holistic care of patients and support for families. However, patients and families continue to express surprise at encountering such personal attention to their wellbeing. Mary's reaction to staff anticipating both her physical needs and providing care that would enhance her general feeling of wellbeing, was an expression almost of surprise.

Aranda and Kelso (1997), in discussing the concept of professional friendships, also talk about the reciprocity that may occur in the caregiving relationships. The reciprocity that I witnessed, rather than being in the form of mutual friendship or support of patients for staff, was certainly evident in the satisfaction that staff expressed for the work they were doing.

Several staff members talked about some of the personal outcomes of working in palliative care.

Karen: I'm still as passionate about it [palliative care]. ... And because you learn here every day that you are here in this unit. I never go away from here without feeling that I have learned or been touched in some way by a patient, a relative or a staff member who's, you know, there's a vast experience here.

David: In spite of what people think about dying, you do get satisfaction in your job, you know, give grandma a good send-off, families are very grateful.

For other staff, such as Lionel, a senior palliative care nurse, palliative care provided a career path he thought wasn't available to nurses in other areas.

Lionel: I said look I might be interested [in the job], can you send me some information ... and she did that, and ... said do you want to come over and have a look at it? And I thought well, if nothing else ... I had no intention of taking the job, at that period in time. ... I thought what the hey, you know, let's give it a crack, worked on a two year plan and still here five years later. ... The palliative care thing's been a whole journey. When I'm talking to you about it, from sort of go to where it is now, it just seems bizarre to me where I am today as a result of the circumstances that have happened.

Judi: But, do you think that's a common story amongst palliative care people?

Lionel: No, probably not. The people that I've spoken to about it, a lot of them see it as being a little bit, oh, unusual, I suppose. Because I've never had a real passion or drive for palliative care, you know. There was nothing inside me that kind of drove me to [pause]. I suppose there was, but look it wasn't always there you know. And there was no kind of religious motivation or you know, motivation to do good or anything like that. ... It was more the way that I saw palliative care positions working, and as a nurse wanting to work somewhere that I could see the impact that I was having, that I could develop my own style, my knowledge base, and you know, work as part of really effective, efficient teams. And for me that was either mental health or palliative care. ... I looked into mental health and thought that is definitely not for me, don't want to go there just yet. I still see that as an option for myself down the track. But at this point of time it's not, I'm just very happy where I am.

Judi: So the teams are the common link between mental health and palliative care? ... Or the power of the nurse perhaps?

Lionel: The roles of the nurse within those teams, and the way the teams are structured. I think, not so much the power of the nurse, but I think the, the way nurses are perhaps perceived, utilised within those teams. I don't think they are any different than any other teams necessarily, but I think they probably are just good teams, and the good teams I've had anything to do with are in palliative care services or mental health teams. That seemed to be where it was at. Just the attitude of the staff seemed right. The relationships between doctors and nurses seemed a lot better, the inclusion of allied health within those teams. ... When I first hit upon it, you know. ... I was a bit surprised by it, because like I say my first introduction to it was just Freda [nurse] and her little team, which was just her and a doctor, and I thought well if that's palliative care then that's enough for me because there's something about that I would aspire to, or would love to think that I'd be able to manage or do some day.

Lionel was a lot more articulate than Karen or David about his motivations for choosing to work in palliative care. He also down-played any personal motivation that may have brought him to work in the area, but did acknowledge the attitude of team members to be a factor. Lionel's motivations may be different from Karen's and David's, who expressed that in some way they appreciated the connection with family members. However, all have similarities with the thoughts expressed by long-term palliative care workers in an earlier study (Webster & Kristjanson, 2002a, 2002b).

The observations I made in the ward settings, accompanying doctors on ward rounds, sitting in family meetings, and following nurses around the wards, uncovered many rote patterns of communication with patients and their families. On many occasions the staff would say almost exactly the same things to people, but seemed to convey an impression of speaking spontaneously and personally in each situation. For example, on one particular day I sat in on five family meetings with two of the same staff, a doctor and a social worker. The format of each meeting was the same, and the introduction to the various topics to be discussed was the same, often using the same words and phrases. There was a set format that these staff members were following. Yet it was also obvious that these staff members knew the individual people involved, knew individual aspects of the physical, social, and emotional situations of the families, and responded appropriately and attentively to the issues and questions that were raised.

I have been left reflecting about the meaning of staff and patient/family relationships, with many aspects of these relationships still to be explored. It seems that aspects of professional friendships are present - care that exceeds what is normally regarded as professional, and reciprocity in the form of staff satisfaction. However, it appears that patients and families place a greater significance on the meaning of these

friendships than do staff. There is a perception by many staff that the loving care they express is commonplace, professional, and part of their job. Perhaps there are individual attributes of people working in palliative care that are expressed as loving care, and that individuals select to work in these areas to meet the needs of expressing these attributes. Nonetheless, perceptions of patients and families indicate that, for them, the care they receive is a novel experience, and they are left with an impression of care, or the people providing it, which is special or extraordinary.

Summary

In this chapter I have discussed the people who participated in my research. I have sketched a picture of the patients, family, and staff within the research sites, and acknowledged that many additional people have in some way also informed the research.

Various team models were identified within the research sites, and a variety of relationships within those teams. The models form a continuum from interdisciplinary, to multidisciplinary, to a core caregiver model of doctors and nurses providing palliative care. Relationships within those teams were discussed including the provision of support and possible sources of staff stress. Although not all relationships between staff and patients and families are positive, overall, the perception by patients and families of the care provided is that of receiving "loving care".

Staff involved in palliative care view their care as part of the job; however, this type of care appears to exceed the expectations of the care recipients. In palliative care, it may be that the ordinary is often extraordinary. In the following chapter I will delve further into some of the practices associated with palliative care, and continue to explore this notion.

CHAPTER EIGHT

THE PRACTICE

The previous discussions of the Politics, Places and People of palliative care provide the backdrop for this chapter, "The Practice". In this chapter I discuss my observations of the practice of palliative care. Much of the underlying culture of palliative care, or my interpretations of it, is brought together in articulating the practices within the various units.

Many of the observations I have recorded and discussed no doubt occur within health care settings in general. I have endeavoured, however, to highlight some of the nuances of health care practice that I found peculiar to palliative care services, and to these palliative care services in particular. Some of my observations are best described as "ordinary." However, there are other observations that are most decidedly "extraordinary" and are worthy of closer attention.

Other dichotomies of care, such as the use of technology, attention to psycho-social-spiritual care, and staff practices are disclosed in this chapter. These dichotomies further suggest some of the tensions that I encountered in palliative care practice, and that will be explored in the next and final chapter of this thesis.

Ward Routines, and The Not-so Routine.

General ward routines within the different units are similar. Nurses work three shifts to provide continuous coverage to the ward. These shifts typically start at 7am, 2pm, and 10pm. Senior medical staff visit the wards intermittently, often on specific days at specific times for regular ward rounds, and spend the rest of their time reviewing patients in other wards both within the hospital and at other facilities, as well as conducting clinics both on and offsite of the hospitals. More junior doctors, Residents, work longer hours and are more consistently on the wards than the senior consultants. Resident doctors may start on the wards at about 7.30am and are sometimes there until 9pm. They too will visit other areas of the hospital, but tend not to have duties at other health facilities. They may be rostered "on call" several nights during the week requiring them to stay within the hospital, and extending their responsibilities to provide

medical cover for several wards. Registrars, doctors who are more senior than residents and often training to become consultants, also spend considerable time on the wards, but less than the Residents. Other health care staff, such as Physiotherapists, Pharmacists, and Occupational Therapists, visit the wards mainly during the hours of 8am until about 6pm, and tend not to work at the weekends. These allied health staff often attend the ward in response to a request for a particular service or referral for a particular patient, as well as routinely attending to check on the progress of existing patients or ward requirements for their services.

Aside from the patients, nurses are the people continuously on the ward, and much of the ward routine seems to be structured around their activities. Conversely, it might be said that the nurses structure much of their routine around the needs of the patients. In either case, the routines are reasonably standard.

Medications

The patients' breakfasts and the nurses' morning tea breaks punctuate the morning routine for the nurses. In between these events, they attend to dispensing medications, usually a four hourly routine, and assist with hygiene care, changing bed linen, helping patients to sit out of bed if appropriate, and attending to any other treatments that may be required. In the larger units, nurses are allocated a group of patients to care for during their shift, and they work in teams. For instance, three nurses may be assigned to care for ten patients for the morning.

Medications are given on a regular basis, dispensing these from prescription sheets that have been written by the doctors. Often a four-hourly schedule is used for medication "rounds." These rounds can be quite lengthy, and sometimes require two nurses working together. At one of the units, when dispensing medications from a trolley that is pushed from bed to bed, the nurses don red coloured smocks over their uniforms, with the message in large white letters saying "Medication Round, Do Not Disturb."

The message here is not a subtle one. The activity in which these nurses are engaged is that of dispensing medications to patients. In accordance with hospital policy many medications require two nurses to check and administer. These include Schedule 8 drugs, so-called "Drugs of Addiction," such as opioids that are used for pain relief and commonly required by patients in palliative care units. The nurses, therefore, are quite busy on these medication rounds and do require concentration to ensure accurate administration of the drugs. Within this unit, the message that the drug round is

important, too important to be disturbed for other things, gives primacy to the act of administering drugs.

Interpreting the prominence of the medication round in this setting leads to the notion of emphasising the pharmacological management in palliative care. Undoubtedly symptom control, and in particular pain control, in each of the palliative care units is of great importance. However, such overt display of the drug round at this unit may serve to perpetuate a treatment or *medical* model of care.

Vital Signs and Nothing More Can Be Done

In acute care facilities nursing duties commonly include "taking observations," which most usually refers to measuring vital signs such as temperature, pulse, blood pressure, and respiration count. These observations are routine, regular activities in many care settings, however, in the study palliative care settings this practice is not routine. During or following some procedures, such as blood transfusion or minor surgical procedures, observations might be taken as part of standard policy for the procedure. Observations in palliative care generally seem to be considered an unnecessary burden for both staff and patients. The measurements are likely to be abnormal, particularly as patients near death, interventions are often not possible, or are inappropriate because of patients' conditions, and therefore taking observations is not considered to be part of routine practice.

However, some people have expectations that in an inpatient health care environment regular observations are the norm. For example, I overheard a palliative care nurse orienting an agency nurse to the ward, and paying particular attention to explaining that regular observations were not required, which surprised the agency nurse. Family members and patients may also have expectations that these practices are the norm, but there appeared to be little explanation given to patients and family members that taking observations is not part of routine palliative care practice.

Other tests are also less common in these palliative care settings than in other health care settings. Pathology tests, blood tests, and x-rays, for example, are often considered to be unnecessary for palliative care patients, who are likely to return abnormal results for many of these tests if they are performed. The underlying assumption appears to be that treatment to correct the abnormalities is not possible because the abnormalities are related to the overall disease and its progression.

Some people have difficulty accepting this, although they are aware of the nature of the disease, that it is incurable, and that treatment to halt the progression is not possible. They fail to connect that this means testing becomes a futile exercise. Ruth, a previous laboratory technician in a hospital, was one of these people. Her mother, Molly, was not at all well from the brain metastases associated with her breast cancer. She was unable to walk, and even standing unaided was becoming difficult. Her condition was deteriorating.

Fieldnote: 21 June 2001

I had some long talks yesterday with Molly's daughter, Ruth. She seems to be very uptight, very anxious about her Mum. She's devoted her life, at the moment, to caring for her mother. She's upset about her mother's food intake, and tests not happening. ... She's asking why and what's happening? In the past she was a lab technician of some sort. She talks about not knowing what her mum's liver function tests are, or why she hasn't got a drip, and so on. She expected, and was waiting for these things to happen. ... She says that she needs to be able to go home and tell the other relatives exactly what mum's condition is, and how can she when there's no test results?

Ruth spent a lot of time on the ward with Molly. The ward staff spent a great deal of time talking to her, and supporting her. I was not privy to the conversations that staff had with her, but I did encourage her to raise her concerns with them. I can only assume that she did and that she was given appropriate answers. However, she remained confused about what was going on.

Personal Journal: 21 June 2001

I really feel for Ruth. She's having a hard time. I think that she feels, with her little bit of medical knowledge, she has the responsibility of reporting all the medical facts back to her family. And because they're not doing the tests she doesn't have the medical information to report back. It just doesn't seem enough for her to know that her mum's got a terminal illness and that she is actually doing something just by being there. She seems to have to be seen to be doing something active.

Ruth did not use the word "active" although that seems to be what she believed should be happening. It is not uncommon that active treatment is equated with "doing something" for the patient, and that not having active treatment is seen as doing nothing. Woodruff (1999) refers to the "nothing more can be done" syndrome (p. 35). He suggests that the helplessness of frustrated doctors, who view a terminally ill patient as a professional failure, may be projected onto the patient and family who may well interpret this attitude as "abandonment."

Pat described her sense of abandonment about treatment from a group of health carers that she had come to know and rely on over a period of time.

Pat: I had Doctor J when I was there [at a major hospital], because he was my doctor with the blood. When I was home I used to go up and have a top up of blood up there ... I used to go there every month or so and get a top up. ... Then he'd send me to hospital to have a top-up [blood transfusion] overnight; that was all right. Then I got so bad ... they got me there and gave me more blood. Then they said, "Nothing we can do for you." And that was it. ... Didn't want nothing to do with me.

Judi: Sort of a bit cold turkey?

Pat: It was cold turkey. And half the time I couldn't have cared less anyway. I was pretty sick. I felt terrible. Then, Dr A [a palliative care doctor] was the one that fixed me up. That's what I say anyway you know, that's the way I look at it. 'Cause she got me to eat and everything.

At a recent cancer nursing research conference, a renowned medical professional, an oncologist, said he would tell patients "there was nothing more could be done." The audience, consisting mainly of nurses, some of whom were palliative care nurses, reacted spontaneously in objecting to his statement, and he qualified his meaning that nothing more could be done towards attempting to eliminate the cancer. This attitude was not one of professional failure, as Woodruff suggests. Rather, this doctor was trying to convey that he would express honest opinions to his patients if and when curative treatment was no longer going to make a difference to the progression of their disease. The negativity of the phrase "nothing more can be done" is unfortunate. In Pat's situation, when active treatment was no longer appropriate, she had been introduced to palliative care services and received symptom control that made her feel better. She saw this as a positive thing. Indeed, more was being done. However, Pat saw that her treating doctors had let her down. It is likely that this team had instigated the referral to palliative care, but perhaps they had not communicated openly to Pat about this. Perhaps if the transfer of care had been made more explicit, Pat would have felt more supported throughout the process.

Technology: Innovation, Invasion or Stuck in a Rut?

Physical symptoms commonly experienced by palliative care patients include pain, nausea, and constipation (Bruera, 1998; Maddocks, 1993), and pharmacological treatments for these problems are commonplace. The way that opioids are used in

palliative care differs from use in other areas of health care, mainly due to the severe and prolonged pain many of the patients experience. Doses of these drugs, as well as the variety and routes of administration, are often rarely seen outside palliative care practice (Woodruff, 1996). Drugs are normally given orally, but when this not possible, a common way of administering them is via a sub-cutaneous syringe driver (Maddocks; Twycross, 1999) and these drivers are used in each of the units of the research study.

Other methods of drug administration can be more invasive, such as intrathecal or epidural administration, which requires that the patient undergo a surgical procedure for placement of a catheter into an area around the spinal cord, through which the drugs are delivered (Maddocks, 1993; Woodruff, 1999). This is considered to be an invasive procedure and undertaken mainly when other types of interventions have not successfully alleviated the symptom or have caused undue side effects. During the period of fieldwork, all but Honeyeater and Possum wards at Heath had patients with intrathecal or epidural catheters. The absence of these catheters at Heath may only be an artefact of the short time I spent there, or it may be indicative of an overall attitude to technological interventions.

Heath does not have on-site facilities available for these types of procedures, although theoretically the staff should be technically competent to care for patients with these catheters, and the accompanying equipment. If such a procedure were to be considered, the patient would be taken to another facility for the procedure. The prevailing attitude amongst the staff seemed to dismiss any technology that was even mildly invasive, as well as treatments that may be seen as active. I noted the following response to the news of an impending admission.

Fieldnote: 22 May, 2001

Another patient is apparently coming in with intravenous antibiotics. There seemed to be some concern over that. One of the other nurses was on the phone to the admitting nurse, saying things like, "Well if you've said it's OK then I guess we'll have to take them, but we don't usually do this." It seemed to be an issue. When the Nurse Unit Manager got back to ward she also was uptight about this. "Politics!" was her comment.

Some of the frustration noted in this response may be related to the perception that Heath becomes a "dumping ground" for patients who are difficult to place. This patient, already being treated with intravenous antibiotics, was already in a health care facility. The staff may have been questioning the decision to transfer him in the first

place, and not the fact that he was receiving antibiotics. However, there were other instances at Heath where new or different treatments were questioned.

Fieldnote: 28 May 2001

I went along on the ward round with the Nurse Unit Manager, Resident, and the senior doctor of the ward who had returned after two weeks leave. Also joining the group shortly after the round started was Dr P, now retired, but who had covered for the other doctor's leave. ... Dr P ... took over a bit, saying who he was to the patients, and things to them like "remember, we had this conversation ... what we've talked about" ... and then [he had] quite a few discussions with the other two doctors about possible causes of symptoms and treatments. He seemed up to date with new things, different things, or different ways. He actually seemed to be enjoying the challenge of thinking about "real patients." This is my perception. [I had initially met Dr P at a function at Heath a few nights previously.] I remember him saying either here or the other night, that when you can no longer "do" you teach. He's currently working part time with a university, so I gather he doesn't get much clinical exposure. So, there was some discussion among the three doctors regarding the various treatments and underlying causes [of the patients' problems]. Dr P had some different ideas. There was some verbal recognition of his time here - he seemed to be admired for his experience, knowledge and caring attitude.

The Nurse Unit Manager later said that if the regular doctor had been there, a lot of the treatment regimes would be different. She advocated that you just stick on a syringe driver with the morphine and the haloperidol and most people are comfortable, or something like that. She said this in the presence of the intern who had been working with Dr P. I gathered that neither of the doctors had a problem with the innovative suggestions given by Dr P, just that it wasn't the way things would have been done if the regular senior doctor had been there. I got the impression that the Nurse Unit Manager thought it was all a bit unnecessary, and overly complicated.

These two examples from Heath illustrate to me that the approach of the staff is to keep things simple. The primary goal is patient comfort. Processes to access technology, such as biochemical analysis of specimens, sophisticated x-rays, and computerised scans, are conducted offsite. Only basic x-ray equipment is available on site and only on specific days of the week. Patients for whom x-rays and scans are required are sent, often by ambulance, to a hospital a few miles away. Because these processes to access technology are not as straight forward as if the facilities are on site, it seems that the simplest approach is seen to be the best approach in this environment.

In contrast, at Waratah the full range of investigative equipment is available, including Magnetic Resonance Imaging (MRI) and Computerised Tomography (CT), as

well as laboratory testing for blood and other tissue samples. At Kookaburra, an impressive computer system is being trialed, and not only are all laboratory results reported on line, but all x-rays and scans are displayed on screen rather than "hard-copy" films. Radiologists' reports are also put directly onto the computer to accompany the graphics. Doctors, therefore, have almost immediate access to these results, and are able to use the computer software to magnify particular areas of interest and make their own interpretation of the results to augment the radiologists' reports. The unit manager proudly displayed this technology to me, which indeed was impressive, and which highlighted the range of technologies being used across the different sites. These technologies and the access to them are very different from the situation at Heath.

From my observations, there is a continuum of approaches to palliative care. This continuum ranges from proactively seeking new technologies through to actively discouraging new technologies and doing things the tried and tested way. Some staff express a need to continually search for new technologies and take delight in the challenges of finding innovative ways to care for the patients. For others, however, who are equally concerned with optimising patient care, the desire to keep things simple appears to detract from embracing new options. I consider this approach to be "stuck in a rut."

The initial palliative approach was developed in response to the over-technological treatment of patients and lack of recognition of the inevitability of the outcome of their disease (Davis & George, 1993). However, changes over time in the technology utilised in palliative care practice have been noted. Bruera and Lawlor (1998) for instance, discuss differences in approaches to care that have become more obvious over recent years. They cite several examples, one being the treatment of hypercalcaemia, which several years ago required quite aggressive treatment, and with recent advances can now be treated relatively simply in a few hours. Bruera and Lawlor go on to argue about the dichotomy between aggressive and palliative treatment, and suggest that not always does a passive approach to treatment provide palliation of patients' experiences of symptoms.

Over time, with technological advances, the balance between maintaining focus on patients' needs and offering appropriate treatments is becoming more delicate. The continuum of approaches to care that I encountered may reflect some of these balancing processes. There may, however, be far more pragmatic explanations for the

observations. Decisions regarding investigations and treatments, and the resultant culture that I witnessed about use of technologies, may be directly related to the ease of access to the appropriate technology. It may be that this is a "chicken and egg" situation, the difficulty being not knowing the driving force for the resultant culture.

Regardless of the level of technology, fundamental aspects of care occur within these palliative care settings, and my observations gave insight into the underpinning cultures as revealed in the following sections.

Basic Care: Nutrition, Elimination, and Hygiene

Nutrition, elimination, and hygiene are personal needs that most adults can attend to for themselves. When illness or disability interferes with the ability for self care, there is an expectation that health care staff will provide these basic needs. Within these fundamental care areas, I noted approaches to care that extended beyond merely meeting patients' needs.

Food: "But if he doesn't eat he'll die!"

A routine activity within a care facility is the provision of meals. As mentioned earlier, patients' meals and staff breaks punctuate the routines within the wards. Commonly, hospital routines surrounding meals differ from those an individual might enjoy at home. This is largely due to the logistical constraints, especially in large facilities, where meal times are structured around the capabilities of the catering staff in terms of preparation and distribution. It is not uncommon for breakfasts to be served around seven in the morning, and the evening meal as early as five in the afternoon. The ward routine, therefore, becomes structured around this schedule.

For instance, night staff typically finishing a shift around about seven in the morning, might commence early morning patient care before five o'clock, waking patients to help prepare them for the day. Sometimes an early morning cup of tea or coffee is served and some of the patients are showered or bathed and sat out of bed in expectation of the breakfast schedule. Some patients may be able to attend to these needs themselves. However, if the nurses are required to assist them then these activities must be attended to relatively early in the morning.

The meaning of food in palliative care settings, however, seems to take on additional aspects. Many of the patients in the units are visibly wasted. A condition known as cachexia, marked weight loss and muscle wasting, is common amongst people with cancer, and is often accompanied by anorexia, that is, loss of appetite (Twycross,

1999; p. 103). As well as this "cachexia-anorexia syndrome," many patients also experience nausea, sometimes from medications, as an effect of the disease, or often as a combination of factors (Woodruff, 1999). Unfortunately, while cancer saps the body's energy reserves, it also saps appetite. Often it is difficult for families to accept that patients are not interested in eating. Twycross suggests the families require explanation to adjust to the changes in food intake and to accept that the attitude of "if he doesn't eat he'll die!" is not appropriate in these cases. A particular example of family members not accepting this approach can be seen in the following situation.

Fieldnote: 22 October 2001

One of the patients in the ward at the moment has many of his family with him. His son and I think some of the other members of his family are GPs. They seem to be having difficulty coming to terms with the fact that he has come to the end of ... radiotherapy. In other words, no more curative treatment is planned. He has been in hospital on another ward I gathered, having intravenous [IV] fluids including TPN, [Total Parenteral Nutrition, which is given for intravenous feeding] and IV antibiotics, in other words active treatment. This is what his son, who is also his [treating] GP, has wanted apparently. He is now dying.

Later in the ward I saw the family, the son and another person, come to the desk to ask for breakthrough pain relief for the man. I also was there when the son came back and said that his father had woken up a little, and wanted some clear soup. Dorothy, the nurse on at the time, made a bit of a fuss about not having any, but eventually rang the kitchen. The soup was obtained from the kitchen but the patient was unable to take any and remained in a semi-conscious state, gradually deteriorating and dying two days later.

It is impossible to know whether the concern shown by this man's son was personal or professional. It was, however, important to him that his father be offered nourishment. The patient was incapable of asking for the food himself, and from my observation did not appear conscious enough to swallow. Despite knowing that his father was dying, the son felt obliged to offer sustenance.

Patients too have expectations that they should eat, even if they are disinterested. When collecting meal trays from patients they would apologise for not having finished their food. They would tell me that they just "couldn't touch it," but wanted to, I assume in the belief that it was important to their recovery. Staff do not force patients to eat but rather employ measures to make food more enticing, or suggest a type of food that may be more appealing. This is concurrent with paying particular attention to pharmacological control of nausea and sometimes even appetite enhancement with

steroids. Some innovative measures have been developed to make food more appealing and improve patients' intakes.

One ward insists that the kitchen send food in a trolley, rather than pre-prepared individual trays for each patient. One of the ward assistants asks each patient what they want from a list of the day's selections. Once the trolley arrives on the ward, individual meals are served and delivered directly to the patient, one course at a time. In this way, not only the selection of food is tailored to the individual tastes of the patients, but more importantly, the size of the portions. Although there are over twenty patients in the ward, the staff serving the meals are often able to identify the specific likes and dislikes of particular patients. For instance, they remember if a patient likes gravy on their meat, whether they prefer their soup in a bowl or manage it better in a beaker. The patients seem to respond to this individual service, many of them commenting to me about how much they enjoyed the food. Pat was admitted to the ward with nausea as an identified problem. The following is a description of how she experienced the meals at the PCU and at another hospital.

Judi: And the meals are OK?

Pat: Oh the meals are lovely.

Judi: Do you like this idea of the trolley business, the way they dish the food out?

Pat: Yes, very nice. What used to make me sick in [another health facility], they'd come up with a trolley and open it up and the smell of food used to make me heave.

The manager of the unit explained that there have been several discussions with the catering managers regarding the continued practice of this individualised service. Although this is the only ward in the hospital that serves meals in this way, she believes that this practice optimises the food appeal to the patients. Rather than being served a tray full of food with all courses served at the same time, individually serving a small portion, one course at a time, encourages patients to taste a little of each, giving them a chance to rest in between. Patients also comment that the odour of food can be off-putting, as Pat did, but food smells emanating from "the trolley" are not as intrusive as those coming from the pre-served meals that arrive on a tray. Pat's daughter, Olive, substantiated this and explained it to me this way.

Judi: People say the food's good here. ... It doesn't look all that great to me. But the patients seem to enjoy it.

Olive: You know what it is? They bring it out on a tray. It doesn't have a lid on it. When you lift up that lid it smells, you understand? And everything mum has is lovely. She couldn't eat the food at [the other place]. And she's fussy, mum's fussy.

Judi: I know that they've talked a lot about how the trolley comes down and they serve from the trolley, and just put small amounts on the plate. And I know that [a staff member] thinks that's important. Do you think that?

Olive: Absolutely. That was the first thing that my husband said, when we came and had a look. ... He said, "Did you see the trolley, did you see them taking the trolley around?" He said that they were taking it [the food] by hand, serving it one at a time. None of these things you stick them on. It's in a bain marie. ... [E]very time mum saw the trolley coming at [the other health facility] she'd start heaving. ... So I can tell you for a fact that it does make a difference. Because most of the people in here ... they can't eat, or they don't feel like eating until they get them sorted out, get them onto the medication whatever ... and they get going, and they love it. And they have all the choices of the sweets, and everything.

All the units included in this study appear to acknowledge the importance of appealing to the individual tastes of patients, although not all are fortunate enough to have a trolley that enables such individualised catering. Each service does, however, attempt to ask patients individually about their preferences. Each unit also keeps a supply of "extras" in the fridge. Foods such as jellies, ice-cream, and food supplements, for example Ensure[®] or Sustagen[®], are offered. Families are encouraged to bring food for the patients, and often this is more appealing and more familiar than the hospital catering.

There is a significant emphasis placed on food in each of the units. Perhaps this is indicative of nurturing generally, of providing nutrition to those in our care. Nurses do not force patients to eat if they are unwilling or unable to do so, but they will endeavour to tempt patients to eat a little if they can. Certainly a great deal of effort goes into activities associated with meals. Often additional staff members, such as nursing assistants and volunteers, are available at meal times to help with the distribution of food as well as assisting with feeding. The nurses too become involved in these activities, usually ensuring that the patients have been fed before going to their own meal breaks. Some family members also make a habit of visiting at meal times to

assist with feeding. Helping with the meals was one of the activities that I often participated in, and which was openly appreciated by the staff.

Although the "early breakfast" is a common characteristic of inpatient care, there are some attempts to individualise the times of serving meals. Patients absent from the ward at the time of a meal return to find that the meal has been reserved for them. These meals are neatly tucked away in the small kitchens, covered in plastic film wrap with a note taped to the tray or the plate instructing all to save this for Mr Jones or Mrs Smith. Each ward is equipped with a microwave, and patients who have been absent when the meals are being served can be offered a hot meal on their return. Similarly, if patients are sleeping at the time meals are served they generally will be left and not disturbed, the meal being offered at a later time when they have woken.

Included in planning of the Kookaburra unit was provision for a well-equipped kitchen. Here individualised meals can be cooked to suit the needs of patients. Only breakfast is served in this way, but patients can basically order their breakfast from the menu, to be prepared and served anytime they wish during a three hour period, 6.30 am until 9.30 am. The manager of the unit was especially proud of this service, and indeed the ability to order an "à la carte" breakfast added to the resort atmosphere that pervades the unit.

Each of the units in some way attempts to cater to individual tastes beyond those that are necessary because of physical limitations of the patient. Anecdotal reports about hospital food are generally quite disparaging. However, in each of the units in this research there is recognition of the patients' compromised appetites and significant efforts are made to maximise both enjoyment of the food and the nutritional benefit.

Bowel Care: A priority in care

Constipation is a common symptom experienced by patients admitted to palliative care services (Sykes 1998), and results from various factors including decreased mobility, decreased food and fluid intake, and the side effects of some drugs, particularly opioids (Woodruff, 1999). Palliative care guidelines recommend that when prescribing opioids, aperients (laxatives) should also be commenced (Maddocks, 1993).

The concern for palliative care patients to maintain good bowel function arises from concern for the general comfort of the patient. Consequences of not attending to bowel function can lead to severe constipation, sometimes impaction, and the interventions to resolve these problems can be quite invasive, even to the point of

requiring surgery. The discomfort of even mild constipation is an additional burden for patients. Bowel care is a significant part of good palliative care practice (Chan & McConigley, 2000).

At each of the units, regular monitoring of patients' bowel status is undertaken. Ward rounds conducted by the doctors, including the senior consultants, includes review of bowel status, and appropriate plans of action geared at prevention of constipation, rather than treatment after the fact. Two of the units have a scoring system to record bowel status, for example, "A1" is a very small amount (A) of fluid faeces (1), while "C4" refers to the result of a bowel action of moderate amount (C) and constipated consistency (4). Another unit regularly uses a "Constipation Flowchart" that is used to guide bowel management decisions. These flow charts appear to give added weight to the perceived importance of bowel management in these settings.

Hygiene: A Gentle Touch

General hygiene care carried out in all the units is aimed to afford patient comfort above all else. Patients with limited mobility are assisted by the use of aids that range from mobile shower chairs to sophisticated electric hoists. Hydraulic trolleys are available for patients who require transfer from bed to shower and back while remaining in a prone position. Spa baths have been installed in two of the units, however, although I have heard anecdotal reports of patients enjoying the spa baths, during my period of observation they were not used. I have inquired of staff from other palliative care units with spa baths, and they too report that they are rarely used.

Patients are offered daily washing, and often given a choice of showers, baths, or bed baths, although staff do not insist on this being a daily regimen. Patients for whom bathing exacerbates their pain, breathlessness, nausea, or other symptoms seem relieved by not having to comply to a daily routine. Veronica, who was extremely thin and had pain that was proving difficult to control, was particularly appreciative of being able to remain in bed. She said she loved the bed baths that she had. This particular procedure has been designed to cause minimal disturbance to patients. A special preparation is used, mixed with hot water, towels are soaked in the solution and gently placed over the patient's body. There is no need to rub vigorously or to dry off after removing the towels. Veronica thought this was wonderful, saying that she felt pampered after one of these. Several of the units used these bathing techniques, which were geared to preventing unnecessary disturbance and increasing patient comfort, a common theme in palliative care practice.

For patients who are unconscious or particularly restricted in their movement however, pressure care is conducted on a strict two-hourly schedule. This activity frequently requires more than one person; in some cases an orderly attends specifically for assistance with turning. In other cases the nurses in the ward attend to this as a joint activity. Hygiene care and mouth toilets are also carried out on a two hourly schedule for these patients.

Throughout my time of observation, I saw many patients who were unconscious or semi-conscious as they approached their deaths. In all the units I found that patients at this point in their illness appeared as if the staff had just attended them. Their beds were clean and fresh, their lips glistening with lubricant, their hair neatly combed. I remarked about this to Gary, a nurse who had been working at the PCU for over ten years. Gary responded that it was important to maintain this care as you were never sure when a relative might come in to visit the patient. He said, "Palliative care is not just for the patients you know."

Beyond the Norm: the Extra Touches

The attention to nutrition, elimination, and hygiene that I witnessed in the units extended beyond meeting patients' basic needs, as I have described in the above. There were additional touches to care that added an extra dimension to meeting the physical needs of patients within these palliative care units.

Social Routines: "Would you care for a drink?"

In most of the units, a small amount of alcohol consumption is encouraged, either prior to a meal, or with the meal. Sometimes a small drink helps improve appetite, and several patients also seem to enjoy the social ritual of a pre-dinner drink. Veronica, a spinster in her early 60s, greatly enjoyed a small sherry before both lunch and dinner. She claimed this increased her appetite. She usually made quite a fuss of pouring the drink, and kept her special glass by the bedside with the bottle. Usually she asked one of the nurses, or myself, to pour the drink for her. I believe that this small act served to break some of the routine of her day, and brought her some feeling of maintaining the rituals she would have been enjoying in her own home. Veronica was accustomed to living on her own, and often requested the people around her, mainly the nursing staff, help her with little things or do things for her in a particular way. Veronica's ritualistic sherry was perhaps, for her, a way of maintaining some control of her routine.

Another patient, Elizabeth, enjoyed a regular scotch, although staff became quite concerned with the amount of Elizabeth's consumption. There was talk about whether Elizabeth had a "drinking problem," and was continuing a pattern in the ward that had been established for some time at home. Elizabeth also lived by herself, but had been widowed for about five years. Although there was concern, there was no attempt to control Elizabeth's drinking, even though the staff felt she had a dependency.

Both Elizabeth and Veronica supplied their own alcohol, visitors bringing it into the units for them. Honeyeater Ward at Heath has a small ward supply of drinks, and every so often the staff take the drinks trolley around. I observed this practice on only one occasion, and although staff said that they often do this, I did not get the impression that it is a regular occurrence. Susan, a long serving nurse at Heath, was the main instigator on this evening. She went around the ward offering beer and sherry to the patients, although few accepted.

Personal Journal: 10 June, 2001

Last Saturday, Susan decided that it should be Happy Hour and set up a trolley with bottles and glasses. It seemed like a spontaneous thing to do. Patients were surprised, so too were some of the newer staff (those who had been there a year or so). Not many really wanted a drink. It occurred to me in observing this that the practice was more to relieve the boredom of the staff than to really engage the patients. The attitude was sort of, it's the weekend, Saturday night, let's have a bit of fun. But I think the patients were just confused. It just didn't seem to work for them. I've heard that other palliative care units regularly have a Happy Hour, patients and families are offered a drink, and it is a social time. I suspect that what I observed was different from this, although perhaps it was a genuine effort to create a social environment for the patients and families.

Throughout my observations, only a few patients accepted or asked for an alcoholic drink. Most often the patients were probably too unwell to be bothered. However, both patients and family members, and even some of the newer staff, were surprised that the practice was permitted. This further highlights the differences between expectations of traditional health care provision and palliative care.

Complementary Therapies: Non-invasive, Comfort Measures

The use of complementary therapies seems to be well accepted in palliative care, as these therapies are seen as non-invasive and often enhance comfort. Beyond an acknowledgment that such therapies enhance feelings of general well-being, however, much scepticism remains among health care professionals. Woodruff (1999) lists

dangers of some treatments, and suggests that there is little evidence for any claims of so called "alternative" treatments that effect a regression or cure of cancer. However, along with Whitlock (1999), Woodruff acknowledges patients' attraction to such therapies as being a sense of involvement, of maintaining hope, and being acceptable because it is natural and non-invasive compared with orthodox treatments that "cut, burn and poison" (p.351).

In the study sites various forms of complementary therapies are practiced. Most commonly, some form of massage is an accepted norm. Often volunteers perform foot or hand massages. Occasionally a nursing staff member has additional skills in this area and offers some form of massage to a patient. Practices such as aromatherapy, reflexology, and Reiki are offered dependant on the expertise of the staff and volunteers working in the particular unit. The availability of these therapies is, therefore, rather ad hoc, and viewed as a pleasant addition to other treatments, not as a standard treatment regimen for any problem in particular.

Everything Else: Psychological, Spiritual and Social Care

Many of the descriptions of palliative care include dimensions of spiritual, psychological, and social care in addition to physical care, and principles of palliative care acknowledge that these issues can be especially relevant for patients approaching their death and for families coping with these events (Saunders et al., 1995; Woodruff, 1999). Existential issues, such as the meaning of life, and psychological distress commonly surface at these times (BolmsJo, 2000). Even when discussing issues such as pain, acknowledgment is given to "total suffering", and the interrelationship of physical, psychological, social, spiritual, and even cultural aspects of the experience (Woodruff, 1996).

Because of this interrelationship, I believe that it is difficult to categorise the care given. However, in this study it has been possible to draw a broad distinction between physical care and other care, especially because of the observational nature of the method. The care that I have described in the preceding sections of this chapter may best be categorised as physical care. The following discussions are about aspects of care that I have interpreted as being *other than* physical care. Further categorisation is difficult, and therefore I have labelled these observations as relating to "Everything Else". By no means is the following an exhaustive review of everything else that goes on within the study sites. It is however, a collection of observations of palliative care practice that I observed and that I consider is not *physical* care.

Who Does "Everything Else?"

Each of the facilities in this research acknowledge that issues of psychological, social and spiritual impact may be present in patients and families within their care. The emphasis on these issues varies, to some extent reflected in the staff mix within the units.

At Waratah the only staff available for non-physical care are social workers and chaplains who work throughout the hospital and only provide services to palliative care patients by referral. Occasionally a consultant psychiatrist may be called to assess if patients have specific problems, such as depression, and instigate appropriate treatment. Other units have dedicated palliative care chaplains, pastoral care workers, social workers, occupational therapists, music therapists and art therapists, who are included as part of the palliative care teams. Additionally, some individual doctors and nurses consider that addressing these issues with patients and families is part of their role, while others tend to defer to the "designated" support persons.

I was at times surprised by this latter attitude. At one site I saw ward staff comforting upset patients and family members, and it appeared were quite comfortable in doing so, yet they called for pastoral carers to attend and take over this care. This is one of my notations.

Fieldnote: Saturday 9 June, 2001.

A patient's grand-daughter came in, and burst into tears. They [the staff] comforted her. Julie [nurse] was going to do something, and saw this girl crying and sort of made a bee-line for her. So it was sort of a priority to comfort this girl. She called the Pastoral Carer to come up and talk with the girl.

Later I spoke with one of the senior staff about this. She explained that there was a long-standing culture of dividing the work into physical and spiritual care.

Fieldnote: Wednesday 27 June, 2001.

I talked about nurses giving away so much of their role, like what I had seen with calling for the pastoral carers. She said this is historical. The previous head of pastoral care said quite clearly "You look after the body and we look after the spirituality."

I also asked the nurses about these situations. They indicated that they felt it was appropriate to hand over this care, as they really didn't have the time. The pastoral carers also felt that they were relieving the nurses of the burden of providing emotional support, the nurses being so busy. The nurses did agree that if other staff were not

present, they did and could provide the emotional support necessary, and found the time to do so.

Talking with colleagues within palliative care, there appears to be some controversy regarding the appropriate personnel to provide counselling and support to patients and families. A variety of attitudes exist within the study sites also. At Numbat, the social worker and occupational therapist perceive that they have appropriate training and provide what they term "counselling" to patients and families as part of their roles, which seems to be accepted by other members of the team. Social workers at Waratah, however, are more involved with assistance in relation to accommodation or financial issues, and occupational therapists are referred to assess patients' homes for equipment that may assist in patient care at home. There is no expectation that these staff have a counselling role, and I suspect that other members of the team would consider this inappropriate if it were raised.

Other roles that may be controversial are those of art therapist and music therapist. I had no experience of either of these prior to this research, and I had considered that both therapies would involve more diversional activities than psychological support. However, the practitioners I met perceive their roles as being psycho-therapeutic.

Music and Art: Diversion or Therapy?

Numbat employs an art therapist on a part-time basis, and Heath has an extensive Music Therapy department. The music therapists not only provides services to the palliative care wards, but also outreach services to home care patients, and contract services to other health facilities in the region. In both sites these therapies have higher profiles than other complementary therapies, and therefore, I conclude, they have a greater legitimacy than some of the complementary treatments used in the palliative care environments. Both therapies are considered, rather than being diversional activities, to have therapeutic value in providing psychological support to patients.

Art therapy has been defined as "a form of therapy in which the making of visual images (paintings, drawings, models, etc) in the presence of a qualified art therapist contributes towards externalisation of thoughts and feelings which may otherwise remains unexpressed" (Waller & Gilroy, 1992, p. 5). Joanne, the art therapist at Numbat, explained to me that rather than using art in therapy she employed a psychotherapeutic approach and used art *as* therapy. She uses art to express emotions that she believes would require much longer sessions to emerge if using other means of

therapy or counselling. Time is a consideration with patients in palliative care, and interpretation of what might appear to be a scribble on a page may reveal issues that impact significantly on the wellbeing of the patient. Joanne referred to anecdotal reports from nurses who found their care, such as pain relief treatments, was more effective after she had worked with some of these patients.

Being unfamiliar with this type of therapy, I also arranged a meeting with Kaye, an experienced music therapist at Heath, to discuss her work more fully. The brief introduction I received allowed me to better understand the aims, which for Kaye are to "assist patients in coming to terms with and preparing for their impending death." Kaye described how she might work with a patient. If the patient is particularly ill, perhaps in a condition where they remain conscious but are not communicating, the therapist may choose a simple melody in a major key that is familiar and comforting to the patient. Working with someone who is anxious and experiencing shallow, rapid breathing, the therapist may select music that will initially match the rhythm of his or her breathing and gradually reduce the tempo, thereby reducing the rate of the patient's respirations. I was very impressed with these examples and could appreciate the physiological changes that the music might achieve.

Music therapy can also assist patients to leave a legacy for their family. A selection of music interspersed with messages to the family, or even composing their own music, can be a tangible remembrance for patients' loved ones. Obviously these activities can have immense impact for the patient and their families in achieving peacefulness in the dying process. In a presentation given by Kaye at a recent conference, she said:

The music therapist allows patients to creatively explore, process and/or resolve emotional issues, communicate thoughts and feelings to their loved ones, friends or carers, reduce pain and other physical discomfort, stimulate an improved emotional and physical well being, and provide a comforting, nurturing and calming environment for patients and their families.

These therapists are employed by the services specifically to counsel patients and family members, assisting them to work through issues relating to the patients' dying. In addition to one to one sessions, Joanne fosters opportunities for patients, families, and staff to work on projects together. During the period of my fieldwork a large mosaic, designed by Joanne and funded by a bereaved family member, was being undertaken as a group project. Many people have been involved in its production. Even

patients confined to their rooms have been involved, with Joanne visiting their bed-sides and asking them to smash tiles, the pieces eventually being used in the artwork.

The group work often occurs in one of the lounges or, in good weather, outside in the gardens. Some people sit and watch while others actively participate. One particular family chose to each contribute at a time when their husband, father, and grandfather respectively, was dying. Each family member contributed an individual piece to the display, which I was told they took as a symbol of the man's life that would endure beyond his death.

Well after my fieldwork was completed, but before finishing this thesis, I attended a church service to dedicate the mosaic as a part of the hospital chapel. Many of the family members who had worked on the piece also attended. This aspect of art therapy is not psychotherapy, however, it was a positive, reflective experience for me and I assume for the family members and staff who had shared in this project.

Other Creative Support

Karen, an the occupational therapist at Numbat, shared with me some of the ways in which she believes families and patients can be supported through this time. She provides assistance to patients to help create significant mementos to leave for their loved ones. One instance she recounted in the following.

Karen: We had a chappie in here, he was estranged from his son in California. ... He'd done an awful lot of running and belonged to these clubs and won a lot of awards and had some medals and things like this. And there was no chance the son was going to be able to make the journey from America here. I can see his face now. ... [H]e accepted the fact that his death was impending and he knew it was just a matter of time so he would talk about his marriage and his loss of his wife and he would ventilate a great deal about that but he'd also talk about his loss of his son. His son did occasionally ring him and so he gradually, it came up about it, what his hobby was and all that sort of stuff, so we gradually put it to him well ... what was he going to do, had he decided what he wanted to do with these medals? And he said, well yes, you know, perhaps he could leave them to the son. So to cut a long story short, time was spent with him over in his own home. He was taken out of here, we took him out of here. We went to his own home, we got the medals, we looked at his history, and we actually in woodwork made up a plaque of medals and it was absolutely lovely and it went to the son in California. Yes.

Again, the range of services offered by the different palliative care units is evident. The role of the occupational therapist at Numbat is far removed from that at

Waratah, where the role is limited to assessing the functional status of patients and arranging appropriate equipment to be installed in homes prior to discharge. Provision of *non-physical* care is diverse, and further highlighted by the emphasis at one unit on the importance of social activities, which are largely absent at each of the other units involved in this study.

Social Activities

The first field site I visited for this research was Numbat. Social activities are a major focus of the unit. About once a fortnight there is some type of social activity. Luncheons are held monthly, to which inpatients, home care patients, and families are invited. Often they have a theme related to the time of the year; for instance Melbourne Cup in November, and Saint Patrick's Day in March, and some of the staff dress in costumes related to these themes.

The activities are organised by staff of the unit, principally the social worker, occupational therapist, and one of the chaplains, however, many other staff participate. Volunteers often assist in serving meals. At my first of these functions, one of the senior doctors spent an hour or more cooking meat on the barbeque. The chaplain likes to serve at the "bar," wine, beer, and soft drinks most usually being provided. The social worker and chaplain take photographs on these occasions and make a point of including all patients and families if possible. Often these activities are held outside in the courtyard garden. Patients who do not wish to leave their rooms, or are not well enough, are often visited by a group of staff and a photo is sometimes taken. Even when a patient is particularly ill and close to death, some families will participate in the luncheons as they have come to know other patients, families, and staff and they appreciate the opportunity to join in.

My initial impressions of these functions were a little sceptical. I queried the "frivolity" of some of the activities, particularly the theme dressing.

Fieldnote: 16 March, 2001

They had a St Patrick's Day lunch today. Apparently they have a lunch each month and an evening each month so there's something every couple of weeks. It was a bit of a party. They'd done it quite nicely. There were volunteers and they had party pies and heaps of food that they were handing out when I arrived. And then they had fish and vegetables and Irish stew, and some sort of vegetable pie, and ice cream. And a cake. ... A lot of the patients were outside. Their families were with them. They seemed to enjoy it. They had Guinness [stout] and wine and soft drink. ... It seemed a bit childish to me. The OT [occupational therapist] who's a reliever at the moment, and the Nurse Manager and

the social work student, Frank. They dressed up. The two ladies were in green, dressed as leprechauns, I think that's what they were, and Frank dressed up as a bottle of Guinness in black with a big black hat. And they had their photos taken with the patients. ... It did seem a bit strange. Childish. Childish for this group of elderly people. A bit like, perhaps nursing home sort of mentality, catering to "poor old demented people." I thought it was a bit demeaning. But a lot of patients seemed to enjoy it. I don't know. There was a woman playing the piano there. Irish sort of songs, sing-along sort of stuff. ... Everything was very noisy I thought ... lots of hilarity, laughter. Which was OK, but if you were sick and some of the patients were in bed, like Mona I saw cringe a bit with all the noise, she was still in bed, she wanted to stay there. And poor old Mr Jones, just sitting there ... in his single room. He's not very well, and he's sleeping a lot of the time. ... And they [the people dressed up] went around and asked if the patients wanted their photos taken with the leprechauns. They got to Mr Jones and they took his photo. I don't think he minded but I'm not sure that he knew too much of what it was about.

As well as monthly luncheons, Numbat hosts monthly wine and cheese evenings. This allows families who may be unable to attend functions during the day the opportunity of participating in the evening gathering. I attended two of these evenings. Again there was music; a pianist and a band. The band was organised by the wife of one of the patients who played with this group professionally. On one occasion one of the nurses with a strong singing voice lead the group singing. Other nurses on duty participated in the functions in between tending to care of those patients still in their rooms.

Staff at Numbat are committed to providing these events, convinced that social interaction between patients and families encapsulates the notion of dying being part of life. Staff also believe that families look back on these events with a fondness that overrides some of the patient suffering they have witnessed, and eases the grief associated with bereavement once the patient has died. As my above fieldnote indicates, I was initially unsure.

I realised when I moved to the next study site that these types of social activities are not typical of palliative care units in the study. Only at Numbat are there any planned activities that include patients and families in a supported social environment. The concept of boredom, or lack of social stimulation, became of particular interest to me once I started making observations at different sites. The following notation explains some of the source of this interest.

Personal Note: Starting fieldwork at Numbat, I was familiar with the culture of palliative care practice in Perth, and knew that social events

were part of that culture. I was initially a little surprised how much effort went into these, and how frequent they were. But I considered that this was the norm. After all, my clinical experience was in home care, and organising social events for patients was the role of the patient's family, maybe with some encouragement from the home care staff. So I accepted the activities at Numbat without question. This was what happened in inpatient palliative care units. I was therefore surprised when I started research in Melbourne. None of these activities occurred, nor was there any real apology for them not happening. There was no expectation that they should. There was no plan for the families to join in social interactions with their loved ones, nowhere the patients could go beyond the bounds of the ward, nowhere they could expect to have medical or nursing staff on hand should they suddenly require it. With this realisation, I began a fresh approach to analysing the meaning of these social activities and the importance attached to them for the patients, families, and staff. I also was interested in how patients felt about the lack of activities.

In all units studied for the research, each patient has a television beside or above their bed, and in all but Waratah there is a patient and visitor lounge, again with a television set. In the mornings someone comes around selling the daily newspapers, and occasionally a volunteer attached to the hospital or from the local library visits with a range of books that can be borrowed. Each unit also has a supply of books, although the choice is not great. Families are encouraged to bring in activities for the patients. Beyond this, there is often little to occupy the patients, or their family members, other than the usual business of the ward.

Evelyn was a patient admitted to Heath with breathlessness, a symptom of lung metastases from breast cancer. She was an ex-nurse and I found myself drawn to talking with her about her impressions of the ward. Evelyn responded to my question about boredom saying that she was quite happy, as long as she had something to read. She talked about the patient lounge where she could go, but because of her breathing she had only walked there once and found it a challenge. She preferred to stay in bed and read.

Some staff express concern that there is little to occupy the patients, and that they might be bored. One patient I came to know, Mr Browne, caused some concern. Tom Browne was a man in his sixties who was considerably active for the amount of pain he was experiencing. This was the main reason he was admitted to the unit, to help with pain control from multiple bone metastases. Until recently, Tom had kept busy making things in his workshop but these activities had been curtailed since his pain had become problematic. Although Tom required inpatient care he was by no means bed-bound. His wife and family visited often but there was little to break the monotony of

his day. He would pace up and down the corridors, and gave the impression of resentment, not just towards the internal constraints of his disease but also the external ones of being contained in this environment. Although he was a sociable chap and spoke with the other patients, they were often too sick to engage with him for very long. There seemed little for him to do. The staff were aware of this. One of the nurses, Gill, discussed this with me.

Gill: We've got no gardens, no balcony, people can't even walk out for a smoke now because we are probably one of the furthest wards from anywhere that you can smoke. So it's a disaster for those people who are convalescing, which is why we don't do it as well. But there are people who are in here, like Tom, who actually needs to be here for his pain control issues or needs to be in a Unit, but really he needs something else to occupy him and we don't have it. Our turnover is a lot quicker now. We've only got an average length of stay of six days, so for the majority of people the issue of doing stuff, we don't always actually have a lot of people who are able to do stuff. A lot of people are either dying and unconscious, or they are acutely unwell.

Gill continued, talking about the proportion of patients who, like Tom, might be bored, some of the activities that had been tried in the past, and the perception that the current resources both human and physical prevented anything being provided for patients in Tom's situation.

Gill: There are some [patients] but I think they are probably only about 50% and we've tried to get somebody up to do things with people. But there are no staff, no resources. We had jigsaw puzzles, books, and things that people could do for themselves. But we found people just weren't able to ... they needed to have somebody with them and we don't have people to do things. There isn't a room to get away and do some whatever, painting, diversional therapy, that sort of stuff. We are not set up for it.

I felt concerned for Tom. Sitting and talking with him I was able to ascertain how restless he was. He often joked about things, but his wife, whom I also spoke with quite often, was really concerned that he was depressed. Gill too was concerned about his situation. However, she also considered the bigger picture of other deficits in the service and conveyed her priorities. She suggested that there were other places that might cater more appropriately for people like Tom.

Gill: So yes, it's a concern. But I have to be honest and probably say that it's not on that list of things if I were to choose to do. If I had a set amount of money, I would be looking at Bereavement people, Social Worker. Not that I don't think it's important, but there are things that I

think that we are lacking more of. And people who are well and need things to do I think probably ought to be in a unit that may be better able to provide it in terms of physical locations and people to do it. I think, yes, not saying that there aren't people, but I think we probably ... have a smaller need than the other units. But yes ... it is awful for people.

From these comments I began to consider that, although palliative care units on the surface had similar aims, and similar language, there were in fact many types of palliative care and palliative care patients. This led to emerging thoughts about a continuum of palliative care. In another conversation with Gill I asked her about the criteria for admitting patients to Waratah Palliative Care Ward.

Interestingly, her explanation was made with a description of the scale of costs of a bed day. Of the three services she mentioned, there is a sliding scale of costs with a \$100 increment between each. The more acute service has a higher cost, the next a \$100 per day less and so on. Her argument seemed to be based on the cost of bed days.

On return to Perth, I also returned to Numbat to consolidate some of the views I was forming. This allowed me the opportunity to delve further into the meaning of the social activities for the people participating in them. In this time, the Nurse Manager had also changed and I asked the new manager about his views of the activities.

Judi: And what do you think about the social activities that happen here? Because that has struck me as being a major difference.

Lionel: This is very unique. I was a bit blown away by it when I got here, and thought it was a bit weird. You know, doctor's dressing up as clowns and people walking around doing all kinds of strange things. But having done the whole Christmas thing, I could see the direct impact that had on patients, the joy that it brought their family and carers. It was very tangible you know.

Judi: What did happen? I wasn't here for Friday Christmas lunch.

Lionel: It was lovely. We had about 70 people turn up. They put a big lunch on, I got dressed in an elf suit, Dr Charles got dressed in a Santa Claus suit, my two girls were the Christmas fairies, we handed out presents, took photos with everyone. Look I wouldn't want to do it every day. But it was actually nice, it felt good. You could see that it actually was appreciated by patients and families ... tears in their eyes, saying thank you.

Judi: Was it something about the last Christmas they might spend?

Lionel: Could have been, I didn't delve that deeply into it. It just seemed like something, you know, it was tangible. Kind of broke down a lot of the barriers between the patients and the families. ... It was a bit sad. ... [With] my girls, we came through the ward a bit later on, and there were a couple of patients in the terminal phase, or moving into it, but we didn't exclude them. Their families were sitting around and we walked in and my daughters handed them gifts. I mean they were out to it, they weren't to know. We sat around and had photos with these people. My daughters sitting on their beds. It was lovely you know. And I thought for the patients' friends to look back on that in a couple of years time it would be a real sense of consolation for them, or strength or whatever.

Judi: So, about the activities. You've changed? You've moved since the Christmas thing?

Lionel: I think there's definitely value to it, yes, without question.

Judi: And what were you thinking before?

Lionel: I thought it was all a bit silly really. Because I'd never seen anything like it before.

Lionel's change of attitude about the activities was similar to mine. I too had observed the meaning of these activities for patients and families and came to appreciate the worth of the events. Pat in particular enjoyed these events and had been attending them since she first became involved with the service. Even when she was at home she would come in to the unit for the functions. She kept a pocket-size photo album with her of photos from the lunches and wine nights, collected during the seven or eight months of her involvement with the unit. She showed me some of the photos.

Pat: Look at me there. And they put all the cans in front of me. They were having a shot at me.

Judi: So tell me, you enjoy this sort of thing?

Pat: Yeah. I think it's good. ... I bet that's a wine night. [Pointing at a photo]. They only take me [my photo] when I've got a wineglass in my hand or something. ... [Another photo.] That's the Melbourne Cup.

Judi: So do you think it's good to have those activities happening around?

Pat: Oh yes, I do, I do. ... But I like to go out in the sun and the fresh air. ... [More photos.] See that's the Melbourne [Cup], and that's another night, that's friends of mine. I said come up to the wine and cheese, so they come up with us. ... That's my husband's cousin. They went to school with this lady that died here. ... My sister's there. That's the first week I was here, 'cause I was in a private room. And I had a birthday on the Saturday. ... They made a cake here for me. And my next door neighbour sent a big beautiful home made sponge with cream and jam in it.

There are many occasions of celebration at Numbat. At these times, at least every fortnight, there are many people preparing for functions, and subsequently participating in them. Sometimes people are in costumes, banners are brought out, and the ward is full of fun and laughter.

Of course, there are problems engaging patients who are dying in activities. Fatigue in cancer patients is commonly reported as the most common symptom, and one of the most difficult to relieve (Curt, 2001; Neuenschwander & Bruera, 1998; Porock, Kristjanson, Tinnelly, Duke, & Blight, 2000; Wharton, 2002). Motivating patients to participate in activities may be difficult because of the overwhelming fatigue they experience. It may also be difficult to gauge whether patients are fatigued, or merely bored, unless the boredom manifests in more serious forms such as depression. The culture at Numbat, however, is to encourage engagement with these activities and the staff work hard to accommodate patient's fatigue and debility.

Important Events in Palliative Care

From the descriptions given in these previous sections, the "routine" activities of the units differ in some ways from other wards. There is attention to patient comfort, medications are frequent, some units are busy with patients coming and going from treatments and investigations, and in one unit there are planned social activities that involve many people.

In each of these units, however, certain events recur that require significant attention and input. Patients with uncontrolled pain, patients who are dying or have just died, and families who are distraught are all commonplace. These appear to be important palliative care events that require special attention.

Pain: The Palliative Care Emergency?

The event that most consistently raised the attention and prompted response from the staff during my period of observation was a patient's complaint of pain.

Sometimes it was a relative's report of the patient in pain that instigated action.

Response to this situation was similar in each of the units, and I considered that this is the equivalent of a cardiac arrest in other wards; an emergency situation requiring immediate action.

In most cases, such a complaint elicits an evaluation of the patient's pain, and administration of an appropriate analgaesic. Nurses suspend other activities as quickly as possible to assess the patient complaining of pain. Meetings may be interrupted to request an order from a doctor or to call a nurse from another situation to check the drug with them (a hospital requirement for some medications). If a doctor's assessment is required, they may need to be called to attend the ward, and there is an expectation that they will respond quickly to this call.

Patient's pain that fails to respond to prescribed treatment within a period of time causes anxiety for both nursing and medical staff. Further actions are instigated, such as an increase of medication or trials of different medications. When pain persists despite these actions, so-called "intractable" pain, staff become particularly concerned. Over time, other specialist teams may be brought in to consult, including doctors, specialist nurses, and pharmacists. Staff, families, and patients become distressed during these events, and increasingly distressed if the pain persists. Pain is perhaps the most dreaded feature of dying, and certainly directly associated with suffering (Woodruff, 1996).

Dying: A Lonely Ride or Going the Journey?

A patient's deterioration is another event that requires significant attention. During the fieldwork I observed that sometimes a patient would experience a slow deterioration, their condition gradually changing, becoming weaker until they "faded away." Such an event is managed by a correspondingly gradual review and information exchange with relatives. Change of medications is considered, perhaps first reducing the number of medications to only continue with those that are enhancing patient comfort, and then replacing oral medications with sub-cutaneous infusions, often via a sub-cutaneous syringe driver, used in each of the settings. The medications in the syringe driver are commonly an analgaesic (pain-killer), an anti-emetic (anti sickness) and an anxiolytic (sedative). Some staff refer to this cocktail as a "terminal pump."

One of the units I visited use little else than the terminal pump, with some of the staff commenting that this combination has been used for years and why change it? "It keeps the patients comfortable, and fiddling about with other things wastes time, time in

which the patient is suffering.” This formed part of my assessment about some people being “stuck in a rut” and I wondered how appropriate use of the syringe driver was for patients.

Personal Note: Although in part I could agree with the use of the syringe driver and those medications in the context of the patient we were discussing at the time, I did feel that it was a generalisation to think this was the treatment for everyone. I also wondered at times with some of the patients who were commenced on a syringe driver if it was started too soon, that is, they probably were still able to manage oral medications and obtain a therapeutic effect from those medications. Perhaps it was not so much a case of starting too soon, but starting too strong. Some of the patients I saw became very drowsy after commencement of the driver, and remained so until they died. I guess I wasn't privy to all the clinical information, but I did at times wonder about the choice of treatment.

The other type of dying event I witnessed was when patients experienced a rapid deterioration in condition. This is usually triggered by a medical event such as an internal bleed into the tumour, or tumour extension to a vital area. Such events are often marked by a sudden exacerbation of symptoms that require immediate assessment and changes in management. Several attempts may be required to achieve relief from the symptom. Often the patient will not return to the same level of consciousness as prior to the event. Such an event not only results in an extensive physical review of the patient, but also requires families to be notified and subsequently supported, and of course the patient if they remain aware of the circumstances. Such an event, therefore, has significant consequences and impact on the ward generally.

As previously mentioned, patients who are dying appear well cared for physically at this time in their illness trajectory. However, I also observed a range of emotional and spiritual support for these patients. In some units, patients who were unconscious and close to death were left alone in between the cycles of diligent physical care. Indeed, the contrast of the impeccable grooming of these people against a backdrop devoid of emotional stimuli made their solitude even more evident.

The patient Gary was caring for was alone in a two-bed room. She had been unconscious since the night before, and had been moved here on the evening shift. Observations of the overall scene with Gary and the patient who was dying was one of sterility. When I entered the room, Gary had obviously just finished attending to the patient's care. Everything was neat and tidy around the bed. The second bed in the room was empty, the bed freshly made and unruffled, the locker alongside clean and bare.

There were few items on top of the patient's locker, a mouth care tray, some tissues, and a box of mints. There was a vase of flowers on a shelf in the corner of the room. Otherwise the room was bare. The patient had a clean starched sheet draped over her, no blankets or quilt on top, and the cot sides on the bed were up. Everything surrounding the patient appeared to be white. Gary was standing near the window, his back to the patient. He was reading a newspaper that he had spread out on top of the spare over-bed table. The attention to physical care that had obviously just been carried out, and the alone-ness of the patient was a significant contrast.

This patient was not the only one I perceived who was "dying alone." I also came to realise that I was not comfortable leaving unconscious or dying patients alone. The following field notes reflect some of my reactions in these situations.

Fieldnote: 19 June, 2001

The Italian man still hasn't died. ... I can't imagine what is keeping him alive. He is so emaciated he is literally a skeleton in the bed. I don't think that I have seen worse. I can't believe he's still going. Although I've seen this before. He is a skeleton. ... It never ceases to amaze me about the reserve people have that allows them to continue to live.

I popped in there this morning, early, and Gail [a nurse] was shaving him. He looked very "cared for", he was washed, the linen was clean and starched around him, shaved of course, and his mouth care had been done. They use some sort of lip balm, which looks glossy on people's mouths. To me, maybe it's the nurse in me, it looks like they've been attended to. They look cared for. I guess it's the attention to detail about these patients. Mouth care. Glistening mouths. Combed hair. Clean beds.

[After Gail went] I sat down with this man for a little while. I don't think that he understands any English. I just felt like sitting there with him, touched his hand a little, sat at eye level, and smiled at him. He stirred a little. I don't know. I guess that's just something I needed to do.

Examining my reactions in these situations highlighted some of the differences in palliative care practice that I was witnessing in the field sites also. As well, I was particularly aware of some of these patients' surroundings, and how sterile they appeared. Patients who are conscious and interacting with others have mess around their beds; half empty glasses, juice bottles, bags of lollies brought in by families, reading glasses, empty pill cups, books, newspapers, and so on. I reflected on this contrast in my journal notes.

Personal Note: The environment seemed so sterile. All the mess that is usually around people, on the overbed table, juice spilt, used tissues, folded newspapers. All the disorganisation that comes with the world of the living, all cleared away. The patient, not moving, not disturbing any of this. All cleared away, all put in order. It was like a sign of the premature death for someone not yet quite there. All clean, and waiting. It concerned me that patients were dying alone.

I did not always witness people dying alone. Many patients are accompanied through this time by long-staying relatives, sleeping, eating, and grieving by their bedside. At one of the units, some patients, otherwise alone, are sought out by volunteers who consider it very much part of their role to be with these patients at this time. I saw volunteers sitting quietly beside patients, perhaps gently touching their hands, occasionally speaking to them even though the patients would remain unresponsive. The volunteers may just be quietly reading beside the bedside, but remaining a presence in the room, and what I consider, a conduit to the living.

Single Rooms

The practice of transferring dying patients to single rooms is undertaken in several units, although sometimes this is limited by the lack of availability of single rooms at the time. Many staff perceive that it is preferable to move people to a single room. The reason given for this is that it affords greater privacy for grieving family members. My observations, however, suggest that there is also an attempt to shield others from witnessing the dying process, with particular concern for other patients and their family members.

Some of the sights, smells, and sounds in hospitals generally are unpleasant, and in the palliative care units these aspects can increase as patients approach death. Indeed, I would not have enjoyed sharing a room with some of the patients I encountered. Lawton (1998) discusses some of these issues, and considers that Western society has come to have certain expectations about what she calls the body's "boundedness." Processes of dying involving loss of body secretions, such as from wounds, fistulae, loss of bladder and bowel control, with the accompanying odours, do not comply with these expectations. Further, she considers that hospices themselves, rather than fostering greater acceptance of dying, may actually serve to "sequester ... the processes of death and dying from the mainstream of social life" (p. 139).

I did not view the palliative care units themselves as marginalising dying patients. Each of the units I observed is part of a larger facility, and therefore, not

entirely sequestered within the confines of the units. However, moving dying patients to single rooms when approaching death may have been attempts to do this. It was not always the case that the "unboundedness" of the body, with accompanying noxious smells, precipitated the move to a single room. Impending death was enough impetus to change the patient's location. The following is one situation that caused me to reflect about these practices.

Fieldnote: 18 June, 2001

I walked into the ward and looked at the book. I was surprised to read that Peg had died the previous evening. As I was reading the book others, who were also surprised, were talking about her. The social worker was there. She said what a terrible fortnight this lady had had, with her family arguing about the power of attorney, and they were talking about moving her out to a nursing home. It really was a terrible fortnight for Peg, however I don't think anyone expected her to deteriorate as she did. I also heard someone say how quickly she went down, that they "only just got her into a single room."

Personal Journal: 18 June, 2001

I felt ambivalent about whether Peg would have wanted to stay in her room or be moved to a single room to die. Would she have wanted this privacy, and the associated panic of moving her so quickly? Although this was standard practice in the unit for people who were dying, Peg had been in the four-bedded room for many weeks. She was moved only an hour before she died. Would it have been more appropriate to leave her to die in more familiar surroundings? And whose comfort was being eased by moving her? Was it the staff wanting to hide death and dying, perpetuating some of the attitudes that palliative care is trying to redress?

A further aspect of Peg's death, and her sudden move to a single room, was reflected in the social worker's dilemma of what to say to another patient.

Fieldnote: 18 June, 2001

The social worker [who was relatively new to the hospital] was also saying that Mrs Smith, another long-timer in that room, was asking about Peg, and that she hadn't known what to say to her. She didn't want to give the bad news, and didn't know what the policy was, or the routine was for this. The nurses said, no, it would have been OK to tell her, she needed to know. The social worker also said that some of Peg's cards were still on the wall above where her bed had been. ... The nurse went to get them, and I said to her that she'd got the job of telling Mrs Smith. Yes, she said. When she came back I asked her how it was. She said that Mrs Smith was sad, but that she was OK; her son was with her. And that she had reinforced to Mrs Smith that everyone is different, and that she must focus on the fact that she wasn't going to die in the hospital, she was planning to go home.

This revealed more about the possible motivations of moving Peg to a single room. The social worker, I believe, was concerned about breaking bad news to Peg's room-mates for fear of upsetting them about the death of a friend. The nurse was concerned that Mrs Smith may be reminded of her own death by the occurrence of Peg's demise. It did appear that moving dying patients to single rooms was "sequestering" death and the dying process.

Reflecting on the notes I made about Peg's death, I was obviously surprised by it, and recorded various aspects of this situation. I particularly noted the attitude of the nurse on whom it had fallen to break the news to Peg's room-mate. I thought she had dealt matter-of-factly with the situation while showing sensitivity to the issue of reassuring Peg's friend. The ability of some of the staff, such as this nurse, to move seamlessly from the routine of ward tasks, to displays of empathy in considering others' responses to loss and tragedy, and back to resume the ward routine struck me. Again the notion of the "extraordinary being the ordinary" in the daily routine of the staff came to mind.

Further demonstrations of the extraordinary being the ordinary are seen in the care extended to family members at these times. Although some patients do die alone, others have many family members who keep vigil by their bedsides. Overnight stays of family members are accommodated in various, sometimes innovative, ways. Often the family members prefer to stay by the bedside, and in some cases the only provision for this is to doze in a chair by the bedside. If possible, recliner rockers are provided, which are a little more comfortable than sitting in the normal visitors' chairs for the night. One of the units has camp beds that are provided for the family members to use. I noted in particular several Asian families, who had many family members, gathered around the dying patients' beds. One man had six or more family members sleeping, or dozing around his bed.

Staff support families through these times. Additional meals are ordered for immediate family members. I saw other family members bringing in food, and either using a lounge area within the ward, or sitting with the patient to eat their meals. Families sometimes take it in turns to return to their homes, shower and change their clothing to return for another period of staying with the patient.

I observed some families continuing this routine for up to a week. They would be exhausted. I had conversations with some of these visitors, and also overheard them speaking with members of staff, amazed that the patient could continue to stay alive.

Often they reached the point of saying that they would be glad when it was over, when the patient had died. Staff also maintained a vigil of caring for the families, "going the journey" with them, taking time to explain the subtle changes in the patient's condition, and what might next be expected.

Death

Obviously, in a palliative care ward the death of a patient is not uncommon. However, whenever death occurs it requires an immediate response from staff to attend to the patient, and more importantly, to support the family.

I saw some families who coped very calmly with the actual death. Other families, however, were extremely upset. Some families engaged in culturally based expressions of grief. Although I did not witness the event, I was told about a Lebanese family who wailed around the patient's bed in response to his death. A student nurse recounted the story to me, and said that it was an awful commotion and that the family was distraught. I asked another member of staff about the incident, and her perception was that it was culturally appropriate and the ward had not been unduly affected by the reactions. I was interested to hear this diversity of perceptions and felt that it reinforced a need for understanding cultural reactions in response to death.

Rituals: Respect for Patients and Staff Coping Strategies

Of greater interest in trying to understand palliative care were some of my observations of staff reactions to death. Although people often use euphemisms for death, I did not expect similar terminology to be used among the staff in these units. However, it is commonplace to see "RIP" with a date and time next to a deceased person's name in a ward diary or on the patient list in the office. Staff also often use the term "passed away" instead of saying that someone has died. This language appears to be commonplace, and occurs in each of the units. Perhaps staff are merely using the common vernacular, although the impression I gained was that people, even those working in palliative care, find it difficult to be blunt when discussing someone's death and need to soften the language to make the message more palatable.

More intriguing than the language are some of the practices that I observed in relation to laying out of patients. Although staff consider these practices to be respectful of the dead person, I found some of what I witnessed to be highly ritualistic and, as an "insider-outsider," quite difficult to comprehend. I was reminded of some of the basic tenets of ethnography, namely to ask not only what do I see these people doing, but

what do these people see themselves doing (Spradley & McCurdy, 1972, p. 9). These are some of my observations.

Fieldnote: 11 June 2001

A patient had died this morning. I didn't really know her. ... I asked one of the nurses if I could go in and have a look at the way she was laid out. There was obviously a towel under her neck, and so her mouth was a bit strange. ... There was a lovely quilt on [the bed], a patchwork quilt. And starched linen, like a scarf around her neck. I guess that was hiding the towel. She had one hand up and one beside her. There was a rose on her pillow. There were also a couple of starched tablecloths on the bedside table and the overbed table, and a bible open with a sprig of something on it. And the touch-lamp was on.

I had not seen these practices before, at least not to this extent. My experience of either participating in laying out people who had died, or witnessing the process, was merely washing the body, putting fresh clothes on and fresh sheets on the bed. On a rare occasion I had seen a rolled towel placed under the jaw to stop the mouth from hanging open, and very occasionally in the home care setting in particular, I had suggested that a family member might like to pick a flower from the garden to place beside the patient's head, on the pillow.

I was intrigued by the procedure at this unit, and paid particular attention to other situations.

Fieldnote: 19 June 2001

[The Italian man finally died. He had looked so emaciated while he was alive, I wondered how he would look now he was dead.] I said to one of the nurses ... had he died? Yes. I commented on how he had looked. She said, "You should see him now." Well, seeing this man laid out, I didn't really think he looked much better. This is only the second body I've seen prepared by the staff. They either pack something hard up under the chin so the mouth doesn't flop open, or they pack the oral cavity. Somehow the neck looks almost webbed. It's not very natural. However, I guess they think it looks good. And all the linen and the famous quilt of course. (Each ward seems to have one.) I was going to say "not how I'd do it" but realised that I really haven't fully explored exactly what they do yet.

Personal Journal: 19 June 2001

I thought it was a bit kitsch actually. But they'd obviously gone to some trouble. ... Someone said ... Heath are renowned for how well they lay out people. Several people said this actually. The nurses at the time, and later when I was talking about things in general, the bereavement coordinator, not a nurse, commented. She said that funeral directors often comment on this. There was a sense of pride from all involved. I was appalled. I thought of those people who for the last hours of their lives had received physical care, and no stimulation, no company, and

yet their "dignity" and "respect" translated to how much attention was given to the artefacts of laying them out.

I continued my exploration of what these rituals meant to the staff involved, and observed some more of these "laying outs."

Fieldnote: Wednesday 20 June, 2001

It's just been two occasions previously [I've seen bodies laid out]. ... The equipment, quilt, pillow case, Bible, flower on pillow, other vases of flowers in the room, starched table covers, lamp, one hand out of the covers resting on the chest. This man did look quite good, apart from being dead and a bit yellow. I think it's a waxy look that dead bodies get. Yellow and shiny. The blinds are half drawn. There's a box of tissues for the relatives [relatives] and a few chairs ready for them also. The lady who died, I offered to help with laying her out. The two nurses said that it would be helpful to pack up her belongings. This provided an opportunity to see how they did prepare the body. They washed her and put on a clean nightie. Then the quilt, a starched pillowslip, another on the overbed table. They left the room with the photos, her personal photos, still on the pin board. (I had already packed them up in her bag, so I was asked to get them out again.) A lamp switched on, blinds drawn. Bible open to Psalm 23. Flowers on the pillow slip, and in her hand, the right arm placed over the chest. Wendy the nurse said, "It's The Heath Way and I've never forgotten it." I asked what was. She said something about dignity for the person. This nurse ... talked about her parents' deaths. Her father, who had a bandage around his chin and was wrapped up in a sheet. And how awful that had been.

I reflected about the concept of dignity for the patient. Was this a display of dignity, or a ritualistic process that assisted staff to cope with some of the sadness associated with the death of a patient, or both? Many of the staff commented on how good patients looked when they had been laid out The Heath Way. Although such ritualistic laying out only occurred at one unit, at other units similar concerns for preserving the dignity of the dead patients were expressed. In the following example, Maxine became very upset because, in her opinion, the undertakers collecting a dead person from the unit failed to show the level of respect that she believed the patient deserved.

Fieldnote: 6 April 2001

Maxine [nurse] was talking again. She was really upset about the lack of dignity for Mr Symes who got carted past everyone by the funeral directors taking the body out of the ward. This was the night of the wine and cheese function, so there were family around as well as patients. "Why didn't they put him in the lounge?" They could have done all these

things. She was really quite annoyed, or upset about this. I thought, is this really concern for the man's dignity?

The motivating attitudes of the staff in reacting to these situations is purported to be preserving dignity for the patient. Given the emotional responses of staff to these situations, it may also be that preserving dignity, or the rituals practised to preserve patient dignity, is an important aspect of staff coping strategies. Wolf (1993) studied various nursing rituals, postmortem care being one of them. She wrote about the latent meaning of this ritual for nurses. Wolf suggests that laying out is nurses' continuation of therapeutic care for the patients, until the gradual relinquishment of responsibility (p. 283) with collection of the body by the orderlies. In palliative care it appears that this final act of caring becomes an important, and sometimes complex, ritual to those caring for the patient, and that is not fully appreciated by those, such as me as observer, not directly involved in the care.

Summary

Observing practices within the units provides a spectrum of palliative care that is difficult to summate. There are some striking differences between the units, most notably the use of technologies and the emphasis placed on the importance of social activities. Similarities between the units I noted to be the emphasis on patient comfort and support for families. Interpretations of these fundamental principles, however, are very different. This further supports the notion that there are different understandings of the practice of palliative care and adds to the difficulty of adequately articulating its meaning.

CHAPTER NINE

UNDERSTANDING PALLIATIVE CARE:

A SYNTHESIS AND DISCUSSION

In the opening chapter I set the scene for this research by outlining the position of palliative care within the Australian health care system and the importance of understanding palliative care in this environment. In this closing chapter I provide a synthesis of the findings from my research, the purpose of which is to add to the understanding of palliative care in the Australian health care context. Within this chapter I also identify limitations of the study, and make suggestions for the direction of future research in this area.

The Research Questions

The purpose of this study was to clarify understanding of palliative care by examining the micro-culture of palliative care practice in a selection of Australian palliative care services. This was achieved by using an ethnographic approach to interpret both the implicit and explicit interactions apparent within these social contexts, and exploring the internal components, processes, rules, and behaviours within these palliative care cultures. The research questions were:

What is the shared understanding of palliative care in Australia?

What are the differences in understanding of palliative care?

The following is a discussion of understanding of palliative care in the context of the Politics, Place, People, and Practice that I studied during this research.

Understanding Palliative Care: Politics

Palliative care in each of the three study locations in Australia grew out of the ideologies presented by Cicely Saunders and Elisabeth Kübler-Ross and emerged at roughly the same time in each location. The individuals who championed palliative care were those who not only had an interest in exploring an alternate model of caring for people who were dying, but also were able to secure resources and pilot these initial programs. Evolution of services within the three cities followed an opportunistic path and this pattern of development resulted in a disparate emphasis on aspects of care within each city. This development laid the foundation for various interpretations of palliative care that I encountered in this research, placed within the broader context of the cities in which the services were located.

One interpretation of palliative care is of a continuum of palliative care based on the level of technology and associated costs of care. Implicit in this interpretation is a bio-medical emphasis on care. This was the palliative care I found within the Waratah region, where it was theoretically possible to match the perceived bio-medical needs of patients with the most cost-effective service in the area. Although in practice there was much overlap between services, attempts were made to optimise both inpatient and outpatient services. This was particularly the case at Waratah Palliative Care Ward, where the highest level of technologically based services was available and where the highest bed-day costs were incurred. Palliative care at Waratah was described by staff as "acute palliative care," underpinning the bio-medical emphasis of this palliative care.

In contrast, a range of discrete palliative care services emerged as another interpretation of palliative care from the research undertaken at Heath. Within this region palliative care constituted a variety of services offering a variety of treatments. While there was awareness of other services and what they offered, there was little coordination or communication between services. Rather than a continuum of palliative care in which patients were matched with services that were perceived to best meet their needs, it seemed that patients were not readily able to move between services, and that the care offered to them was governed by what was routinely available at a particular service. Therefore, palliative care in this environment was understood within the context of a specific service rather than an overall approach to care, and could range from acute inpatient and consultative services to "extended care" or nursing home-type facilities.

A third interpretation of palliative care emerged from the study based at Numbat, and is one in which services appear to be integrated, offering a similar range of

treatments despite having no formal lines of coordination or overarching administrative body. Within this region, communication among the services was possible because of the contained environment of a small city and was most likely enhanced by having a well-developed home palliative care service. The home care service provided care throughout the metropolitan area and acted as a conduit to link the inpatient facilities, resulting in an integrated palliative care service, despite having different management bodies. Patients appeared able to move through this palliative care system according to choice, often based on convenience of location, rather than a need for specific treatments or financial constraints.

Diversity and Common Difficulties

Australia is a geographically large country with a relatively small population. Some people might assume that palliative care, emerging at about the same time in various locations, is practised in much the same way throughout the country. However, the findings of this study indicate that, rather than homogeneous palliative care, there is a diversity of palliative care practice, at least within three major Australian cities. Interpretations of palliative care appear to depend on factors that include the historical development of services, the structure of the governing health authority, and the size of the population served.

Notwithstanding the different interpretations of palliative care encountered, in each of the sites staff expressed frustration at the lack of support for palliative care, the challenge of competing alongside acute care for funding and recognition, and difficulties explaining palliative care to people outside their service. Staff talked about administrations' lack of understanding of the need for resources, such as staffing levels or the cost of painting and decorating the units, and of conflicts with specialists from other areas. The underlying message was that palliative care was misunderstood, consequently it was under-resourced, and that people working in the area were fighting to champion the cause.

These results are similar to those found in previous work, in which inadequate funding, low profile, and lack of support for palliative care were noted by palliative care nurses (Webster, 1999) and long-term palliative care workers were described as "soldiering on" despite being under-resourced and poorly supported (Webster & Kristjanson, 2002b). Many people I encountered during the conduct of this study were encouraging of research that attempted to provide a better description of the nature of palliative care, specifically because it was perceived that it would help support "the

cause.” A common view was that palliative care is the “under-dog” of the health care system.

Understanding Palliative Care: Place

The services initially chosen for study in this research were selected for similar characteristics, namely inpatient units that had been established as palliative care services for several years. All were in some way attached to a parent facility, and had previously been used for some other type of health care service. As previously discussed, addition of a fourth facility that differed considerably from these criteria was largely serendipitous, and provided an invaluable contrast by which to examine the places of palliative care practice.

Palliative Care Environments: Home Away From Home?

Within each of the three study sites attempts had been made to create environments that differed from other wards within the parent hospitals. This was achieved by creating colour schemes that differed from their austere hospital surroundings, through allocating spaces for non-hospital activities such as lounge areas, and through the use of soft furnishings such as curtains and cushions that added ambience as well as comfort to these areas. Artefacts, including paintings and pets such as tropical fish and canaries, added further interest and “homeliness” to these environments.

These spaces also included the trappings of medical facilities; hospital beds with bedrails, commode chairs, hand-basins, soap dispensers, and multi-bedded rooms. Not only were there obvious signs of medical care, but sounds from call bells, nebulisers, patients coughing and struggling for breath, and the smells of faeces, urine and disinfectant. Despite attempts to improve the décor of these environments, there was little doubt that these were health care facilities.

The literature suggests that most people, if given a choice, prefer to die at home (Kaur, 2000; Saunders et al., 1995), and that palliative care environments are home-like, welcoming places (Bridge, 1989; Charles-Edwards, 1983). However, rather than being home-like atmospheres, a more accurate description of the units in this study is that they were less institutionalised environments than the health care spaces that surrounded them. Attention to the aesthetics of the units were attempts to make the best of the environments, and make them appear less hospital-like.

Similar findings were reported in earlier work (Webster & Kristjanson, 2002a) in which long-term palliative care workers described their work as “making the best of an awful situation” and environments as being full of “fun and laughter” (p. 21), despite the sadness of people dying. Control of the environment may be part of an overall mission of palliative care workers to make the best of things, a reaction against the “awful situation” that is ultimately death and grief. In this way, palliative care extends not only to palliation or “cloaking” (G & C Merriam Co, 1975) of disease-related factors, but also of the physical environment in which care is provided. Attention to physical aspects, such as the décor of the units, is one tangible way of cloaking the situation, to “make the best of things” for people who are dying.

Understanding Palliative Care: People

The people involved in palliative care practice in this study were identified as patients, family members, and staff. Patients and family members were a relatively homogeneous group throughout the study sites; however, the staff mix varied considerably. The following provides an overview.

Patient Profiles

Criteria for admission to each facility were similar in many respects. Adult patients, having a life-limiting disease, were admitted for symptom control and support as well as for terminal care. One service, which utilised state-of-the-art technology of its parent hospital, further stipulated that the ward was for “*short term* [italics added] acute symptom control.” Patients’ length of stay was generally shorter here than at the other units, although often patients stayed longer than anticipated due to their declining condition or uncertainty about their prognoses. Overall, patient characteristics were similar in each of the facilities.

All patients were diagnosed as having an incurable disease, most usually cancer. The majority of patients were elderly (60 years and older), the youngest were in their forties. The few non-cancer patients, who generally had multiple medical problems, were sometimes transferred from other units specifically to die and were only in the palliative care units for 24 to 48 hours before death. Other non-cancer patients remained in the palliative care units for extended periods of time, in several cases up to 12 months, with the reason given for the extended stay being a lack of available alternatives.

Staff expressed concern about caring for these patients, querying whether this was appropriate use of the palliative care units. Perceived problems with short-stay admissions were that often only physical care was possible, with the implication that staff did not have an opportunity to prepare patients psychologically or spiritually for death. Long-stay admissions were considered to be inappropriate because these patients required high levels of physical care that detracted from time spent with other patients. In general, it appeared that patients with symptoms related to progression of cancer, who required treatment to either stabilise their symptoms within a defined period of time or terminal care to support them until they died, were considered by staff to be the most appropriate to receive care in these settings. These attitudes influenced decisions about which patients would be admitted to the units, and most likely about which patients were referred to the units.

In each of the study facilities, lack of understanding about different cultures was apparent. Communication with non-English speaking patients could be problematic, staff mostly relying on English-speaking family members to interpret for patients and other family members. There appeared to be little discussion with either family members or patients about the cultural meaning of patients' illnesses and impending death. Lack of understanding about cultural practices in general and death practices in particular was apparent. For example, staff expressed impatience with religious practices, such as family members praying around the bedside, when this involved more than one or two family members and when the prayers were conducted loudly. From time to time educational sessions about death practices of different religions were conducted for staff, and may have informed staff about some practices, such as preparation of bodies after death. Generally, however, they seemed ill prepared and unsure about offering appropriate care to patients from non-Anglo-Australian and non-Christian cultures. Staff appeared most prepared to care for middle-aged to elderly cancer patients from English speaking, Christian, Australian backgrounds.

Some of the discomfort in caring for certain patients was grounded in concerns about practical issues of meeting patients' needs, such as staffing levels for patients requiring high levels of care, and to some extent skills and knowledge about less familiar diseases and treatments. However, the rigid opinions that some staff expressed about eligibility criteria seemed to be contrary to the notion of palliative care being responsive and flexible in meeting patients needs. Palliative care evolved as a reaction against institutionally driven care (Parker, 1998) and "patient and family centred care"

(Palliative Care Australia, 1999b, p. v) is purportedly a hallmark of palliative care provision. The narrow range of patients and families who were considered eligible to receive this care seems to conflict with this perception of palliative care.

The Family

Each facility acknowledged that the “patient and the family” was the unit of care, and *family* was taken to mean those people who had a significant relationship to the patient, such as the spouse, children and siblings. Family could also include people from patients’ local communities, such as fellow church practitioners. Each of the facilities studied made provision for care of the families within the limits of their respective resources. Policies about visiting hours and numbers of visitors were relaxed, and provision of services ranging from overnight accommodation facilities to tea and coffee making access, were aimed to make visitors feel welcome to the units. Staff specifically sought to explain to family members about changes in patients’ conditions, and gave them opportunities to discuss their feelings about these situations.

Sometimes it was difficult for staff to prioritise which family members to support. At times this resulted in conflicts and over-burden for some staff members. Although the literature suggests that “family” is best defined by the patient (Commonwealth Department of Health and Aged Care, 2000), staff were not noted to confer with the patients about inclusion or exclusion of various family members. Usually, they deferred to the one or two people whom they assumed to be the most appropriate, the perceived “next-of-kin”, but they also attempted to be inclusive of extended family members. Sometimes this could extend to groups of ten or more people, for example patients’ church communities. Trying to support all people involved in the patient and family unit was not only burdensome, but could also result in tensions when staff members tried to support various family factions, as well as advocating for the patients.

Again, interpretations of palliative care, in this case the notion of “the patient and family as the unit of care” (AAHPC, 1994, p. 2) were left to individual staff members to decide. Not only did this create a dilemma for staff members in deciding whom to include as family and dealing with divisions within the patient and family units, it also created an increased workload. Staff, therefore, were balancing the tension between efficiently organising their work and providing their construction of appropriate palliative care.

Staff

One of the major differences between the study sites was noted in the composition, construction, and relationships of the palliative care teams.

Interdisciplinary, multidisciplinary, and core caregiver team models, as depicted in Figures 5 to 8 in Chapter 7, were identified. Interpretations of palliative care were linked to these team models, indeed it is likely that the team models evolved according to the palliative care interpretations of the setting.

Within the interdisciplinary model, approaches to palliative care were holistic, with shared decision making and blurring of disciplinary boundaries. Physical care was no more important than other aspects of care provision, and all team members were encouraged and supported to provide emotional, psychological, and spiritual care to patients and their families within the bounds of their abilities. This was the case, even though the social worker, chaplain, and art psychotherapist, for example, had more formal qualifications in this area. Implicit in this interpretation of palliative care was a shared philosophy of care, regardless of discipline, and respect for contributions to all areas of care from other members of the care-giving team.

In contrast, the multidisciplinary team interpreted palliative care to be holistic care provided by inclusion of staff from different disciplines carrying out particular tasks within their discipline. Some individual team members provided support beyond the bounds of their particular discipline, but this was not expected or actively encouraged. There was also considerable power vested in the Nurse Unit Manager within this team model. The reporting relationships allowed the possibility for the Nurse Unit Manager to be the only person in the team with full knowledge of all aspects of the care being provided to particular patients.

The core caregiving team at Waratah Palliative Care Ward, comprising doctors and nurses, was consistent with the interpretation of palliative care at this service, being mainly concerned with bio-medical care and control of symptoms. Other disciplines were represented and provided care within the palliative care unit, but only doctors and nurses were defined as dedicated palliative care staff.

In each of the study sites, however, despite the different models and interpretations of palliative care practice, the concept of a palliative care *team* was a dominant feature. This was highlighted in the attitudes of the team at Waratah, who had clear constructs about inclusion in their team. Although the allied health staff from the parent hospital performed duties within the palliative care unit, attended palliative care

team meetings, and considered themselves to be part of the team, the palliative care doctors and nurses did not. This was evident in subtle communications at team meetings and exclusion from some ward conversations.

Although team composition varied greatly, attitudes to staff support were quite similar. Staff generally chose to find support for their work in informal ways among their peers, rather than using the formal support mechanisms such as hospital employee assistance programs. They used opportunities at team meetings and handovers to discuss issues of concern. In addition, social events including staff dinners were organised at various times throughout the year, and were viewed as an important part of maintaining team morale. Previous work among long-term palliative care workers also identified that collegial support was valued (Webster & Kristjanson, 2002a, 2002b), and other authors have suggested that sustaining people who work in palliative care is related to a team approach and the value of a shared philosophy towards care (Thompson, Rose, Wainwright, Mattar, & Scanlan, 2001; Vachon, 1997).

Understanding Palliative Care: Practice

Palliative care practice differed considerably between the study sites, reflected in the various disciplines involved within the palliative care team and the different emphases on their various roles. A core principle, however, was attention to patients' symptoms. Treatment of symptoms revealed some of the different interpretations of palliative care.

The Focus of Care: Pain, Other Symptoms, and the Place of Technology

Each palliative care service was principally concerned with managing patients' physical symptoms, most notably pain. A patient complaint of pain was viewed as an "emergency" and precipitated immediate action on the part of the staff. Patients experiencing other symptoms were also of concern to staff, and attention to symptom control was paramount. Approaches to symptom control, however, varied markedly between the services, most notably in the use of technologies.

Several authors have noted advances in knowledge of, for example, pain mechanisms, and the concomitant advances in technology that can enhance symptom control for patients (Billings, 2000; Bruera & Lawlor, 1998; Campbell & Currow, 2002). However, traditionally, palliative care practitioners were highly wary of technological interventions. Palliative care evolved in response to an ignorance of the plight of dying people and approaches that continued to subject patients to aggressive

and futile curative treatments (Aranda, 1999; Elsey, 1998; Kaur, 2000). At some of the study sites, staff used methods that were familiar to them and could be relied upon to ensure patient comfort with minimal intervention. At other study sites recent technologies were advanced, and linkages were formed between palliative care and acute care services. Sophisticated diagnostic testing procedures were also used.

Another common feature of practice in the study sites was the underlying concept of improving patients' Quality of Life, which influenced decisions about methods of symptom control. Quality of Life has been described by Twycross (1999) as relating to "an individual's subjective satisfaction with life, and ... influenced by all the dimensions of personhood – physical, psychological, social and spiritual" (p. 4). In the study sites, treatments that were perceived to enhance, or at least not detract from quality of life were viewed positively. However, there was variation between staff perceptions of the impact of treatments on patients' quality of life. These perceptions were influenced by the underlying interpretation of palliative care within the particular service.

Given that advances in technology now provide options for care that are far less invasive than was the case ten or twenty years ago, decision-making need no longer be based on a simple matter of refusing certain treatments. To do so may be interpreted as being "stuck in a rut." However, staff in some services were reluctant to consider new methods of treatment and preferred to "keep things simple." Perhaps this is understandable after many years working in palliative care, where traditionally technological procedures have been viewed as counter to improving patients' quality of life. Embracing a more technological approach to palliative care may require a major paradigm shift.

In summary, decisions regarding control of symptoms appear to involve a complex process of cost-benefit analyses in which medical possibilities, patients' quality of life, and available resources are all considered. Various interpretations result in tensions related to perceptions of enhancing or detracting from quality of life, as depicted in Figure 9.

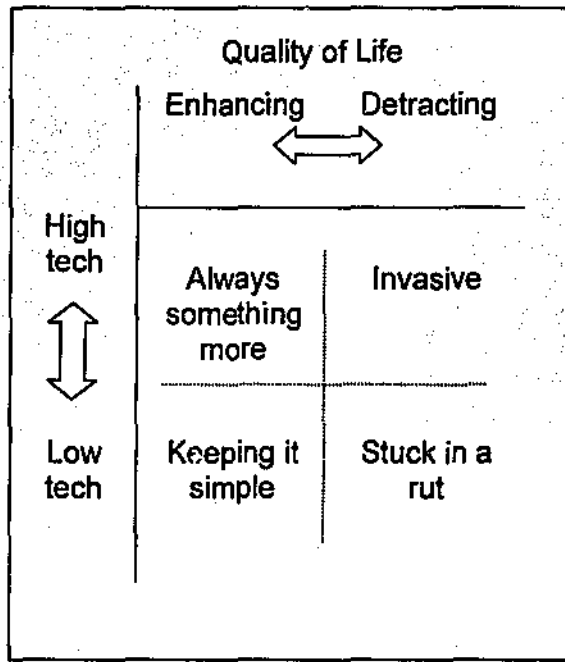


Figure 9: Relationships between perceptions of the use of technology and quality of life.

Psychological and Spiritual Support: Acknowledging the Nebulous

Palliative care principles include acknowledgment that psychological and spiritual issues are particularly relevant for patients approaching their death and for families coping with these events (Saunders et al., 1995; Woodruff, 1999). Existential issues, such as the meaning of life, and psychological distress related to unresolved conflicts, for example, commonly surface at these times (BolmsJo, 2000).

Acknowledgment of these issues, however, does not necessarily provide clarity about how to address them in the care setting, evidenced by the different approaches witnessed in the study sites.

Each facility acknowledged that there were nebulous issues that were important to patients and families within their care, but the emphasis and the designated responsibility for attending to these aspects of care varied. At one site psychological and spiritual care were considered to be the sole province of the hospital chaplaincy services. Other services had dedicated palliative care chaplains, pastoral care workers, social workers, occupational therapists, music therapists, and art therapists who were considered the appropriate people to provide support in these areas. In some services all team members appeared to have a mandate to provide this support; in other teams

individual members, regardless of their discipline, appeared to be comfortable addressing these issues with patients and families and did so. Other staff were clearly uncomfortable and either ignored opening comments made by patients and family members, or sought out other persons whom they considered were more equipped to address the area.

Although from my observations many patients were well supported, there did not appear to be formal mechanisms in any of the services for assessing these needs, planning interventions to address them, or evaluating the outcomes of the interventions when they were addressed. The diversity of approaches to providing care in these nebulous areas, together with the intrinsic difficulties of measuring and communicating them, suggests that there was significant potential for patients and family members to not have these needs met. I encountered some patients and family members who were obviously struggling emotionally and perhaps would have benefited from more support; I suspect there were others with similar but unidentified needs.

Interpretations of the psychological and spiritual aspects of palliative care resulted in a diversity of practice between the services, depicted in Figure 10. Services with a strong focus on psychological and spiritual support included social workers, occupational therapists, art, and music therapists in the palliative care team. These staff were perceived to have specific skills in these areas, and were likely to encourage and support other team members to provide this care to patients and family members. Services with a weak focus on psychological and spiritual care tended to use services outside the palliative care team, such as referral to psychiatrists to assess patients for depression, and hospital chaplains who provided spiritual or religious support throughout the hospital. Individual team members might also take it upon themselves to support people in their care, but this was entirely dependent on the individual staff members' attitudes and availability.

One characteristic of services with a strong focus on the psychological and spiritual support was the extent to which the palliative care providers embraced the notion of "accompanying patients on their journey toward death." This notion of journeying is commonly expressed in both popular and academic publications when discussing psychological and spiritual support for people who are dying. For example, Cassidy (1995) talks about "The Loneliest Journey" being that "which takes us through the 'dark valley' of illness and fear to the gates of death" (p. ii). The idea that palliative care counters the abandonment that may be felt when curative measures cease suggests

that palliative care is about supporting people on this journey. The notion of “going the journey” was apparent in some of the descriptions in the findings. So too, however, was the notion of “dying alone” when patients were both physically left alone, such as when transferred to single rooms, and symbolically left alone without addressing their psychological and spiritual needs.

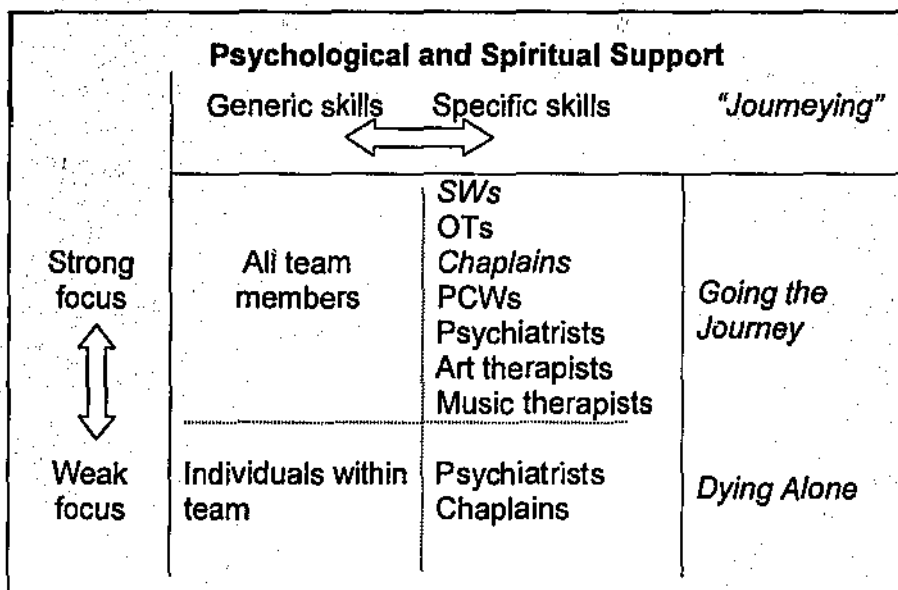


Figure 10: Diversity of approaches to psychological and spiritual support.

Psychological and spiritual care within the study sites was acknowledged as being part of palliative care practice. However, not only was there wide variation in practice between the study sites, there was also a large potential for patients’ and family members’ needs to remain unrecognised.

Social Support: Practical Help and Social Events

Each palliative care unit in the study acknowledged the need for social support for patients and their families. Social Workers’ assistance with welfare issues such as pensions, housing, and transport was universal, but only one service included social events as a high priority in their care provision. Staff at Numbat were committed to hosting luncheons and wine and cheese evenings on a regular basis, convinced that social interaction among patients, families, and staff supported the notion of dying being part of life. Staff also believed that families looked back on these events with a

fondness that overrode some of the patient suffering they had witnessed, and that such memories eased the grief associated with bereavement once the patient had died.

There is little reported in the literature to support this view, although the notion of palliative care as a health promotion issue, championed by Kellehear (1999), resonates with the underlying aims of Numbat's activities. One recent study from the USA, a matched retrospective cohort of elderly bereaved spouses, suggests a longer survival rate of spouses whose partners received hospice care than for those whose partners did not (Christakis & Iwashyna, 2003). Of course, these results cannot be used to generalise about the impact of provision of social activities at Numbat. The study, however, does support opinions of palliative care practitioners who believe that good palliative care has a positive impact on the surviving family members. These beliefs and the testimonials from family members to the staff at Numbat have been sufficient to encourage them to continue these activities.

The organised activities at Numbat prompted identification of the concept "Living Until You Die," one of the catch-cries of palliative care. This is the concept contained in the early writings of Dame Cicely Saunders, who stated that "You matter because you are you and you matter until the moment you die" (1975). In contrast, patients at other services were observed to be left alone once physical care was attended, a concept that could be interpreted as "Waiting to Die." It could be argued that some people, rather than waiting to die, are too fatigued to be engaged in social activities. Fatigue in cancer patients is reported as the most common symptom, and one of the most difficult to relieve (Curt, 2001; Neuenschwander & Bruera, 1998; Porock et al., 2000; Wharton, 2002). Staff at Numbat did acknowledge this, and that sometimes engaging patients to participate in activities of any kind could be problematic. They suggested that it was sometimes difficult to gauge whether patients' disinterest was because of their overwhelming fatigue, or whether they were merely bored.

Understanding Palliative Care: Competing Tensions

The study has identified a diversity of practice across the study sites, underpinned by different interpretations of palliative care. Various tensions, some existing between services, and some even within services, have been identified. These tensions are summarised in the following diagram, Figure 11. For each of these tensions, there are positive and negative anchors. These have been my interpretations of palliative care within the various study sites. In the preceding sections I have attempted

to provide the contexts within which the positive and negative viewpoints of the people involved in palliative care have been interpreted.

<i>Positive implication</i>		<i>Negative implication</i>
Always Something More	←————→	Invasive
Keeping It Simple	←————→	Stuck in a Rut
Going the Journey	←————→	Dying Alone
Living Until You Die	←————→	Waiting to Die
Fatigue	←————→	Boredom

Figure 11: Constructs interpreted from observation of palliative care.

These results indicate that, rather than there being a common operational definition of palliative care across all settings, a so-called “homogeneous palliative care,” the ways in which palliative care is interpreted can vary widely, even within the same country. Clear articulation of these variations is important for all stakeholders: patients and families, staff, funders, and policy makers.

Methodology and Limitations

In Chapter 3 I discussed the methodology used for this study, interpretive ethnography, and the reasons behind this choice. The previous research I had undertaken indicated that close observation and interpretation of palliative care practice was required to investigate peoples’ understandings of the concept. Ethnography allowed for this investigation, examining the overt and implicit aspects of palliative care culture in the study sites. An ethnographic approach proved to be an appropriate choice in meeting the research aims. Using the process of the iterative ethnographic research cycle (Spradley, 1980), namely data collection, recording, and analysis, new ethnographic questions arose. This process allowed the freedom to explore different aspects of palliative care and for the diversity of palliative care practice encountered to emerge.

Design Limitations

There were, however, several limitations to the design, some of which were recognised and accepted at the outset. The decision to examine only three services

throughout Australia, and attempting to draw conclusions about Australian palliative care from this sample, was made because of resource restrictions, including time, of the study. However, choosing three different locations of services resulted in some interesting and important differences, particularly when looking at the historical development of services within the areas and the models of palliative care that have evolved.

The research questions were purposely broad, and as Spradley (1980) suggests, initial observations provided a broad overview with generation of new ethnographic questions narrowing to more focused observations. However, starting from such a broad base, the time limitation of two months in each city was restrictive. The volume of data obtained from two months in each site was, however, enormous. Further time in each site may have provided additional information to the study. However, if further time was available, or future research planned, more targeted study would be an appropriate next step. For example, a series of micro-ethnographies underpinned by more focussed research questions, such as understanding the construction of “family” by palliative care staff, may prove useful rather than continued study of the overarching concept “palliative care”.

Data collection, analysis, and interpretation were conducted as an iterative process both throughout the fieldwork and beyond the observational period of the research. Some analyses were made while field work was being conducted, and could be checked out in subsequent observations. Other analyses, however, occurred over time, some after the periods of observation had finished, and further observation and development of these ideas was not possible.

It was also recognised from the outset that the study was limited to only inpatient facilities, despite the knowledge that much palliative care practice occurs in the community and that governments are encouraging a move to provide more services in the community (Calder, 1998; Commonwealth Department of Health and Aged Care, 2000). Again, time and resource restrictions dictated that boundaries be placed around the research, and the decision was made to limit the study to inpatient facilities where more concentrated observations of practice could be made. Although I spent several days observing practice in the community in the services that included home care teams, these periods of observation were not enough to interpret community practice. Rather, these periods of observation were used to augment understanding of the culture of the inpatient units by reactions and interactions with the home care services.

With hindsight, criteria set for participant involvement in formal interviews was too rigid, resulting in few tape recorded interviews. I conducted many informal interviews, and although I endeavoured to recall and record many points of these conversations, transcripts of tape recordings providing verbatim data would have been useful. I can only trust that recall to the best of my ability has allowed me to make fair interpretations of these many conversations, as well as the contexts in which they occurred. Indeed, as the research instrument for the entire research project, I trust that my interpretations have been a fair representation of the observations I encountered and that I have injected sufficient rigour into the process for the reader to judge it so.

The Research Instrument and Rigour

From the outset, I gave considerable attention to the role I would play as the research instrument for this project. The duality of the nurse-researcher role, the insider-outsider status that being a palliative care professional afforded me, and the risks of “going native” were all aspects of my role which I recognised before entering the research sites, and each of which played out while I was engaged in the research. My accounts of these events through the preceding chapters have been as open and truthful as possible. This reflexivity is one of the measures that I have taken to address the rigour of the research. Inclusion of my personal reflections and subjectivity throughout the thesis may appear strange to some readers, but I believe has been necessary to achieve the authenticity that I have endeavoured to achieve in this thesis.

As discussed previously, rigour in ethnographic studies is concerned with the trustworthiness of the reported accounts. The ethnographic approach in itself demands that the researcher explores the field for truth value, and throughout the research I constantly sought “respondent validation” (Hammersley & Atkinson, 1983) to further add to the rigour. I have also used triangulation, among respondents, between sites, and with results from previous research, to further validate the findings. Again, I leave the reader to judge the trustworthiness of the interpretations presented in this work.

Significance of the Findings: So What and What Next?

The diversity of approaches to care illustrated in this small study of three palliative care services highlights the difficulty in constructing a concise and meaningful definition of palliative care. Indeed, the study has increased understanding about the challenges inherent in previous attempts to clarify the concept and the resultant abundance of definitions and associated terminologies that are found in the literature. Although many broad concepts related to palliative care were common to

each study site, differences in practice resulted from the interpretations of these concepts.

Palliative Care: Philosophy or Practice?

At the outset of this research there was an implicit question raised, "*What is palliative care?*" Having conducted the research and examined the results I have come to the realisation that there may be no answer to *that* question. The research question has evolved with the research. Rather, the questions asked and to some extent answered in this study have been: "*What are the dimensions of practising palliative care?*", "*How are these interpreted in line with contextual limitations of practice?*", and "*What tensions have resulted in these interpretations?*"

At the end of this study, rather than a succinct definition of palliative care, various constructs contained within palliative care have been identified, as shown in Figure 11, each of which represents a continuum along which individual services might be placed. Further observation may result in additional constructs being added to this picture. Rather than homogeneous palliative care, interpretations of palliative care are highly contextual and likely to be constantly evolving within those contexts.

The notion of palliative care as a philosophy or a philosophical approach to care appears to be more appropriate in understanding the concept than searching for a succinct definition of palliative care. Palliative care philosophy is a concept discussed by Saunders (2001b) and suggested by Bruera and Lawlor (1998). The latter authors make the point that "... the great success of palliative care during the last 30 years is due to its ability to differentiate between doing things right and doing right things" (p. 24). This is a subtle and perhaps crucial distinction. Findings from this study suggest that there is no *right way*. Rather, the resultant interpretations of palliative care are contextual and fluid, and a response to the time and place in which it is practiced. There are, however, some fundamental aspects upon which practice is based.

Underpinning all palliative care practice that I witnessed there is a belief that it is possible to improve the subjective experience of dying for people who are on this trajectory. With this overarching goal, there is also a philosophy of making the best of things, of being creative – with space, resources, and with the patients themselves. Palliative care practitioners appear to constantly be standing back and asking "what can we do within the bounds of this situation?" in essence, doing the *right things*.

Implications of the Research

Each of the services studied was interpreted to be making the best of things, although practice occurred in differing contexts, and different interpretations of palliative care were identified. Recognition of this diversity has implications for palliative care planning and policy, particularly in relation to current Australian Government initiatives contained in the National Palliative Care Strategy.

The aim of this strategy is primarily to broaden the focus of palliative care to provide services “that are consistent across Australia” (Commonwealth Department of Health and Aged Care, 2000, p. 1). This statement implies that there should be consistency in meeting a minimum of standards of palliative care across Australia. However, the diversity of palliative care arising from contextual interpretations is unlikely to ensure that there is consistency of services. What is required is a clear articulation of how palliative care is interpreted, such that inconsistencies between services can be identified. Only with a clear articulation of the underlying interpretation of palliative care can decisions be made to either address the gaps between services, or make appropriate use of services to meet identified needs of the patients and families requiring the services.

Further implications relate to the government’s strategy and the aim of delivering palliative care to “all people who are dying.” One issue of concern arising from the research is my perception about staff’s uncertainty in meeting the cultural needs of some people. This has particular significance given the multi-cultural diversity of the Australian population, with 15% of Australians in the 2001 census reported as speaking a language other than English (Australian Bureau of Statistics, 2004). The services examined in this research undertook some educational initiatives to address gaps in staff members’ knowledge but there were no formalised or consistent systems in place for this. Continued acknowledgment of the cultural diversity and attention to understanding the meaning of illness, dying, and death in different cultural contexts appears necessary to fulfil this part of the national strategy.

A second issue also relates to delivering palliative care to all people who are dying, and is concerned with the disease profiles of people receiving palliative care. Lack of representation of non-cancer patients in this study is consistent with the literature, which reports an unmet need for palliative care services for people dying from other diseases (Addington-Hall, Fakhoury, & McCarthy, 1998; Currow, 2001). Services in this study did not perceive that non-cancer patients were overtly excluded

from their care, but underlying attitudes about inclusion of non-cancer patients did appear to create a barrier to including these patients. The issue of providing palliative care to all people who are dying, however, may be more complex than a change in attitude that would widen access to existing palliative care services.

The original focus of palliative care was on patients with cancer, however, it was never intended that palliative care should be limited to that patient group (Saunders, 2001a). Diseases such as progressive neurological conditions, end-stages of cardiac, respiratory, renal and liver disease, and the multiple medical problems including dementia of older people, are reported as potentially benefiting from palliative care (Addington-Hall & Higginson, 2001b; Parker, Maddocks, & Stern, 1999). It has been suggested that palliative care for these patients may require skills specific for their diagnostic group, and the question has been raised about whether palliative care practitioners expand their knowledge base or encourage practitioners in other areas to expand their knowledge base about palliative care (Addington-Hall & Higginson, 2001a; Fallon, 2004). In this regard, extending palliative care to all people who are dying is a complex issue. It is likely to be further complicated by the results of this research, namely that when looking to extend the focus of palliative care to a more diverse patient population, there is substantial diversity of practice within the existing model of care, which is *cancer* palliative care.

Original Significance of the Research

At the outset of this research three factors were identified as having significance for the conduct of this study; the current public focus on end-of-life issues and possible confusion about these issues, the reported need for expansion of palliative care services, and the associated need for increased palliative care funding from a competitive and diminishing health care budget. The findings from this study have immediate relevance to these areas of concern.

The confusion surrounding end-of-life issues that clouds understanding about palliative care would be assisted by providing a clear and concise understanding of palliative care, however, this remains difficult. Lack of awareness about palliative care was discussed in Chapter 1, where I identified that communicating a clear understanding of palliative care was problematic for reasons that included funding arrangements between states and the Australian government, and different models of care such as palliative care in hospitals, inpatient units, and in the community.

As this study has indicated, even within the inpatient model, palliative care is best described in abstract terms of an underpinning philosophy of care, and operationalising the philosophy requires contextual interpretations that consist of a number of dimensions. The diversity of practice observed was not examined in the context of State: Federal funding arrangements, although these may have added to the different political contexts noted between the different cities. Study results indicate that individual services may need to more clearly articulate the dimensions of care, and where they rank on these dimensions. Communication about less abstract constructs of palliative care by articulating these dimensions of care may improve understanding of palliative care among the wider community.

Arguments for expansion of services that were outlined in Chapter 1, namely a likely increase in the incidence of cancer in an ageing population, a shortfall in rural and remote services, and unmet need among non-cancer patients, remain relevant. The issues associated with the latter point in relation to these research findings have been discussed above. Referring again to Chapter 1, concern was noted by palliative care professionals that extending palliative care without due regard to its essence may erode the “essential character and ... unique contribution currently made by palliative care services” (Nightingale, 1998, p. 21). Given the diversity of practice identified in this study, and the range of interpretations among a variety of dimensions, it is unclear what the essential character of palliative care might be, and therefore, what might be eroded. Again, a clear articulation by services of the ranking of dimensions of care that are provided would assist in ensuring palliative care is not diminished with expansion of services.

The third area of significance originally identified for this research was that of a need for increased palliative care funding from a competitive and diminishing health care budget, which also remains relevant. Arguments for supporting and expanding palliative care and attracting the necessary resources need to be strong when there are competing interests from other areas of health care that are no doubt equally deserving. Within the study sites, palliative care interpretations were influenced by the resources available to them. Without clear understanding and articulation of the desired level of dimensions of palliative care, funding levels are likely to continue to dictate how palliative care is interpreted.

A recent consultation document issued by Palliative Care Australia (2004) recognises some of the concerns currently facing expansion of palliative care, including

raising issues about clarifying concepts of palliative care, which the authors of the document concur is considered as both a specialty area of practice and as a philosophy of care (p. 10). This document, unlike this thesis, is a draft *policy* paper, and makes some significant suggestions for a coordinated approach to providing palliative care across Australia. Recognising some of the issues of significance that I too have identified, Palliative Care Australia also acknowledge that there is "considerable diversity ... around the country" but relate this to the "ways that health services have sought to provide *access* [italics added] to palliative care" (p. 12). However, the diversity in dimensions of practice that I have identified in this work and that impact on interpretations of palliative care may further inform policy initiatives, such as this one, in teasing out models of best practice in palliative care.

The findings of this study suggest that the current situation of identifying a generic need for "more palliative care" requires refinement. There is a need to be more explicit about the *type* of palliative care particular services are to provide, and for individual services to clearly articulate their practice models and ranking on various dimensions of palliative care practice.

Future Research

Expansion of this research could be undertaken to address some of the gaps that I identified in the initial design of the study. Micro-ethnographies to further investigate attitudes towards referral of non-cancer patients to services, investigation of services in other sites such as rural areas of Australia, and a similar study of community-based palliative care, are some of the directions for research that may add to understanding of palliative care.

As well as conducting further ethnographic studies, some specific areas for comparing outcomes of care would be useful in developing best practice models for palliative care. Investigation of the various team models may prove useful, with measurement of outcomes for staff in relation to support and stress reduction as well as recruitment and retention issues. Positive outcomes for staff may also impact on outcomes for patients and families, given some of the research relating to the caring relationship in palliative care such as notions of reciprocity and professional friendships (Barthow, 1997; Trygstad, 1986).

Some research and discussions have been presented in the literature about the use of technological interventions, outcomes for patients, and attitudes of caregivers towards the use of various technologies in palliative care (Archer, Billingham, &

Cullen, 1999; Rouseau, 2002; Vitetta, Kenner, Kissane, & Sali, 2001). However, given the diversity of practice and attitudes that underpinning the interpretations of palliative care that were encountered in this research, further investigation appears warranted. Examination about availability of technological options, uptake of those options, and cost-benefit analyses in terms not only of financial costs, but also patient outcomes including quality of life, place of care, and length of survival, would be useful.

Diversity of practice in psychological, spiritual and social dimensions of care are also areas for further development. Recently published clinical practice guidelines for the psychosocial care of adults with cancer (National Breast Cancer Centre and National Cancer Control Initiative, 2003) may provide direction for these aspects of care that will result in less diversity of practice. Of particular interest for future study is the area of social activities that were such an intrinsic part of the interpretation of palliative care at one of the study sites, and the effects of these activities for patients, family members, and staff. Although it may be difficult to design a study to measure impact on health outcomes for these populations, research into these areas would provide invaluable information about the health promotion aspects of providing social support, and influence best practice models of care for surviving family members.

Conclusion

In this concluding chapter I have drawn together the interpretations made from ethnographic observation of four Australian palliative care services to answer the research questions "What is the shared understanding of palliative care?", and "What are the differences in understanding?" Rather than providing a succinct answer to the underlying question, "*What is palliative care?*" results of the research show a diversity of practice that is best understood within the context of the particular service. The major findings are summarised in the following paragraphs.

Although palliative care professionals held common notions of being the "underdog" of the health care system, political forces within those systems, including the historical opportunities for development of services, resulted in variations of approaches to palliative care according to location. Common approaches to provision of care were found in creating an appropriate physical environment for patients, with an underlying mission to "make the best of things." This was seen as a further expression of palliation, cloaking an otherwise institutional environment with home-like decorations.

Patients cared for in the palliative care settings were a similar cohort of middle aged to elderly cancer patients, and family members were included in care in all of the services. In general, staff shared expectations of appropriate types of patients and showed discomfort or lack of understanding in caring for non-cancer patients, or patients from non-Australian, non-Christian, and non-English speaking backgrounds. There were, however, significant differences in the composition and reporting relationships of the palliative care teams in the different sites, interdisciplinary, multidisciplinary, and core caregiver models being represented. Regardless of the team model, palliative care workers found support from informal relationships with colleagues and valued these relationships.

Fundamental aspects of palliative care practice, such as the notion of holistic care, the importance of symptom control, and acknowledgment of psychological, spiritual, and social aspects of care provision, were present in each of the sites. Interpretations of these aspects, however, revealed several dichotomous attitudes towards the same concepts. One notable example was in the use of technology, where procedures could be viewed as both enhancing and detracting from quality of life. Diversity of palliative care practice was highlighted in the range of technology used in the different services, as well as the social activities that were a major focus in one service, and virtually absent in the others. These two areas in particular, use of technology and of social activities, are worthy of further research to explore cost-benefit ratios in terms, not only of pecuniary investment, but also outcomes for patients and family members including survival time and quality of life.

Implications of this research are particularly relevant at this time when the Australian Government is providing support and promotion of palliative care to ensure access for all dying people within Australia. The diversity of practice uncovered in this small sample of Australian services suggests that not only is awareness of palliative care necessary for these activities to succeed, but a clear articulation of the *interpretation* of palliative care is also necessary if all stake holders' expectations are to be met.

This ethnographic study of palliative care practice was undertaken with the aim of improving understanding of palliative care. The diversity of palliative care practice uncovered serves to provide a deeper understanding of the complexities of palliative care.

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APPENDIXES

APPENDIX A

**Attitudes towards palliative care: A preliminary survey of
nurses and community members**

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Research Report

November 1999

The purpose of this study was to compare attitudes towards palliative care held by four different social groups who had different prior experiences of palliative care. The model of attitude formation provided by Zanna and Rempel (1988) that postulates relationships among attitudes, beliefs (cognitive information), feelings (affective information), and behaviours (information regarding past behaviour or behavioural intention), was used to guide this study. The four groups included were palliative care nurses, non-palliative care nurses, bereaved persons, and community members. These groups theoretically represent a range of individuals who may have different palliative care attitudes, beliefs, and feelings, according to differences in past behaviour. In this case, past behaviour refers to the extent to which these individuals had been exposed to palliative care.

Definition of Terms

For this study, palliative care nurses were defined as Registered Nurses who had at least two years experience post-registration and who had worked in a palliative care service for a minimum of two years. Non-palliative care nurses were Registered Nurses who had at least two years experience post-registration and had never worked in a palliative care service. Bereaved persons were individuals who had been identified by a palliative care service as being the significant family member or friend in the provision of care to a patient of the service, who had subsequently died. The death occurred at least twelve months prior to the study. Community members were defined as adult, English speaking members of the community who had not had direct experience of palliative care services either as a provider or as a consumer (patient or bereaved), and who were not health professionals. A palliative care service was a recognised provider of palliative care as listed in the Directory of Hospice and Palliative Care Services (Australian Association of Hospice and Palliative Care [AAHPC], 1997).

Other Variables of Interest

Demographic variables including age, gender, education level, religion, and socio-economic status were collected to allow description of the sample. In addition, these variables were assessed with respect to attitudes towards palliative care as there is some empirical and theoretical literature to suggest that they may have been relevant. For example, Hamel and Lysaught (1994) described possible influences different religious beliefs could have in relation to attitudes toward palliative care, and a recent Australian study reported that patients level of symptom distress may be associated with their socio-economic status (Kristjanson et al., 1998).

Selection of health professionals for the study was limited to nurses. The interdisciplinary team is integral to palliative care (Woodruff, 1993) and a larger study of attitudes to palliative care would ideally have included representatives of various disciplines. However, palliative care nurses are acknowledged as major contributors to the team, having most continuous contact with the patient and family, and coordinating much of the team functioning (Carson, Williams, Everett, & Barker, 1997; Greene, 1984). Therefore inclusion of only nurses was appropriate for the purpose of this study.

There is some evidence that formal education and personal death-related experiences may influence attitudes toward dying patients (Brent, Speece, Gates & Kaul, 1991; 1992-93), and questions were included regarding formal palliative care

education (for both groups of nurses), and recent experience of death of a close family member or friend (for both groups of nurses and the general community). Responses to those questions were also examined in relation to attitudes toward palliative care. These questions were designed to allow the researcher to confirm the accuracy of assignment of participants to sample groups on the basis of experience of palliative care, rather than in relation to education, or to death-related experiences.

One further inclusion in the study was that of behavioural intention toward palliative care services. Considerable discussion exists within the psychology domain regarding the relationship of attitudes to predicting behaviour (Breckler & Wiggins, 1989; Eagly & Chaiken, 1993; Greenwald, 1989). The possible prediction of behaviour in relation to attitude to palliative care was beyond the scope of this study. However, questions were included regarding participants' intention to use palliative care services in the future, and the relationship between attitudes toward palliative care was to be examined. It was thought that results from this analysis may result in the development of hypotheses testing in subsequent research projects.

Research Questions

The research questions for this study were:

1. What beliefs and feelings are generated in response to palliative care?
2. To what extent are there differences in attitudes towards palliative care among the four groups?
3. What is the relationship between (a) beliefs about palliative care and attitudes towards palliative care, and (b) feelings about palliative care and attitudes towards palliative care, for the four groups?

If there were no differences between the groups, then

4. What is the relationship between (a) beliefs about palliative care and attitudes towards palliative care, and (b) feelings about palliative care and attitudes towards palliative care, for the entire sample?

The following relationships were also examined.

5. What is the relationship between attitude to palliative care and demographic variables of age, gender, religion, education level, and level of income?
6. What is the relationship between attitude to palliative care and (a) palliative care education (b) recent experience of death of a close family member or friend?
7. What is the relationship between attitude to palliative care and behavioural intention to use palliative care services?

Literature Review

Using a model of attitudes proposed by Zanna and Rempel (1988), Cohen (1995) investigated three groups of nurses working in nursing homes in metropolitan Perth in relation to their attitudes to the attitude object "palliative care in nursing homes". The groups were directors of nursing and clinical nurse specialists (one group), registered nurses, and nursing assistants (n=76 in each group). Beliefs,

feelings, knowledge and overall attitude to palliative care in nursing homes were measured. It was found that cognitive (beliefs) and affective (feelings) information significantly and independently predicted attitudes of nurses, and that knowledge contributed to attitudes of the first group, but was not a significant contributor to attitudes of registered nurses or nursing assistants. Cohen's study was, however, restricted to nurses in nursing homes, and made no comparison of nurses working in different environments, nor of residents', families', or community members' attitudes.

Comparisons of attitudes to palliative care between palliative care nurses and general nurses were not found in the literature, although some comparative studies, examining differences between palliative care nurses and other nurses, were forthcoming. Brockopp, King, and Hamilton (1991) reported that palliative care nurses (n=32) were found to have more positive attitudes towards death and less death anxiety than nurses working in areas less likely to encounter death, such as psychiatry (n=44) and orthopaedics (n=29). Other comparative studies have looked, for example, at differences in knowledge of pain management finding that hospice nurses (n=48) had higher knowledge scores than intensive care nurses (n=52) ($Z = -3.3176$; $p < 0.001$) (Fothergill-Bourbonnais & Wilson-Barnett, 1992). Steele and Melby (1995) also compared hospice, hospital and community nurses knowledge and beliefs about AIDS, in which hospice nurses (n=14) were reported as being more knowledgeable, exhibiting a more positive approach and being less fearful.

Attitudes to palliative care of staff in a curative environment were reported by Kinzel, Askew and Godbole (1992). Generally positive attitudes to palliative care were reported amongst nurses (n=117) and doctors (n=16) employed at a Michigan veterans hospital. Self ratings of levels of satisfaction, feelings of depression, discouragement, and confidence in providing technically competent care were examined in relation to care for terminally ill patients. However, the survey, whilst stated as reflecting attitudes to palliative care, appeared to more precisely reflect attitudes to caring for terminally ill patients. Another study reported opinions of hospital medical (n=17) and nursing staff (n=23) in relation to management of terminal illness in a Paris University Hospital (Vidal-Trécan et al, 1997). Almost half (48%) the nurses surveyed defined the terminal care period as "nothing further to be done" and three of the 17 physicians involved in the study referred to palliative care units as "death departments". Only one physician wished to see a specific palliative care unit in the hospital. These attitudes, of course, must be viewed in the context of cultural and social forces (Vidal-Trécan et al., 1997). However, Prior and Poulton (1996) described their experiences in acute Australian hospitals, and commented on the "paradox" of providing palliative care specialities in a curative environment. They related some of the staff comments, such as viewing palliative care as "failure", refusing services because "the patient is not that bad", and the palliative care nurse as "sister death".

Such comments as these noted by Vidal-Trécan et al. (1997) and by Prior and Poulton (1996), suggest that unfavourable attitudes toward palliative care may prevail amongst hospital nurses and doctors not working in palliative care. On the other hand, palliative care nurses have been noted to generally find reward and satisfaction in their work, describing it as a vocation rather than a job (McNamara, 1996). These observations are indicative of a favourable attitude towards palliative care.

Surviving carers are reported to express greater satisfaction with patient care provided in hospices than in hospital settings (Seale, 1991; Wakefield & Ashby, 1993). However, survivors' attitudes towards palliative care have not been reported, and may be unfavourably influenced by memories of the death of a loved one rather than the positive responses to the care received.

There is a dearth of research addressing community attitudes to palliative care, although attitudes to end-of-life decisions were looked at in a Queensland survey in which 67% (259) of medical practitioners and 53% (486) of community members responded (Steinberg, Najman, Cartwright, MacDonald & Williams, 1997). Community members were found to support greater choice and control over end-of-life decisions compared with medical practitioners. The study reported that 17% of community members had a family member who had received palliative care services and that responses were unrelated to this experience of palliative care. However, responses to end-of-life decisions may not be indicative of attitudes towards palliative care and further, there may be differences among members who have different prior experiences of palliative care services.

In summary, review of the literature suggests that differences in attitudes towards palliative care between palliative care nurses and non palliative care nurses may be found. Attitudes of surviving carers and community members are unknown. This study aimed to broaden the scope of Cohen's research by examining attitudes of a wider range of individuals towards palliative care, and beyond the nursing home domain.

Attitudes

In everyday language the term attitude has several connotations. Some colloquial uses of the term imply personal characteristics, such as a bad attitude, a poor mental attitude, or merely "attitude" - implying a type of arrogance. However, more commonly, an attitude is taken as the opinion held towards some object or issue. This latter use of the term is the one most consistent with that used in the psychology and social sciences domain (Eagly & Chaiken, 1993). Within psychology there have been various approaches to attitudes over time.

Different definitions and ways of operationalising the term "attitude" are noted in the literature. Ajzen and Fishbein (1980) restrict the term to "a person's evaluation of any psychological object" (p. 26). Bem (1970) simply described attitudes as likes and dislikes. Zanna and Rempel (1988) comment that definitional issues arise that are centred around debate between a single versus multicomponent viewpoint of attitudes.

Zanna and Rempel (1988) describe attitudes as "items of social knowledge, built from the experiences, beliefs, and feelings generated by the attitude objects" (p. 315). The conceptualisation of attitudes as "the categorization of a stimulus object along an evaluative dimension based upon, or generated from, three general classes of information: (1) cognitive information, (2) affective/emotional information, and/or (3) information concerning past behaviours or behavioural intentions" (p. 319), provides useful direction for the research problem underpinning this study.

History and definitions of attitudes.

Ostrom (1968) cited the period between 1930 and 1950 as being marked by significant activity in the study of attitudes, and considered this the emergence of

attitude theory. Early contributions were notably that of attitude measurement, attributed to Thurstone, and attempts by Allport to integrate various approaches.

Allport in 1935, (cited in Pratkanis, 1989, p. 72) defined an attitude as "a mental and neural state of readiness, organized through experience, exerting a directive or dynamic influence upon the individual's response to all objects and situations with which it is related." Criticism of this definition arose because of the assumption of predicted behaviour, Pratkanis preferring a definition free from theoretical assumption, namely ... "a person's evaluation of an object or thought" (p. 72).

Other definitions have also suggested behavioural links, for example Rokeach (1968), who further conceptualised attitudes as enduring rather than momentary. "An attitude is a relatively enduring organization of beliefs around an object or situation predisposing one to respond in some preferential manner" (Rokeach, 1968, p. 112). Eagly and Chaiken (1993) suggested that more appropriate than "enduring" is the term "tendency", as some attitudes are temporary. Further definitions and ways of operationalising the term "attitude" include Ajzen and Fishbein (1980) who restricted the term to "a person's evaluation of any psychological object" (p. 26) and Bem (1970) who simply described attitudes as likes and dislikes. Eagly (1992) conceptualised attitudes as evaluative tendencies and in a general definition applicable to the various approaches provided by Eagly and Chaiken (1993), attitude was defined as ... "a psychological tendency that is expressed by evaluating a particular entity with some degree of favor or disfavor" (p.1).

A reconceptualisation of attitude construct.

Zanna and Rempel (1988) identified some of the issues in the study of attitudes to include multicomponent versus unitary conceptualisations of attitudes, attitudes as enduring dispositions versus episodic assessments, and the relationship between affect and evaluation, sometimes considered to be the same concept, sometimes seen as distinct entities. In response to these issues, Zanna and Rempel (1988) offered a reconceptualisation of the attitude construct, defining an attitude as ... "the categorization of a stimulus object along an evaluative dimension based upon, or generated from, three general classes of information: (1) cognitive information, (2) affective/emotional information, and/or (3) information concerning past behaviour or behavioural intentions" (p. 319). Further elaborating, the "evaluative dimension" was seen as a value comparison, the simplest form being good or bad, and "categorization" implying a level of cognition before a value judgement can be made. Attitudes therefore they considered to be items of knowledge.

Zanna and Rempel (1988) stressed the importance of examining the detail of the attitude, provided by the contribution of beliefs, feelings and behaviours. Their concept was an attempt to combine and explain other models, by examining which source or sources of information the attitude is based upon. Thus both unitary and tripartite models were considered. Further they suggested that the stability of an attitude is to some extent, dependent upon the source of the information which is dominating in that evaluation. This afforded an explanation for the episodic nature of some attitudes. Attitude "ambivalence" may occur when sources of information provide contradictory implications to the overall evaluation, creating seemingly inconsistent and variable attitudes. It is suggested that the stability of an attitude may be strengthened by the degree of congruence between the sources of information upon which it is based. The issue of discriminating between attitude and affect was

supported by Zanna and Rempel who regarded affective information as one of three possible sources on which the evaluation may be based.

Model selection for attitude measurement of palliative care.

Examining the various approaches to attitude measurement, the model described by Zanna and Rempel was thought appropriate for this study, allowing both an evaluative measurement of the attitude object "palliative care" and examination of the sources of information contributing to formation of the attitude. Zanna and Rempel (1988) recommended that attitude be measured independently, using a simple rating or evaluation measure of the attitude object, such as favourable-unfavourable. Affects, cognition and past behaviour were recommended to be measured using participants' recall and their direct ratings. Correlational strategies were suggested by Zanna and Rempel (1988) as being useful for comparison of groups whose attitudes may be different, or indeed the informational bases of attitude formation may differ.

Method for attitude measurement.

The semantic differential scaling method has commonly been used for attitude measurement (Eagly & Chaiken, 1993). Traditionally this consists of a series of bipolar adjectives, each rated on a seven point scale. A single item semantic differential of Favourable-Unfavourable would follow the suggestion of Zanna and Rempel to use an evaluative measure of attitude. Cohen (1995) used this methodology to measure attitudes toward the attitude object "attitudes to palliative care in nursing homes", and used participants' free-responses to generate beliefs and feelings.

As an alternative to the traditional approach of using ratings of prepared checklists, Eagly, Mladinic and Otto (1994) used free response measures to investigate cognitive and affective bases of attitudes towards social groups and social policies. They criticised the traditional approach as being likely to reflect attitude-consistent responses and not individual beliefs and feelings toward the attitude. Therefore a single item Favourable-Unfavourable semantic differential scale to measure attitudes towards palliative care, and free-response measures to generate beliefs and feelings in relation to the attitude object, palliative care, was selected as appropriate methodology for this study.

Conceptual Framework

The model of attitudes as proposed by Zanna and Rempel (1988) provided the conceptual framework for this study. (See Figure 1). The attitude construct was conceptualised as attitude toward the attitude object, "palliative care". Information from past behaviour, as one of the sources of information in the model, was conceptualised as the independent variable, of which there were four levels, namely palliative care experience as a provider (nurse), consumer (bereaved), or no palliative care experience as provider (nurse) or consumer (community member). The cognitive source of information was conceptualised as "beliefs about palliative care", and the affective source as "feelings about palliative care". Additional variables were added to the model to examine relationships in respect to attitude towards palliative care.

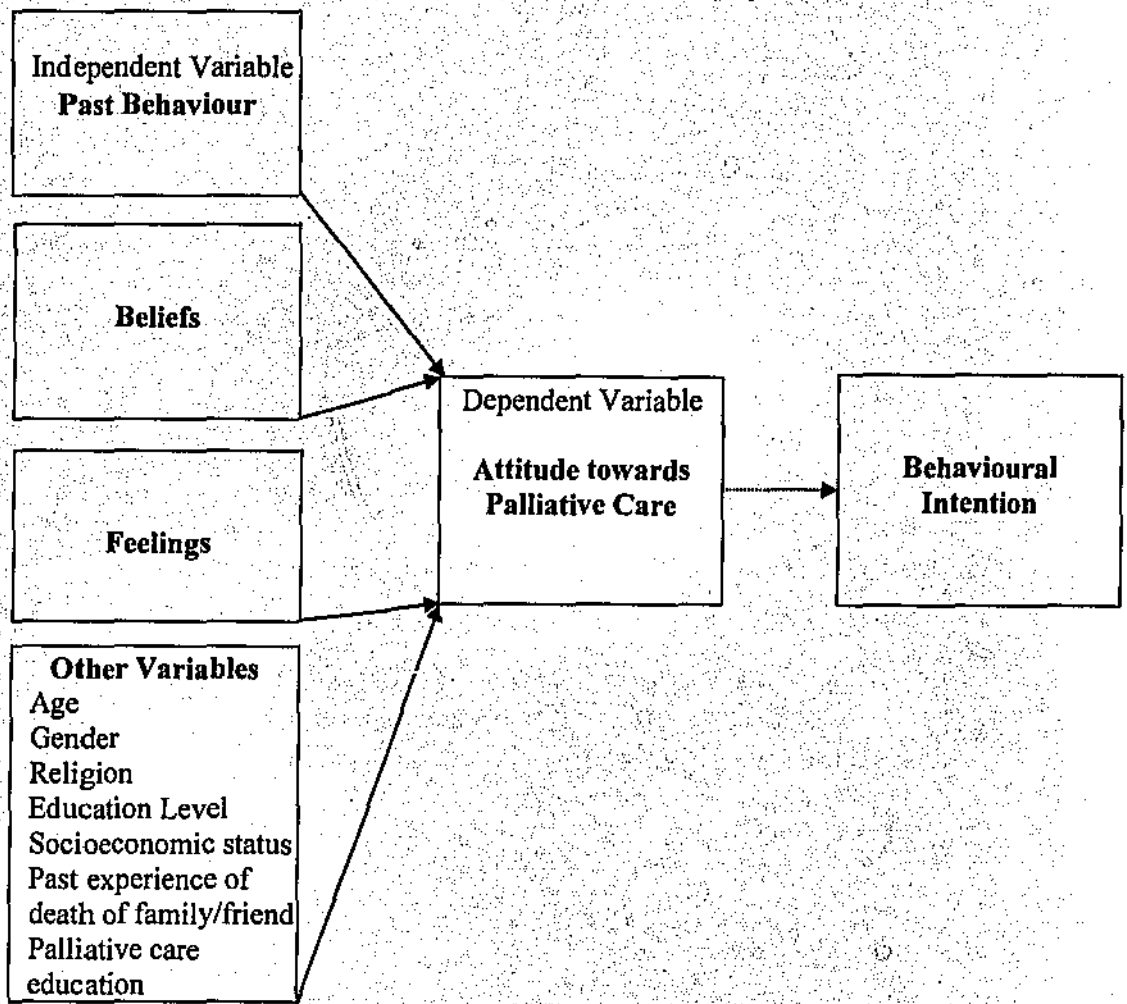


Figure 1: Conceptual framework of attitude formation.

Design

This study was a comparative survey of differences among groups. Attitude to palliative care was the dependent variable. Group membership, of which there were four levels, was the independent variable. The study included a qualitative analysis of beliefs and feelings about palliative care, and examined other factors that may be associated with attitudes to palliative care.

Pilot Study

A pilot study was conducted using a convenience sample of 32 participants, eight from each of the four groups. To enable measurement of test-retest reliability, the tool was administered twice, with a one-week interval between data collection given that attitudes would be unlikely to change during this period. Overall response rate was 97%, with 27 (84.4%) participants returning surveys at both time intervals.

Participants in the pilot study were predominantly female (75%) with an average age of 46 years. Participants were reasonably well educated with 55% having attended college or university; annual family income showed a bimodal distribution with approximately 30% of respondents having an annual family income of \$40,000 or less and approximately 35% having an annual family income of over \$70,000. Little variation was found amongst participants according to religion, with approximately 60% indicating their religion to be either Catholic or Protestant, and the remaining 40% selecting the "no religion" option.

Aims of the Pilot Study

The aims of the pilot study were to identify potential sources of response errors, areas of ambiguity, the time required to complete the instrument, and to determine the test-retest reliability of the instrument. Questions regarding the survey were asked at both time points. Feedback indicated that between half and three quarters of respondents had difficulty with the survey, which took about half an hour to complete. (Responses are summarised in Table 1.) In addition, twelve respondents (48%) at Time 1 and seven (28%) at Time 2 commented that they had difficulty with the section that asked them to list emotions. Difficulty with the rating scale was expressed by 3 (11%) at both time points, who also stated that the survey was "hard". However, nine participants (32%) were supportive of the aims of the study itself.

Table 1: Feedback from Pilot Study Respondents According to Group at Time 1 (T1) and Time 2 (T2)

	Palliative care nurses		Non palliative care nurses		Bereaved persons		Community members		Total	
	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2
Number providing feedback	8	7	6	4	6	7	8	7	28	25
Number expressing difficulty	5	5	6	2	4	3	6	5	21	15
%	62.5	71.4	100	50.0	66.7	42.9	75.0	71.4	75.0	60.0
Average time taken (minutes)	27	20	30	25	32	22	31	23	30	22

Sources of response errors and ambiguity of questions.

The section that asked respondents to report feelings about palliative care was reviewed and indicated that some refinements were needed. Although some comments indicated that participants had difficulty reporting "feelings about palliative care", and some requested a checklist of emotions, only one participant did not complete this section of the instrument. All other respondents were able to generate some emotions in response to the attitude object "palliative care". Several responses given were beliefs rather than emotions, although these numbered only 10 out of 194 (5%) responses given at Time 1, and 4 out of 188 (2%) responses at Time 2.

Ambiguity.

Comments made by some participants indicated an ambiguity in the scoring method. It was not clear whether the scores given for beliefs and feelings reflected how favourably participants responded to palliative care, or if their responses indicated the strength of their beliefs and feelings. As well, one participant noted that it was confusing having one scale (1 to 7) for scoring "attitude towards palliative care", and another (-3 to +3) for the belief and feeling scales.

Difficulty of the survey.

Review of the instrument suggested that the instrument appeared bulky and that formatting may have made the instrument appear overly complex. Several comments indicated that instructions were not clear, and that examples given may also have been confusing.

Response bias.

Whilst reviewing the pilot instrument it was also noted that the accompanying letter could have been a source of bias. The content of the letter gave strong

indication of the researcher's involvement and commitment to palliative care. This, or the personal contact the researcher had with this convenience sample for the pilot study, may have accounted for the small range of responses in scoring "attitude towards palliative care". Table 2, frequencies of responses by group, shows the range of attitude scores obtained for Time 1 and Time 2.

Table 2 Pilot Study: Frequencies of Attitude Scores by Group

Attitude Score: Possible Range = 1 to 7	Palliative care nurses		Non palliative care nurses		Bereaved persons		Community members		Total	
	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2
N	8	8	7	6	7	7	8	7	30	28
Attitude score = "7"										
n	7	7	5	3	7	5	5	4	24	19
%	87.5	87.5	71.4	50.0	100	71.4	62.5	57.1	80.0	67.9
Attitude score = "6"										
n	0	0	1	2	0	2	1	2	2	6
%			14.3	33.3		28.6	12.5	28.6	6.7	21.4
Attitude score = "5"										
n	0	0	0	0	0	0	2	1	2	1
(%)							25.0	14.3	6.7	3.6
Missing scores										
n	1	1	1	1	0	0	0	0	2	2
(%)	12.5	12.5	14.3	16.7					6.6	7.1

Revision to the instrument.

Feedback from the pilot survey resulted in changes to the instrument in preparation for use in the main study. Clarity was improved by rewording the instructions, changing examples given, listing examples of emotions, and re-formatting the survey forms. Rating scales used for all scores were consistently structured from -3 to +3. The perceived difficulty of the survey was addressed by adding a comment to the accompanying letter, acknowledging that the type of survey may be new to the participant, and offering telephone contact with the researcher if clarification was needed. The letter was also changed to reduce the previous bias of encouraging positive responses to the attitude object, "palliative care".

Reliability.

Test-retest of the pilot survey was undertaken to investigate the stability of responses over time, in this case a one-week period. This reliability was assessed using Spearman's correlation rho (r_s), comparing attitude scores at the two time points, as well as belief and feeling score subscales.

Correlations were $r_s = 0.74$, $p < 0.01$, ($N=25$) between attitude scores, $r_s = 0.68$, $p < 0.01$, ($N=27$) for the belief scales, and $r_s = 0.87$, $p < 0.01$, ($N=24$) for the feeling scales. These findings provide evidence for the stability over time of the measurement method. According to Nunnally and Bernstein (1994) reliability estimates for an immature/newly developed instrument should be at least 0.70.

Discussion

Results of the pilot study were limited by the sample size, the possible bias introduced in the letter sent to participants, and the lack of clarity in the instrument. The negatively skewed distribution of attitude scores obtained at both time points of the study indicated that respondents used an abbreviated range of response items. Several factors may have influenced these findings. The social desirability effect arising from the bias of the letter sent to participants, together with a positive scaling measure, from +1 to +7, may have suggested that a positive response was required in relation to attitude towards palliative care. It was felt that using a scaling measure with possible scores from -3 to +3, as was the case for scoring the belief and feeling scales, may prompt greater recognition of the dichotomous possibilities of the scoring scale. It was also noted that respondents in the pilot study were predominantly female, and reported a high level of education. This pilot sample therefore were more likely to have had a caregiving role, and possibly a more informed attitude towards health care issues generally, and in turn have been more likely to indicate support for palliative care.

Main Study

Four groups were required for this study, each to meet the criteria as previously specified. The target number for each group was forty. Sample size was based on a power analysis for ANOVA (Cohen, 1977). A sample of 160 was required to detect a 0.25 difference, $u=3$, $\alpha=0.05$ with 74% power.

Palliative care nurses were initially sought from two of the palliative care services in Perth, although to achieve the target number, additional services were approached during the study. Non-palliative care nurses were recruited from general wards (not specialist units) of one of the teaching hospitals in Perth. Bereaved persons were identified by staff of two palliative care services in Perth, and approached to assist with the study. In each of these three cases, representatives of the institutions involved were requested to distribute the surveys to potential participants who met the stated selection criteria to ensure that anonymity of participants to the researcher was maintained.

Community members were recruited by the researcher using a random sample of 200 names from the current edition of the Perth white pages telephone directory. Random number generation was matched to page numbers of the directory. Telephone contact was made to establish criteria and willingness to participate in the study. The selected telephone numbers were used until a "hit", considered to be someone answering the call (rather than an answering machine), was achieved. Once answered, discussion with the person was undertaken to ascertain if they met the inclusion criteria and were willing to participate in the study. Of the 200 phone numbers used to recruit this group, 69 people met the criteria and agreed to participate, and were subsequently mailed a survey. People not meeting the criteria totalled 46; 23 because they had personal experience of palliative care, 12 because they were health professionals, another six were deemed to have difficulties communicating in English, and five people were under the age of eighteen. There were 56 people contacted who declined to participate; 42 refused outright without giving a reason (and they were not asked), nine said they were too busy, and five stated that they were too old. At the time when recruitment ceased, 29 of the 200 numbers selected remained unassessed; nine of these were connected to answering machines, and 20 telephone numbers remained unanswered. Table 3 summarises the response rates for all groups recruited for the main study.

Table 3: Response rates for recruitment to the main study by group

	Period of recruitment	Distributed	Invalid returns	Received (valid returns*)	Response rate (valid returns) %
<u>Palliative care nurses (Group I)</u>					
PCU** 1	11 weeks	19	0	12	63.2%
PCU 2	11 weeks	30	0	9	30.0%
Additional sources	6 weeks	27	0	18	66.7%
Total	18 weeks	76	0	39	51.6%
<u>Non palliative care nurses (Group II)</u>					
Hospital 1	14 weeks	200	4	39	19.5%
Total	14 weeks	200	4	39	19.5%
<u>Bereaved persons (Group III)</u>					
PCU 1	14 weeks	80	3	28	35.0%
PCU 2	15 weeks	74	11	15	20.2%
Total	20 weeks	154	12	43	27.9 %
<u>Community members (Group IV)</u>					
Total	15 weeks	69		39	56.5 %
Total	21 weeks	499	16	160	32.1%
All Groups					

*Survey returns were considered to be 'valid' if an attitude, belief, OR a feeling score was given. Several surveys were returned without any data. Two surveys were returned with demographic data only, and were therefore not included. Further, feelings given by one participant did not relate to palliative care (but rather to the crime rate, which was referred to as an example of how to complete the survey). These feelings and accompanying scores were also omitted from the analysis.

** Palliative Care Unit (PCU)

Instrument

The instrument used was a self-administered questionnaire, comprising four sections, which was a modification of the pilot instrument resulting from the issues identified in the pilot study. (See Appendix 1 for the revised instrument).

Demographic Profile of Participants

The demographic details of participants in the main study are summarised in Table 4. The majority of respondents in each group were female (73% overall), with an average age of 48 years, although the average age of Group III respondents, bereaved persons, was higher at 62 years. This might be expected given the

likelihood that these participants were probably bereaved spouses of patients involved with the palliative care services. The majority of participants in each group were of a Christian religion (73% overall). Most participants, 71% overall, were well educated, having either a trade or professional qualification, which held for each of the four groups. Family income levels were lowest for bereaved persons, which may be indicative of this older age group no longer being in the workforce, and if widowed, being a single income family. Nurses generally reported a higher family income, and 46% of palliative care nurses had an income above \$70,000 per annum. Palliative care nurses represented an older age group than the general nurses, and their higher incomes were probably indicative of double income families.

Table 4: Main Study Participants' Demographic Variables

	Group I Palliative care nurses n = 39	Group II Non palliative care nurses n = 39	Group III Bereaved persons n = 43	Group IV Community members n = 39	Totals** Missing data not included n = 160
Male	4	4	16	19	43
Female	35	35	27	20	117
Average age (years)	47	38	62	46	48
Age range	27-61	20*-56	28-89	27-74	20-89
<u>Education Level</u>					
Didn't complete high school	2	0	11	3	16
High school	7	4	10	10	31
Trade, Uni	30	35	23	25	113
<u>Religion</u>					
Christian	29	23	37	27	116
Jewish or Buddhist	1	2	1	0	4
No formal religion	9	14	5	10	38
<u>Family Income</u>					
Up to \$10K	0	0	8	2	10
\$11-40K	6	11	18	10	45
41-70	15	19	6	17	57
Over \$70K	18	8	6	7	39

* One participant aged 20 may not have met inclusion criteria of being a registered nurse with at least listed two years post-registration experience. A decision was made to include this participant's responses, which showed no particular anomalies compared to other respondents' data.

**Missing data not included. Totals will not tally with total responses per group.

General Responses to the Survey

The pilot study identified several areas of concern with the survey instrument and measures were taken to correct these deficits by revision of the survey instrument and rewording of the accompanying letter. Returns of the main survey however, suggested that problems still existed with the design of the instrument.

One of the major sources of confusion occurred in the interpretation of the scores given to self-generated beliefs and feelings. The survey instrument requested scoring from -3 to +3 to indicate "a rating according to how favourable or unfavourable to palliative care you consider that belief [or feeling] to be" (see Appendix). It was not clear whether participants fully understood this rating system, or rated responses according to the strength of the belief or feeling expressed. For example, the response "palliative care is soundly resourced" was expressed as a belief with a rating of -3. Did this participant consider that palliative care was indeed well resourced and this detracted from the favourability towards palliative care, or did this participant strongly believe that palliative care was under-resourced? In this instance the participant gave favourability towards palliative care a +3 score and other responses indicated an overall support for palliative care. Without recourse to explore the meaning of the response, the intent was not known.

Scoring of some other responses appeared to be incongruous. For example, one respondent rated palliative care favourably, with a score of +2, and the belief "palliative care gives patients a purpose in life" was rated -2, that is, the belief had an unfavourable impact on attitude towards palliative care. The dilemma in interpreting the survey became whether this participant intended to mean that they considered providing a purpose in life is at odds with what palliative care should be providing, or did this person believe that palliative care does not provide a purpose in life? Again, the anonymity of the survey meant that it was impossible to examine the responses beyond the responses given on the survey forms. This suggested that a more in-depth analysis of beliefs and feelings about palliative care was required to ascertain the factors that contribute to attitudes towards the concept.

Consideration was given to making some attempt to interpret the intent of the scoring and adjust the scores accordingly. However, it was felt that because it was not possible to accurately assume the intent of the respondents, the raw scores would be used for the statistical analyses required for the study.

A further shortcoming noted in the returned responses was lack of differentiation between beliefs and feelings. Table 5 shows the number of beliefs and feelings generated, and also the number of "feelings" that did not express an emotion.

Table 5: Number of data items given as Beliefs and Feelings about palliative care by group

	Group I	Group II	Group III	Group IV	Total
<u>Items given as beliefs about palliative care</u>					
Beliefs	300	201	200	201	902
Participants	39	37	41	38	155
<u>Items given as feelings about palliative care</u>					
Total "feelings"	276	160	168	143	747
Participants	39	38	40	35	152
"Feelings" not expressing an emotion (% of total "feelings")	20 (7.3%)	41 (25.6%)	20 (11.9%)	45 (31.5%)	126 (16.9%)
Participants	8 (20.5%)	12 (31.6%)	12 (30.0%)	12 (34.3%)	44 (28.9%)
(%)					
<u>Total items given as beliefs and feelings about palliative care</u>					
Responses	576	361	368	344	1649
Participants	39	38*	42*	38*	157*

*Three participants did not record any beliefs or feelings.

The total number of combined data items generated by the survey was 1649 with only three participants not recording any items. Of the total 747 "feelings" responses, 16.9% were considered to not express an emotion, and therefore more appropriately labelled "beliefs" about palliative care. The participants generating these items represented 29% of those responding to this section. This may be attributable to the apparent difficulty of the task. Anecdotal reports also suggested that expressing a belief rather than an emotion may be linked to socialisation of people generally to avoid being overly assertive, couching beliefs in statements commencing "I feel that ...", rather than the more assertive statement "I believe that ...". Further investigation was considered to be beyond the scope of this study.

Unlike the pilot study in which feelings were given as, for example, sad, angry, concerned, the emotions generated in the main study were often qualified. For instance, "I feel angry that palliative care is underfunded by the government", was a response given by a palliative care nurse. Rather than an analysis of the emotion "anger", a more meaningful analysis resulted from an analysis about concern for funding of palliative care by people working in the area. Therefore, individual

content analyses of beliefs and of feelings were not undertaken, but rather an analysis of all responses, and frequencies of categories of responses by respondents, was recorded. Frequency by respondent was deemed to be a more appropriate measure than overall number of responses given in a certain category, because some respondents were likely to give multiple responses about the same topic.

Research Questions

With these limitations in mind, the following research questions were examined.

Question 1: What beliefs and feelings are generated in response to palliative care?

A content analysis was performed on data obtained from the survey Sections 2 and 3, self-generated beliefs about palliative care, and self-generated feelings (emotions) about palliative care respectively. The analysis for the main study was conducted by combining belief and feeling items and the content considered in the context of each group. As previously stated, it was felt that this provided a more meaningful analysis of what different groups of people considered about the subject "palliative care".

Table 6 provides responses for the top 10 items for *all* respondents.

Table 6: Combined responses of respondents in each group, with top 10 rankings for all groups.

	I n=39	II n=39	III n=43	IV n=39	All n=160	Rank
Overt support for palliative care – eg. an essential service	12 30.8%	28 71.8%	18 41.9%	15 38.5%	73 45.6%	1
Family – in some way included in care	18 46.2%	25 64.1%	Implicit	13 33.3%	56 35.0%	2
‘Dignity’: dying with dignity	1 2.6%	8 20.5%	27 63.0%	9 23.1%	45 28.1%	3
Easing family’s burden, supporting, reassuring, being available			31 72.1%	11 28.2%	42 26.3%	4
Inadequate funding	21 53.8%	9 23.1%	5 12.8%		35 21.8%	5
Pain control / analgesia		20 51.3%	12 27.9%		32 20.0%	6
Staff are / should be special / experienced		14 35.9%		15 38.5%	29 18.1%	7
Patient choice / patient centred care.	11 28.2%	11 28.2%		5 12.8%	28 17.5%	8
Choice re place of care				1 2.6%		
Concern that some people do not receive palliative care – eg. non-cancer diagnoses, country people, all socio-economic groups	15 38.5%	2 5.1%	3 7.0%	6 15.4%	26 16.3%	9
Low profile/ lack of support	14 35.9%	6 15.4%	1 2.3%	5 12.8%	26 16.3%	9
Emotions: sadness, fear, depression, unhappiness			26 60.5%		26 16.3%	9

	I	II	III	IV	All	Rank
	n=39	n=39	n=43	n=39	n=160	
Participants who had residual sadness/depression (ie. expressed these feelings and DID NOT express feelings of support)			4 9.3%		22 13.8%	10
Frightened at prospect/difficult to discuss				18 46.2%		
Need palliative care education for all health personnel, including medical students, GP's	14 35.9%				22 13.8%	10
Doctors are in control, palliative care is seen as defeat. Patients are not referred early enough.		8 20.5%				

The responses tabled above represent a vast array of opinions regarding palliative care and issues surrounding palliative care. These responses can be grouped into several broad categories. However, it remains necessary to consider the context of the responses in relation to membership of the different groups in the study. The following discussion considers some of the results in this context.

Support for palliative care, feeling supported, and the flip side – feelings of sadness and fear.

All groups expressed overt support for palliative care, representing a total of 46% of all respondents. It should be remembered that the statements given were self-generated and not part of a structured survey. Therefore, it cannot be assumed that participants who did not state an opinion interpreted as “overt support” did not support palliative care, merely that there was no mention of that in the responses given.

Within this category of responses, items that indicated sadness or fear about the topic were given by community members, 61% of bereaved persons, and 46% of general community members. Family members indicated that they felt sadness, fear, depression or similar emotions at the time of losing a loved one, which was not an unexpected finding. A large proportion, 72%, of this group also stated that they felt reassurance or support from their experience of palliative care. Individual responses were examined and it was discovered that 9% of this group mentioned the “negative” emotions without also mentioning feeling supported. This figure was considered to be a group who had “residual sadness”, although once again the free response methodology does not allow any certainty to be made of this conclusion. Overall, 16% of the bereaved persons seemed to be dissatisfied with palliative care. In respect

to the general community, 28% expressed reassurance that palliative care services were available should they be required.

Awareness issues.

This category of responses was decided on the basis of responses given that admitted to not understanding the meaning of palliative care, or gave responses that were considered to not reflect palliative care practice. Only general community members gave such responses, 23% indicating that they did not know about palliative care. Some participants gave responses that obviously confused palliative care with nursing home facilities, and 23% made specific reference to aged care in some way.

Aspects of care.

Various aspects of care were mentioned. Family inclusion was recognised in some way by many participants. Bereavement and grief support however, although mentioned by 28% of palliative care nurses was only included by 1 (2%) family member. Patient choice was not mentioned by family members but was by each of the other groups, 18% overall. General nurses (51%) frequently mentioned pain control or analgesia in association with palliative care although no palliative care nurses listed this. Again, palliative care nurses expressed concern about some of the aspects perceived to be lacking in palliative care, 10% mentioning research, and 8% concerned that palliative care was becoming too technical and reverting back to a medical model.

Issues surrounding dying, moral and ethical concerns.

This issue of dignity was expressed by 28% of participants, 63% of bereaved persons mentioning this. Quality of life was a concept mentioned by 12% of all participants, and 26% of palliative care nurses.

Mention of euthanasia was made by a total of 20 (12.5%) participants, 28% of palliative care nurses, 10% of non palliative care nurses and of general community members, and only 2% of bereaved persons. However, given that it has been clearly stated by Palliative Care Australia (formerly AAHPC) that euthanasia is not a part of palliative care practice (Palliative Care Australia, 1999), it is interesting that this proportion of participants refer to euthanasia in a survey about palliative care. Obviously there is an association between the two. A closer examination of the responses about euthanasia given by these 20 participants is provided in Table 8.

Table 8: Comments of 20 participants mentioning euthanasia

	Group I	Group II	Group III	Group IV
Concerned that comparison of euthanasia with palliative care detracts from support for palliative care	5			
Euthanasia and palliative care should not be compared	3			
Comparison raises palliative care profile	1			
Palliative care is the preferred alternative to euthanasia	3	2		
Euthanasia should be legalised		1		1
Euthanasia is wrong			1	1
Euthanasia is included in palliative care		1		2

These responses indicate that, among these participants, palliative care nurses are generally concerned about the comparison of euthanasia with palliative care, although one participant felt it helped raise the profile of palliative care. One bereaved person believed that euthanasia was wrong. Among non-palliative care people, two general nurses felt palliative care was the better alternative, others supported euthanasia or assumed that it was included in palliative care practice.

Palliative care staff issues, including relationship with other health professionals.

The notion of team was expressed by 39% of palliative care nurses, and 10% of general nurses. It was not mentioned at all by general community members, although this 39% of this group mentioned that palliative care staff are, or should be, experienced. Palliative care nurses were concerned with issues such as linking with other sectors of health care (18%) as well as providing palliative care education (36%). One general community member (3%) was under the misapprehension that "professionals" did not work in palliative care, and mentioned nurses among these non-professionals.

Administrative issues.

This category of responses was considered to include items that referred to issues of health care delivery in general. Over half the palliative care nurses (54%) expressed the idea that palliative care was not adequately funded. This opinion was

also expressed by general nurses and bereaved persons, 22% of participants overall expressing this notion. General community members (44%) were concerned about the cost of palliative care and how it was funded, and two (5%) believed that palliative care was “dollar driven”. A small number of participants in each group considered that more palliative care facilities were needed (5% overall), and 16% of respondents indicated that palliative care had a low profile in the community, with 36% of palliative care nurses expressing this view.

Responses by Group

The following Tables 9, 10, 11, and 12, show the top 11 responses given by each group of participants.

Table 9: Top 11 responses given by palliative care nurses

Response	Number of participants	% of group	Rank
	N=39		
Inadequate funding	21	53.8%	1
Family – in some way included in care	18	46.2%	2
Team	15	38.4%	3
Concern that some people do not receive palliative care, eg. people with non-cancer diagnoses, country people, all socio-economic groups	15	38.4%	3
Low profile/lack of support	14	35.9%	4
Need palliative care education for all health personnel, including medical students, GPs	14	35.9%	4
Overt support for palliative care; eg. it is an essential service	12	30.7%	5
Patient choice/patient centred care	11	28.2%	6
Specific mention of bereavement followup after patient’s death	11	28.2%	6
Mention of symptom control in general	10	25.6%	7
Quality of life	10	25.6%	7

Palliative care nurses responses indicated concern about health service issues, such as resources, facilities and access to palliative care, as well as education for other health professionals as well as the general public (related to the low profile). Care issues included family, team, patient choice, and quality of life.

Table 10: Top 11 responses given by non-palliative care nurses

Response	Number of participants	% of group	Rank
N=39			
Overt support for palliative care; eg it is an essential service	28	71.8%	1
Family – in some way included in care	25	64.1%	2
Pain control/ analgaesia	20	51.3%	3
Staff are/ should be “special”/ experienced	14	35.9%	4
Patient choice/ patient centred care	11	28.2%	5
Inadequate funding	9	23.1%	6
“Dignity”: dying with dignity	8	20.5%	7
Holistic care, including using the terms physical, psychological, spiritual, emotional together	8	20.5%	7
Doctors are in control, palliative care is seen as defeat. Patients are not referred early enough.	8	20.5%	7
Low profile/ lack of support	6	15.4%	8
Team	4	10.3%	9

Non-palliative care nurses generally gave fewer responses than palliative care nurses. They were supportive of palliative care (72%), some participants noted funding (23%) and lack of profile (15%) as issues. The main care issues mentioned were inclusion of family (64%) and pain control (51%). Several comments (21%) were included that indicated frustration with doctors from other areas not referring patients early enough to the palliative care team. The team was noted by 10 %, these comments suggesting that the nurses appreciated assistance from the palliative care team within their hospital.

Table 11: Top 11 responses given by bereaved persons

Response	Number of participants N=43	% of group	Rank
Easing family's burden, supporting, reassuring	31	72.1%	1
"Dignity": dying with dignity	27	62.8%	2
Emotions of sadness, fear, depression, unhappiness	26	60.4%	3
Overt support for palliative care; eg it is an essential service	18	41.9%	4
Pain control/ analgesia	12	27.9%	5
Preference to be cared for / die at home	11	25.6%	6
Overall seemed dissatisfied with palliative care	7	16.3%	7
Warm, peaceful environment, unrestricted visiting	7	16.3%	7
Inadequate Funding	5	11.6%	8
Lack of information from doctors	5	11.6%	8
Participants who had residual sadness/ depression (ie expressed these emotions and DID NOT express feelings of support)	4	9.3%	9

Some bereaved persons expressed concern for issues of funding (12%) however, most issues from this group were related to their personal experience of palliative care. The highest ranking item was feeling supported (72%), although admitting that it was a difficult and sad experience (60%). Care issues were related to dignity (62.8%), dying at home (26%), and some dissatisfaction with care (16%) such as lack of information from doctors (12%).

Table 12: Top 11 responses given by general community members

Response	Number of participants	% of group	Rank
	N=39		
Frightened at prospect/ difficult to discuss	18	46.2%	1
Concerns re cost: expensive, and who pays	17	43.6%	2
Overt support for palliative care; eg it is an essential service	15	38.5%	3
Staff are/ should be "special"/ experienced	15	38.5%	4
Family – in some way included in care	13	33.3%	5
"Dignity": dying with dignity	9	23.1%	6
Palliative care is for old people/ associated with aged care facilities	9	23.1%	6
Admitted to lacking knowledge	9	23.1%	6
Concern that some people do not receive palliative care. It should be available to all especially those with a non-cancer diagnosis, and for country people, and all socio-economic groups	6	15.4%	9
Quality of life	6	15.4%	9
Patient choice/ patient centred care	6	15.4%	9

Many general community members admitted to fear or discomfort when considering the topic of palliative care (46%). A similar number (44%) were concerned with the expense of the services, although 39% expressed support for palliative care. Care issues included mention of staff and the need for them to be experienced (39%), inclusion of family (33%), the concepts of dignity (23%), quality of life (15%), and patient choice (15%). Some misconceptions were held, 23% equating palliative care to aged care. Several participants acknowledged that they lacked knowledge about the topic (23%).

Research Question 2: To what extent are there differences in attitudes towards palliative care, among the four groups?

The following table, Table 13, summarizes data obtained for attitude score by group. Of the 160 participants included in this study, only six (3.8%) expressed a neutral or negative (unfavourable) response towards palliative care.

Table 13 Main Study: Frequencies of attitude scores by group

Attitude Score: possible range -3 to +3	Group I	Group II	Group III	Group IV	Total
'+3'	30	26	35	25	116
(%)	(77.0%)	(66.7%)	(81.4%)	(64.1%)	(72.5%)
'+2'	8	7	5	8	28
(%)	(20.5%)	(17.9%)	(11.6%)	(20.5%)	(17.5%)
'+1'	0	1	1	2	4
(%)		(2.6%)	(2.3%)	(5.1%)	(2.5%)
'0'	0	0	1	2	3
(%)			(2.3%)	(5.1%)	(1.88%)
'-1'	0	0	0	1	1
(%)				(2.6%)	(0.63%)
'-2'	0	1	0	1	2
(%)		(2.6%)		(2.6%)	(1.25%)
'-3'	0	0	0	0	0
(%)					(0%)
Missing	1	4	1	0	6
(%)	(2.5%)	(10.3%)	(2.3%)		(3.75%)

Research Question 3: To what extent are there differences in attitudes towards palliative care, among the four groups? As well, to what extent are there differences in belief scores and feeling scores among the four groups?

The average attitude, belief, and feeling scores for each group are summarised in Table 14.

Table 14: Average Attitude Scores, Belief Scores and Feeling Scores by Group

	Palliative care nurses	Non- palliative care nurses	Bereaved persons	Community members	Total
<u>Mean Attitude Scores (range -3 to +3)</u>					
Mean	2.789	2.600	2.762	2.308	2.617
SD	0.413	0.946	0.617	1.217	0.865
N	38	35	42	39	154
<u>Mean Belief Scores(Range -3 to +3)</u>					
Mean	1.893	2.326	2.360	1.413	1.999
SD	1.216	1.139	1.057	1.370	1.250
N	39	37	41	39	156
<u>Mean Feeling Scores (Range -3 to +3)</u>					
Mean	0.886	1.783	1.858	0.762	1.329
SD	1.142	1.337	1.498	1.552	1.468
N	38	38	40	38	154

Using the Kruskal-Wallis one way analysis of variance by ranks, there was no significant difference in attitudes towards palliative care between the four groups. Significant differences however, were found between the groups in relation to feelings scores, chi-square=20.047, df=3, p=0.000, and belief scores, chi-square=20.110, df=3, p=0.000. Mean ranking for both feelings and beliefs scores were bereaved persons, non palliative care nurses, palliative care nurses, and general community members. Although these results were statistically significant, little can be surmised about these findings because of the known difficulties with scoring these items.

Discussion

Differences in attitudes towards palliative care between the four groups in this study were not identified. The favourable attitude of the majority of participants (96%) indicated that a response bias may have been present, despite modifications made as a result of the pilot study. Generation of beliefs and feelings remained problematic, and little can be concluded from the quantitative results obtained from the main study.

However, the qualitative survey generated over 1600 data items and provided a wealth of information on participants' perspectives about palliative care. It was evident that, despite support for palliative care, a diverse range of concepts, including misconceptions, were held. In general, palliative care nurses expressed concern about the position of palliative care in the health care system, non-palliative care nurses viewed palliative care as including the family and providing pain control for patients, bereaved family members expressed the notion of dignity, and general community

members held some obvious misconceptions or admitted to lack of knowledge about the topic.

Given the diversity of responses found in this study, further examination of conceptualisations of palliative care may prove informative. More in-depth study, using multiple methods such as interview, participant observation, and repeated surveying, would provide a more targeted approach to further elicit community members' understandings about palliative care.

This study provided the background and impetus for continued exploration, and led to the researcher being accepted for a PhD program.

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Survey
Attitudes Towards Palliative Care

This Survey asks you for your attitudes, beliefs and feelings concerning Palliative Care.

In the sections that follow, you will be asked to provide *your personal views* on Palliative Care. The Survey usually takes about 30 minutes to complete and *there are no right or wrong answers.*

***Please complete ALL FOUR sections of the Survey
and return in the reply paid envelope provided,
within a week of receipt.***

Section 1

Attitude Towards Palliative Care

Palliative Care

is care provided for a person with an active, progressive, far advanced disease with little or no hope of cure and for whom the primary treatment goal is quality of life. (Palliative Care Australia Inc., 1998)

Please think about Palliative Care for a few moments and then record your attitude (*personal viewpoint*) towards Palliative Care below. Do this by *circling* the number which best indicates that attitude.

If you have an unfavourable view of Palliative Care, circle a number at the left (negative) end of the scale; if you have a favourable view of Palliative Care, circle a number at the right (positive) end of the scale; circle zero to indicate that you have a neutral view of Palliative Care.

Please answer the following:

	Unfavourable			Favourable			
My personal view of Palliative Care is:	-3	-2	-1	0	+1	+2	+3

Section 2

Beliefs About Palliative Care

This section concerns your beliefs. Beliefs are *thoughts* or *ideas* about a topic, which you *believe* to be true.

Example:

“I believe that crime is on the rise” might be *one* of your personal beliefs about the crime rate.

Now, think about your beliefs concerning Palliative Care and record those beliefs on the next page. Space has been provided to record up to ten beliefs. Write down as many beliefs as you can, although you *do not* have to fill all ten spaces. As you record your beliefs, give each a rating according to how favourable or unfavourable to palliative care *you* consider that belief to be. Again, there are no right or wrong answers. You are asked to write what you personally believe.

Example:

If you were asked about your beliefs concerning the current Australian National Anthem, “Advance Australia Fair”, you might write:

I believe...	Unfavourable					Favourable		
Advance Australia Fair is fitting for formal occasions.	-3	-2	-1	0	+1	+2	(+3)	
Advance Australia Fair sounds monotonous.	-3	(-2)	-1	0	+1	+2	+3	

The statement “*I believe Advance Australia Fair is fitting for formal occasions*” would probably indicate that you are in favour of the current National Anthem, and you would rate it towards the positive end of the scale, perhaps circling ‘+3’.

“*I believe Advance Australia Fair sounds monotonous*”, would probably indicate you have an unfavourable view of the current National Anthem, and you might rate this statement ‘-2’.

Now answer the following:

My beliefs about Palliative Care:

I believe...	Unfavourable				Favourable		
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3

Section 3

Feelings About Palliative Care

This section asks you for your feelings (*emotions*). Emotions are things we feel about a topic, and answer the question "How do I feel?"

Example:

Feelings might include emotions such as sadness, happiness, anger, excitement, fear, dread, and so on.

Now, consider your feelings with regard to Palliative Care. Record those feelings (emotions) on the next page. Space has been provided to record and rate up to ten feelings. Write down as many feelings as you can, although you *do not* have to fill all ten spaces. As you record your feelings, give each a rating as to how favourable or unfavourable to palliative care you consider that feeling (emotion) to be, just as you did with your beliefs in Section 2.

Example:

If you were asked for your feelings (emotions) concerning the amount of crime reported on television, you might write:

I feel...	Unfavourable				Favourable		
frightened	-3	(-2)	-1	0	+1	+2	+3
reassured by being informed	-3	-2	-1	0	(+1)	+2	+3

"*I feel frightened*" (by the amount of crime reported on TV) would probably indicate that you are not in favour of the amount of crime reported, and you might rate this emotion '-2'.

"*I feel reassured by being informed*", might indicate that you feel in favour of the amount of crime reported, and so you might rate this response with '+1'.

Now answer the following:

My emotions about Palliative Care:

I feel...	Unfavourable				Favourable		
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3
	-3	-2	-1	0	+1	+2	+3

Section 4

Personal Information

Please answer the following questions and tick (✓) the appropriate box where indicated. (Do not write your name on this form.)

1 Gender

Male

Female

2 Age last birthday

.....years

3 Highest level of education

Completed Primary School

Completed some High School

Completed High School

Trade or TAFE

College / University

4 Religion:

Protestant

Catholic

Jewish

Other Please state:

No Formal Religion

5 Approximate Annual Family Income:

- Less than \$10,000 per year
- \$11,000 to \$20,000
- \$21,000 to \$30,000
- \$31,000 to \$40,000
- \$41,000 to \$50,000
- \$51,000 to \$60,000
- \$61,000 to \$70,000
- Over \$70,000 per year

There were four versions of the questionnaire, the following to included as indicated.

For all nurses:

Have you undertaken any formal Palliative Care education?

Yes No

If YES, briefly list the course/courses you have undertaken.

.....
.....

For nurses and general community members

Have you recently (within the last 12 months) experienced the death of someone close to you, either a family member or friend?

Yes No

For all participants

If you or a close family member or friend were found to have a life-threatening or terminal illness, would you use a Palliative Care service?

Yes No Not Sure

For non-palliative care nurses?

Would you recommend using a palliative care service to a patient?

Yes No Not Sure

**Thank you for taking the time to complete this survey.
Please return within one week in the reply paid envelope.**

APPENDIX B

"But isn't it depressing?" The Vitality of Palliative Care

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Abstract / A common question about palliative care from those unfamiliar with the work is, "But isn't it depressing?" This view distances palliative care workers from the general public and reflects a deeply held belief that matters associated with death and dying are negative. Published definitions fall short of capturing a full understanding of the work, making it difficult to communicate the meaning of palliative care. This qualitative study examined the experiences of six long-term palliative care workers. Palliative care was described as "a way of living" and, throughout the descriptions, the concept of "vitality" emerged as the core meaning of palliative care. In the current economic environment, where there is competition for health care funding, more widespread agreement about the meaning of palliative care is important if informed decisions are to be made about allocation of resources.

Résumé / Dans le domaine des soins palliatifs, une des questions les plus courantes que l'on nous pose au sujet du travail est « N'est-ce pas déprimant ? » C'est ce point de vue qui distingue les soignants en soins palliatifs du grand public et qui reflète une croyance profondément enracinée que la mort et tout ce qui l'entoure est négatif. Les définitions qui sont citées et reconnues ne parviennent pas à capturer la nature du travail et, de ce fait, il devient encore plus difficile de communiquer aux autres toute la signification des soins palliatifs. Dans cette étude qualitative on examine la nature du travail de six personnes travaillant dans le domaine des soins palliatifs depuis longtemps. Les soins palliatifs y sont décrits comme une « manière de vivre » et à travers les descriptions la notion de « vitalité » émerge comme étant le noyau significatif des soins palliatifs. Dans la situation économique actuelle où la compétition pour des argents pour les soins de santé est forte, il est important que la signification et la nature des soins palliatifs soient de plus en plus propagés si l'on veut que les décideurs prennent des décisions éclairées lors de l'allocation de ressources.

INTRODUCTION

This descriptive qualitative analysis of the experience of six long-term palliative care workers was undertaken to add to our understanding of the meaning of palliative care. Although a

number of authors have discussed the effectiveness of palliative care in alleviating suffering of dying individuals (1-3), the meaning of palliative care may not be well understood. Poor understanding has been demonstrated by, for example, the Palliative Care Council of South Australia, which conducted a survey amongst the general public in which half the respondents were unable to offer some description of palliative care (4). More recently, Palliative Care Australia (PCA) conducted a telephone survey in which three out of four people were found not to understand the meaning of palliative care (5).

Evidence suggests that support for palliative care is worthwhile. Benefits, such as improved quality of life (6), increased family satisfaction with care (7,8), and positive outcomes of bereavement support related to future family well-being (9-11), indicate the value of using palliative care services. There have, however, been reports that current palliative care services fall short of providing for current needs, especially in rural and remote areas (3,12-15), and that the need for services is expanding. In most developed countries, 80% to 90% of palliative care patients have a cancer diagnosis (15-18), and data suggest the prevalence of cancer is increasing (3). Expansion of palliative care services to meet current and future demand appears warranted.

Other issues that highlight the need for understanding of the concept are the recent debates surrounding euthanasia and care of terminally ill people. Palliative care professionals and organizations have clearly stated that palliative care practice does not include the deliberate ending of life (19-21). The public, however, may make false connections between palliative care and euthanasia, with these considered to be one and the same, or to be related care alternatives (22). Controversies over legalization of euthanasia have increased communities' interest in care of the terminally ill and have created opportunities for governments to commit funding to this area of health care.

Uninformed communities, including funders and politicians, may make decisions that result in a lack of support for palliative care and further strain existing palliative care resources, while the need for these services is actually increasing. It is important that palliative care not be misunderstood or diminished because of an inability to articulate the concept. Therefore, research to examine understanding of the meaning of palliative care appears timely.

AIM

The purpose of this study was to describe the meaning of palliative care from the perspective of long-term palliative care workers. Palliative care is delivered, where possible, by interdisciplinary teams. Participants representative of disciplines involved in palliative care provision were, therefore, selected to elicit descriptions of everyday experiences. These descriptions were examined for meaning, attitudes, and feelings about palliative care, guided by the central research question, "What is the meaning of palliative care held by long-term palliative care workers?"

LITERATURE REVIEW

Extensive literature review prior to data collection can predetermine conceptions of the researcher (23). The approach taken in preparation for this study was to examine the literature solely to confirm that a gap in knowledge existed. Although there is a growing body of literature on palliative care, little was found concerning the specific question of this study. Three main areas were considered relevant—definitions of palliative care, studies of palliative care workers, and comparisons of palliative care with other types of care.

Definitions of Palliative Care

A review of the literature revealed several definitions of palliative care, a selection of which is listed in Table 1. Comments of major features are included in the table.

Substantial debate regarding definitions of palliative care among palliative care authors was noted. For example, the World Health Organisation (WHO) definition (24) has been criticized for focusing solely on cancer patients (14), and descriptions of palliative care patients as dying or terminally ill have been criticized for ignoring patients who were concurrently receiving curative treatments (2,25). Associations such as the Canadian Palliative Care Association (CPCA) and PCA (formerly AAHPC), have also recognized definitional difficulties, and have

made several revisions to their definitions of palliative care over time (26–29). Table 1 includes examples of these revisions.

Studies of Palliative Care Workers

Literature related to interdisciplinary palliative care workers was reviewed to determine if this writing might augment definitions or understanding of the meaning of palliative care. Some studies considered occupational stress (30), or roles of a specific discipline such as nursing (31–34). Palliative care workers' descriptions have included service and education needs (35), the meaning of aspects of bereavement services for nurses and volunteers (36), and shared value systems, stress, and coping of palliative care nurses in the conceptual context of the "good death" (37). The studies reviewed showed a variety of aspects of palliative care, but did not include representatives of all disciplines involved in palliative care, and considered only particular aspects of palliative care provision.

Comparisons of Palliative Care with Other Types of Care

Some researchers have attempted to explain palliative care by making comparisons with other types of health care services. Jacobson (38) discussed two complementary systems of cancer patients' treatment—one concerned with cure, the other with the relief of symptoms of an incurable illness. Elements of palliative care were described by making comparisons with curative models, for example, "hospice is not terminal care as usually provided in a traditional acute care system" (38, p.202). This approach provided some comparative explanation of palliative care, but also revealed the difficulties of identifying the elements of palliative care.

The literature review indicated that some attempts have been made to give the meaning of palliative care through definition, descriptions by care providers of aspects of palliative care, and comparison with other types of health care services. However, ongoing difficulties in gaining an understanding of palliative care from the palliative care worker's perspective suggested that there was continued uncertainty about how to articulate adequately the meaning of palliative care.

METHODS

An inductive analysis, using thick descriptions and direct quotations of personal perspectives, was used to discover shared meanings of the experience.

Figure 1 / A SELECTION OF PALLIATIVE CARE DEFINITIONS

Source	Definition	Comment
World Health Organization, 1990 (24)	<p>Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families.</p> <p>Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment. Palliative care:</p> <ul style="list-style-type: none"> • affirms life and regards dying as a normal process; • neither hastens nor postpones death; • provides relief from pain and other distressing symptoms; • integrates the psychological and spiritual aspects of patient care; • offers a support system to help patients live as actively as possible until death; • offers a support system to help the family cope during the patient's illness and in their own bereavement. 	Major criticism has been that this definition relates to people with cancer.
Woodruff, 1993 (2)	Palliative care provides for all the medical and nursing needs of the patient for whom cure is not possible, and for all the psychological, social, and spiritual needs of the patient and the family, for the duration of the patient's illness, including bereavement care.	Not all patients "for whom cure is not possible" will benefit from palliative care. Separates medical and nursing needs from other needs. Assumes an interdisciplinary approach but fails to acknowledge the team approach.
Canadian Palliative Care Association (CPCA), 1995 (26)	Palliative care, as a philosophy of care, is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with a life-threatening illness. During periods of illness and bereavement, palliative care strives to meet physical, cultural, and religious values, beliefs, and practices. Palliative care is planned and delivered through the collaborative efforts of an interdisciplinary team including the individual, family, caregivers, and service providers. It should be available to the individual and his/her family at any time during the illness trajectory and bereavement. While many service providers may be able to deliver some of the therapies that provide comfort and support, the service of a specialized palliative care program may be required as the degree of distress, discomfort, and dysfunction increases. Integral to effective palliative care is the provision of opportunity and support for the caregivers and service providers to work through their own emotions and grief related to the care they are providing.	A comprehensive although lengthy definition.
CPCA, 1997 (27)	Palliative care is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with, or dying from, a progressive life-threatening illness, or are bereaved.	Significantly shortened, this definition was revised from the 1995 version, and in 1998 circulated to representatives throughout Canada. Consensus was not reached.
Australian Association of Hospice and Palliative Care (AAHPC), 1994 (28)	"Hospice and Palliative Care" is defined as a concept of care which provides coordinated medical, nursing, and allied services for people who are terminally ill, delivered where possible in the environment of the person's choice, and which provides physical, psychological, emotional, and spiritual support for patients, and for patients' families and friends. The provision of hospice and palliative care services includes grief and bereavement support for the family and other carers during the life of the patient, and continuing after death.	A cumbersome definition. Physical, psychological, emotional, and spiritual support may not necessarily translate to holistic care.
Palliative Care Australia (PCA) formerly AAHPC, 1999 (29)	<p>Palliative care is specialized health care of dying people aiming to maximize quality of life, and assist families and carers during and after death.</p> <p><i>This definition prefaces the PCA publication of Standards for Palliative Care Provision and is followed by several further statements about palliative care, seven core values for palliative care standards, and six domains (physical, psychological, social, spiritual, cultural and structural) in which palliative care standards are applied.</i></p>	Most recent definition issued by PCA. In this version, the word "hospice" has been omitted. There is no mention of the professional team. Specialized care is not described.

Participants

Long term palliative care workers were purposefully selected on the basis that the meanings and perceptions of palliative care might not have been evident in initial or peripheral experiences of palliative care. The criterion for long term was a minimum of five years experience in the past 10 years in an Australian palliative care service (39).

A sample of six participants was considered sufficient to achieve a comprehensive description of the shared experience of palliative care. Purposive sampling was used to recruit a range of health care workers: nurse, doctor, volunteer (who had received a palliative care volunteer training program), chaplain, counsellor, and an allied health worker, in this case a social worker.

Following approval from the Edith Cowan University Committee for the Conduct of Ethical Research, an information sheet outlining the project and participants' involvement was mailed to each participant. Prior to the first interview, written consent was obtained and participants were informed that they had the right to withdraw from the study at any time.

The six participants shared 69 years of experience working in palliative care services, individual experience ranging from five to 17 years. Five participants worked in Perth. The sixth had never worked in Perth, but had been involved with palliative care services in other cities. All participants had college or university level education, their average age was 48 years, and four of the six participants were female.

Face-to-face, tape-recorded interviews were conducted at each participants' place of choice. Four were conducted in the workplace, one at a participant's residence, and one at the researcher's residence. Each participant was interviewed once only, and interviews lasted approximately one hour. All participants were contacted following their interviews. Five of them asked to view the transcript. Three participants were also sent preliminary analyses of the combined data. None of the participants wished to withdraw any part of their data from the study. Those who reviewed the preliminary analyses confirmed the emergent themes, and agreed that further interviews would not significantly add to the data.

ANALYSIS AND VALIDATION

Analysis of the data occurred throughout the study, guided by the method described by Colaizzi (40). Interviews were transcribed verbatim, and were read to obtain a feeling for and to make sense of the descriptions. Significant statements were extracted, meanings formulated,

then clustered into themes. The themes were integrated into a description of the experience of palliative care, and a core meaning of palliative care for this group of people emerged from refinement of this description.

Throughout the analysis, the researcher paid particular attention to the process of bracketing (23), setting aside preconceptions and allowing the subjectivity of the participants' experiences to emerge. This involved constant reflection and peer debriefing with research colleagues.

Validation of the findings was made by constantly referring themes back to the original transcripts, and by member checks, to establish the truth-value of the emergent themes (40). Another researcher independently reviewed coding of data, and consensus was reached on the meanings elicited from the study. An audit trail was maintained throughout the study by clearly documenting in field notes contextual information, methodological and analytical decisions, processes, and personal responses (41,42).

FINDINGS

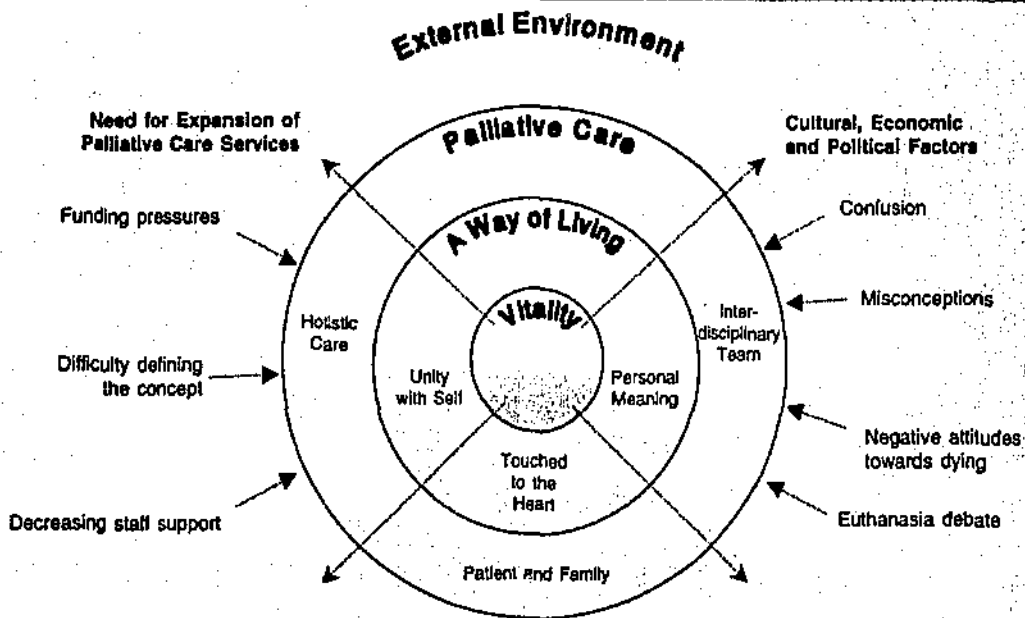
Analysis of the experience of the participants is depicted in Figure 1. This figure reflects the complex integrated layers of experience described by these long-term palliative care workers. The following sections describe the emergent themes within the conceptual framework shown in Figure 1, starting from the core of the experience and moving to the external environment.

Vitality: the Core

Central to the figure is the notion of vitality. Vitality has been defined as "the capacity to live and develop" (43). Vitality is associated with energy, life, animation, and importance (44). These are not concepts commonly associated with palliative care. Throughout the participants' descriptions of their experiences, the notion of vitality was common. Participants displayed animation when describing their experiences, and articulated the importance of their experiences in terms of personal growth for patients, families, and caregivers. Interactions with patients, families, and colleagues were described as meaningful, and the physical workplace as being full of fun and laughter.

Vitality is at the core of Figure 1, radiating out through each of the layers. Participants' descriptions are discussed in the following explanations of the model's layers. The animation of these descriptions provided an understanding of the vitality contained in palliative care experiences for these people.

Figure 1 / CONCEPTUAL FRAMEWORK OF THE MEANING OF PALLIATIVE CARE FOR LONG-TERM PALLIATIVE CARE WORKERS



A Way of Living: the Experience of Being a Palliative Care Worker

The second layer in the figure represents the concept "a way of living". Participants expressed their involvement in palliative care as more than a job, and said that over time their work became part of a way of living. Participants clearly differentiated their workplaces from their personal environments. However, working in palliative care allowed for individual experiences that affected both personal and professional aspects of their lives.

"You have to always be professional and you have to know about your boundaries when you're working with people in palliative care, but at the same time I think it's an area of work that always makes you think. Sometimes it makes you feel an awful lot....That's the thing about engaging you on different levels."

Three aspects of a way of living were identified: unity with self, touched to the heart, and personal meaning.

Unity with Self. Working in palliative care provided an environment in which the individual's inherent values were congruent with the professional values of palliative care.

"It comes back again to these values that are congruent with me, and my life and beliefs. You don't feel like you're putting yourself on hold when you go to work. You can take yourself along and be in there with people at a much more meaningful level."

Participants' descriptions of their jobs clearly indicated the pleasure they experienced.

Touched to the Heart. Participants described emotions that were elicited by experiences encountered in the workplace. These descriptions indicated the depth and personal nature of the emotions.

"I've come away and...something that's almost so precious, so unlike what you experience in the outside world. That intimacy of the moment."

"Most of them [volunteers] have had their hearts touched by something."

Personal Meaning. The experience of working in palliative care provided a strong sense of fulfillment for the participants in this study. They indicated that, as well as allowing personal values to be brought to the workplace, the work itself encouraged personal growth. The lessons from the workplace were considered as adding meaning to the individual's professional and private lives.

"It's also the sense of achievement, when everyone else sees death as such a failure. All kinds of miraculous things happened in the last weeks of life and that you've facilitated some of that....There's...an exquisite edge, that razor's edge between life and death, and where you're very conscious of what you're doing in your own life or what you're not doing."

"But what kept me committed to hospice and palliative care has really been the...belief that it's

much more humane, it's much more compassionate, it's much more rewarding work. It's more meaningful than a lot of the work I've done in the acute care scene."

Vitality of a Way of Living

The "way of living" described by participants included personal connections, significant emotional experiences, and meaning for the individual. Palliative care work was described as a privilege, with involvement providing the opportunity for personal growth and professional fulfillment.

"So the physical presence of this person comes to an end but, you know, the memory lives on...all that the person meant to those lives, whose lives they have touched, lives on. In spite of what you believe on a spiritual level, you know, it's different to each individual, but the preciousness of that moment and that time in a person's life, and if you can just get a glimpse of that then I think that's an absolute privilege. And it's real."

Not only were these experiences perceived as being meaningful and rewarding, but the animation with which these experiences were recounted provided a sense of energy and excitement about the personal opportunities afforded by this work.

"It's very freeing and allows me to explore my own spirituality in the face of what I see on a daily basis and the people that I talk with. So that's exciting, too. Sounds good doesn't it?"

The descriptions of palliative care as a way of living for these participants were interpreted as encompassing a sense of vitality about the experiences. Hence, the figure shows vitality radiating through the second layer of the diagram.

Elements of Palliative Care

The third layer in the figure depicts the concept "palliative care". Definitions of palliative care include three common elements that were expressed by participants in this study: the patient and family, holistic care, and the interdisciplinary team. Descriptions of these elements provided insight into the meaning of palliative care for these long-term palliative care workers.

The Patient and Family. The first element, the patient and family, was interpreted as encouraging patients and families to maintain control over their care and their lives. This was further translated into part of the philosophy of palliative care—to put egos aside, to feel respect for patients as individuals, and to care for them according to the patient's and family's needs and not staff or organization agendas.

"Whatever's important to the patient, we actually fit into that care, without saying, sorry...not allowed....It's like, let's meet these people's need, within reason, because there comes a time when they're not going to have a life left to actually do any of these things. So taking him outside in the wheelchair five times for a cigarette in the day, it's not a chore. It's something they need to do to feel more comfortable with life. And it's important."

"When people come here...they relax. They're cared for in a new way, in a different way, that they're respected as individuals. They're perhaps not treated as a cancer diagnosis, or a motor neuron diagnosis, or whatever they might have, but as people, as human beings, who are much more than the disease, who have that spiritual part of their lives, who have the social part of their life, and who want to continue to keep that whole circle of life continuing. Along with the families who are also able then to participate."

Holistic Care. The second common element described by participants was expressed as a focus on holistic care. This holistic approach included treating patients as individuals, offering them respect and control, and viewing them as whole people and not as physical, emotional, social, and spiritual problems.

"I believe that when a person is dying, it's not just about the body breaking down....All the questions and meanings that come up for people. I just think all of them is engaged in the process of dying."

"That concept of caring for the whole person is really how I understand and explain palliative care. The idea of enabling people to gain as much quality in their life as is possible under the circumstances. That's what we're trying to do. With the...spiritual, social, psychological, physical side of things. Offering that whole kind of care."

The Interdisciplinary Team. The third element mentioned was the interdisciplinary team. The delivery of care was viewed as a team effort and not as individual efforts of professionals from different disciplines. The philosophy of respect and caring for others was demonstrated in attitudes toward team members. Participants felt supported by colleagues, and had not found this teamwork experience in other areas of health care.

"I actually think you work as part of a team, whereas in other areas you might actually be part of the team but really your skills, your expertise is not always recognized....I also think, too, that within palliative care that you actually are better supported amongst your colleagues, although they don't always do it right. I think generally speaking that people understand where you're coming from. Most of the time."

Being part of a team was seen not only as necessary in supporting the individual working

in palliative care, but also in caring for the complexity of needs of the patients and families.

"What I have learnt in becoming involved in palliative care is teamwork....I can't remember who actually said it, that one person cannot be expected to meet all the diverse needs of the dying person and their family. And that might be part of what makes you a survivor in palliative care as well. You can actually, very comfortably integrate into this teamwork environment and find a team you're comfortable with. You're then not only using your own skills and expertise, but also encouraging and facilitating your other trusted team members."

Links with Vitality

The palliative care element "patient and family" was described in terms of respect and support for the individual, with encouragement to achieve family reconciliations, fulfillment of lifetime dreams, and fostering of positive memories.

"[Palliative care is about]...making what is going to be an awful situation no matter what, because somebody's dying, as good as it possibly can be. To leave the memories that are as good as they can possibly be, given that event."

Holistic care was acknowledged to be necessary to achieve the positives of the experience.

"[Palliative care is]...working with others...to provide the best possible care for people who are dying...minimizing symptoms, maximizing quality of life...making it possible for the patients and the family to see some meaning, to gain some positives out of the experience."

The third element, the "interdisciplinary team", was discussed in terms of supportive relationships and respect for team members in a vibrant work environment and amongst people who enjoyed being there.

"It's a ward full of fun and laughter....We've got lots of colour and light....The nurses reflect that. There's a lovely openness. They're full of life. They're not, you know, withdrawn and hiding because they don't fit into other areas of nursing. They're definitely not that. They enjoy being here. That's the thing."

Throughout the descriptions of the positive experiences of personal growth for patients, families, and caregivers, the vitality of palliative care emerged. Patients were well supported, staff professionally fulfilled and personally enriched, and families were left with healthy memories that allowed them to flourish and grow rather than mourn and retreat. Participants agreed that, contrary to the common notion held by people outside the area, the work is not depressing.

"I mean, a lot of people ask how you keep managing to deal with it...the standard thing...you work in palliative care, how depressing....The response is...well, it's sad sometimes, but actually it's much more rewarding than anything else I've ever done."

The External Environment

The outer layer of Figure 1 depicts the external environment in which palliative care is situated. This environment includes political, cultural, and economic factors present in the community. Participants discussed influences that palliative care may have in the external environment, and some of the pressures of external factors on palliative care.

Participants suggested that palliative care promoted health, not only for bereaved individuals, but for communities as a whole.

I'm really interested in the social significance of palliative care, and the necessity of facing death and supporting the bereaved in order to promote health and well-being in people.

They [the bereaved] can look back and see that there were some positives that came out of it....It's long been a hobbyhorse of mine that, if we do it that well and we do bereavement follow-up well, then we're going to reduce the incidence of a whole range of grief-associated illnesses, both psychological and practical problems. I firmly believe that that's the major area of preventative medicine.

Most participants expressed concern regarding economic pressures on health care generally and the perceived impact on palliative care provision. Some areas mentioned were less staff support, competition between services for funding, inadequate funding to provide services in areas of need, lack of support for psychosocial needs including bereavement care, and experienced staff leaving palliative care.

Maybe it's indicative of the health system per se, at the moment...budget, finance, the way accountability is being structured....things like staff support, and you can parallel it sometimes to psychosocial support for patients. It's not always a priority when the other pressures are on.

I've been a little disillusioned since those early years, because I've seen some dreadful tensions, political rivalries and jealousies, and you know...competitive tendering, the forced amalgamation of services, the destruction of programs that were working.

The participants included in this study have continued their involvement with palliative care services whilst experiencing frustration and regret about the current health care funding situation.

Vitality of Palliative Care in the External Environment

The social significance of the outcomes of palliative care described by some participants was interpreted as positive life experience that encouraged growth and enhanced health in the wider community. In this sense, palliative care may be seen as a positive influence on both the individual's and community's capacity to live and develop, again raising the notion of vitality in association with palliative care. Current economic pressures, described in terms of changes to care provision, were of particular concern to participants, who interpreted these pressures as threatening to the vitality of palliative care.

TRANSFERABILITY OF FINDINGS

The positive perceptions and experiences of palliative care reported here may reflect the fact that those interviewed were long-time palliative care providers who had chosen to remain in the specialty area because of their work satisfaction. However, these individuals were deemed to be the most appropriate key informants who could disclose the elements of palliative care and describe it most fully. Although the core concept "vitality" suggested a central positive perspective of palliative care, participants were not hesitant to express negative experiences or concerns about palliative care services, such as lack of funding, worries about abilities to provide high quality care, and acknowledgment of difficult patient care scenarios. This indicated that a "social desirability effect" was not overshadowing their descriptions. The positive viewpoints expressed appeared to be sincere and carefully considered, and indicated that, despite the challenges of care delivery, the core of the work remained energizing and vital.

The extent to which these results can be transferred to other palliative care contexts awaits further study. It is not possible to claim that the results of a qualitative study, such as this, can be generalized. Rather, by reporting these findings, it is hoped they will foster further exploration.

DISCUSSION

Descriptions of the long-term palliative care workers in this study allowed interpretation of the core meaning of palliative care as "vitality". This was expressed in the interpretation of work in palliative care as a way of living, the concept of palliative care itself, and the impact of palliative care on the community.

The notion of vitality does not appear to be captured in the definitions of palliative care shown in Table 1. Examination of these definitions shows that two of them use the term "active" in relation to therapies, and that the WHO (24) definition states that palliative care "affirms life", and uses the phrase "quality of life". Quality of life is also used in the most recent PCA (29) definition. These three terms are consistent with the notion of vitality. However, when used in definitions within the context of "dying people", these terms may not be sufficiently explained to allow the vitality of palliative care to emerge. This is likely, given that perceptions of palliative care may be contrary, such as the notion that palliative care work is depressing.

One study found in the literature used the term "vitalizing" in describing the experience of being a hospice nurse (45). This study provided a structural analysis of the experiences of 18 hospice nurses and, within one of the themes identified as "pursuing meaningful hospice care", described experiences that were both vitalizing and devitalizing. Vitalizing experiences were those with positive connotations, including aspects such as caring in accordance with one's own values, and growing personally and professionally. These concepts were found to have similarities with the elements "unity with self" and "personal meaning", described previously in the concept "a way of living".

One recent qualitative study of five rural palliative care nurses explored a similar theme. Nurses were described as "living palliative care", which involved being required to participate in related activities beyond normal working hours, and a lack of anonymity in small rural communities (46). However, living palliative care appears to differ from the concept of a way of living. The former suggests the individual is recognised as a palliative care worker in numerous aspects of community life and has little choice in assuming this role outside the workplace. In the case of palliative care as a way of living, the individual is described as making a personal connection between the lessons of the workplace and application of those lessons to personal life—making a decision to live one's life congruent with work experiences. Further investigation of rural palliative care professionals with regard to shared meanings of palliative care would add to the current research.

Several other studies of nurses working in oncology or palliative care settings have included descriptions of their finding personal meaning and reward in their work (31,47-49). Some authors have highlighted the social con-

text of caregiving relationships, using the term "professional friendships", which allows for reciprocal communication and caring (49-51). The concept of professional friendships was not explicitly found in the current study, although personal meaning and job fulfillment were well described.

Challenges of palliative care work were extended to palliative medicine by Kearney (52), who suggested that physicians faced a choice of confining themselves to "symptomatology" or to healing in a broader sense. He encouraged physicians to value a deeper level of healing by embracing the human experience for themselves and, in turn, the patients in their care. This concept of "healing" is similar to the idea of finding positive aspects in tragic life-threatening circumstances, such as those described by the psychiatrist Viktor Frankl (53). Frankl drew upon his own experiences of being imprisoned in concentration camps during the Second World War and became founder of the "logotherapy" school of psychotherapy, based on the premise that "man's search for meaning is the primary motivation in his life" (53, p.121). Comments by Kearney and the work of Frankl suggest that people who are facing death feel motivated to search for meaning. The personal growth and family reconciliations mentioned within this study may be indicative of that search for meaning.

Review of the literature revealed that other researchers have discussed several of the aspects identified in this current study. However, the only study to identify the notion of vitality in respect to the experience of working in palliative care, using the phrase "vitalizing experiences", is that of Rasmussen, Sandman, and Norberg (45).

The Future of Palliative Care

Participants in this study, although expressing frustration with external pressures, continue to work in palliative care. Technological advances and new knowledge in palliative care have improved the care available to terminally ill patients, often decreasing suffering and increasing their quality of life (54). However, political and economic pressures that shape decisions about resource allocation have been outlined by Nightingale (55), and emphasize the importance of broad-based informed understanding of palliative care.

Further research is required to explore the meanings of palliative care from the viewpoint of other health professionals, health policy makers, recipients of palliative care services, and general community members. Identification of vitality as the core of palliative care for this

group of long-term palliative care workers has, however, introduced a concept not commonly associated with palliative care.

CONCLUSION

This research has enhanced current definitions of palliative care by explaining the meaning of palliative care in this group of long-term palliative care workers. Contrary to the notion of this work being depressing, palliative care focuses on the positive aspects of living, providing an opportunity for personal growth and enhanced meaning for carers. Identification of the vitality of palliative care for this group of people extends the understanding of palliative care, and may provide direction for future research and health service planning and use.

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Long-Term Palliative Care Workers: More Than a Story of Endurance

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ABSTRACT

This study sought to explore the stories of long-term palliative care workers to generate an understanding of their experiences of working in palliative care for an extended period of time. Six health professionals participated in the study, each of whom were currently working in a palliative care service, and each of whom had been working continuously in palliative care services for a minimum of 5 years. Descriptions of their experiences provided insight into the reasons for choosing this work, the stages they went through along the way, and the factors that sustain and challenge them as they continue to work in the area. Five phases in the trajectory of working in palliative care were described: The Awakening, Making the Connection, Committing to the Philosophy, Reaping the Rewards, and Soldiering On. Results from this study may be helpful to educators and administrators who endeavour to develop and support this workforce. Furthermore, the descriptions provided in this study may provide direction for individuals working in palliative care who may be called on to reflect on their own work trajectory and their commitment to the field.

INTRODUCTION

THE EMPIRICAL AND ANECDOTAL LITERATURE about the work of caring for dying people indicates that for many people working in palliative care there are beneficial outcomes associated with the work. For example, comparative studies of occupational stress in various areas of health care have shown that palliative care workers experience higher job satisfaction and lower levels of burnout than workers in other specialty areas.^{1,2} However, the experiences of long-term palliative care workers have not been well documented in the literature. In particular, little is known about the process that palliative care health professionals experience as they commit to this work. A more in-depth and fo-

cused understanding of this process was deemed to be worthwhile because this information might be helpful to educators who are endeavouring to help health professionals prepare for these roles. Also, administrators might benefit from this type of knowledge so that they could more attentively support and foster the development of this workforce. Furthermore, individuals working in the field might also reflect more closely on their experiences as long-term palliative care workers as a means of professional self-care monitoring.

To this end, this study sought to explore the stories of six long-term palliative care workers with the goal of generating an understanding of their experiences of working in palliative care for an extended period of time.

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BACKGROUND LITERATURE

The work of caring for individuals facing life-threatening illnesses has received some attention in the literature and is acknowledged to be a source of stress.^{3,4,5} It has been shown that health professionals may experience frustration and a sense of professional failure in their work with oncology patients.⁵ Areas of concern for health professionals include management of the patient's suffering and the increasing complexity of decisions about patient management.⁶ These issues may occur against a backdrop of organizational responsibilities that conflict with clinical demands, and worries about the impact of overwork on home life.⁶ Much of health professional training does not prepare clinicians for the intensity of grief, anger, frustration, and resentment that can be displayed by patients and families who are in an end-of-life crisis.⁷ Many health professionals may also hold unrealistic expectations about their role and how they can be expected to help.^{8,9}

Health professionals who choose to work in palliative care have possibly self-selected to work in an area that others might find more difficult. The challenges of this work, however, remain. The literature indicates that repeated exposure to deaths and traumatic experiences may have a cumulative effect on health professionals, and suggests that it would be inappropriate to assume that those working in the field are coping well

and able to make the transition to this work easily.^{10,11} The experiences of those who have chosen to work in palliative care and who have remained in this work over a sustained period of time warrant exploration. The experiences of these individuals, their reflections on decisions to remain in the work, and their perceptions of the process that they have undergone or are continuing as they commit to this work and its challenges may be especially informative. According to Patton,¹² qualitative inquiry cultivates the most useful of all human capacities—the capacity to learn from others. Therefore, a qualitative approach to generate an understanding about the process of working in palliative care was developed.

METHOD OF INVESTIGATION

A descriptive qualitative study was undertaken to allow participants to freely express their experiences in their own words. A semistructured interview guide (shown in Table 1) was used to frame the interview while allowing participants to respond openly about perceptions of working in palliative care. One-on-one interviews were conducted with each participant and the interviews were transcribed verbatim. An inductive analysis using detailed descriptions and direct quotations was used to report the experiences of individuals working in palliative care.

TABLE 1. INTERVIEW GUIDE

-
1. How long have you worked in palliative care?
 2. How did you get started working in palliative care?
 3. What keeps you working in palliative care?
or
What kept you working in palliative care?
 4. What do you like about palliative care?
 5. What do you like about working in palliative care?
 6. What don't you like?
 7. What are some of the (memorable) experiences you have had?
 8. What experiences do you think reflect what palliative care is about?
What experiences do you think have not been reflective of palliative care?
 9. What is it about these experiences that capture what palliative care is about?
What palliative care is not about?
 10. How do you explain palliative care to other people?
 11. Have you had personal experience of using a palliative care service?
 12. What impact has this experience had for you?
-

These questions are purposely broad, attempting to capture the meaning of palliative care as experienced by the participant. It is desirable not to introduce any preconceptions of the researcher, or of current definitions of palliative care that may be known to the participant.

PARTICIPANTS

Six palliative care workers, each of whom had been working for a period of at least 5 years in a recognized palliative care service, were purposefully selected for participation in this study. Purposeful sampling in this instance refers to a deliberate effort to recruit participants from each of the usual team discipline groups, and a "recognized palliative care service" refers to services listed in the Directory of Hospice and Palliative Care Services in Australia.¹³

Participants included a range of health care workers representative of the interdisciplinary team involved in palliative care practice: a nurse, doctor, volunteer (who had received a palliative care volunteer training program), chaplain, counselor, and an allied health worker, in this case a social worker. After institutional ethics approval, potential participants were mailed an information sheet outlining the project and inviting their involvement in the study. All those approached agreed to participate in the study. Written consent was obtained prior to interview, and participants were informed that they had the right to withdraw from the study at any time.

Characteristics of participants

The six participants shared 69 years of palliative care experience, individual experiences ranging from 5 to 17 years, and all experience had been gained in Australian palliative care services. All participants were currently working in palliative care, and had worked continuously in palliative care for the stated period. Four of the six participants had worked in more than one palliative care service during this time.

Detailed demographic descriptions have been purposely omitted from this paper to protect the

identity of the participants. A summary of broad demographic data is given in Table 2.

Face-to-face, tape-recorded interviews were conducted at each participants' interview location of choice. Four were conducted in the workplace, one at a participant's residence and one at the researcher's residence. Each participant was interviewed only once, each interview lasting approximately 1 hour. All participants were contacted after their interviews and given the opportunity to review their transcripts. Five of them requested this, and three of these participants were also sent preliminary analyses of the combined data. None of the participants wished to withdraw any part of their data from the study. Those who reviewed the preliminary analyses confirmed the emergent themes, and agreed that further interviews would not significantly add to the data.

ANALYSIS AND RIGOR OF THE RESEARCH PROCESS

Analysis of data occurred throughout the study, guided by the method described by Colaizzi.¹⁴ Interviews were transcribed verbatim, read to obtain a feeling for and make sense of the descriptions, significant statements were extracted, meanings formulated, and then clustered into themes. The themes were then integrated into descriptions of the experiences of palliative care.

The process of bracketing¹² was used throughout the analyses, the researcher endeavoring to set aside preconceptions and allowing the subjectivity of the participants' experiences to emerge. This involved constant reflection and peer debriefing among research colleagues.

TABLE 2. SUMMARY OF PARTICIPANT DEMOGRAPHICS

Gender	Age (years)	Years working in palliative care	Formal palliative care education
Female	53	17	Yes
Female	41	9	No
Male	51	7	Yes
Female	44	5	Yes
Female	50	15	Yes
Male	50	16	Yes
	Average age: 48 years	Average time in palliative care: 11.5 years	

Confirmation of the findings was made by constantly referring emergent themes back to the original transcripts and by member checks to establish the truth-value of the themes.¹⁴ Each author independently reviewed coding of data, and consensus was reached on the meanings elicited from the study. Consistency was addressed through auditability and was achieved by documenting a clear decision trail throughout the study.¹⁵ Field notes were maintained, including contextual information, methodological and analytical decisions, processes, and personal responses.¹⁶

FINDINGS

The questions included in the interview guide allowed participants to express their experiences in palliative care freely. The guide also encouraged a sequential account of their experiences. These accounts allowed the researchers to identify several phases of the experience of working in palliative care as participants described events that they had encountered over time. A trajectory emerged as a common experience amongst the participants, although individual differences in specific events were evident.

Five phases of experience were identified in the trajectory: The Awakening, Making the Connection, Committing to the Philosophy, Reaping the Rewards and Soldiering On. Table 3 summarizes the key points within each phase of the trajectory.

The following descriptions elaborate on the progression through time, and the exemplars given allow further exploration of the processes through this trajectory.

The awakening

Participants in this study described their initial exposure to the concept of palliative care. In their descriptions the notion of an awakening emerged. The Awakening was a period of time in which participants first became aware of palliative care. The awareness began as a vague interest or curiosity about death and dying and a smattering of information about the concept of palliative care.

I suppose I freaked out a bit about death and dying. I hadn't had much to do with death and dying at the time, but it just seemed like something I'd like to know more about.

Specific people sparked this interest. The people mentioned were notable palliative care workers such as Cicely Saunders, Elizabeth Kübler-Ross, Joy Brann, and Rosalie Shaw. These women have all been pioneers in the palliative care field, the former two in the international sphere, and the latter two in Western Australia. The descriptions given by participants characterized these people as charismatic leaders who were revered for the work that they had initiated. They made a lasting impression on participants and many reported not expecting to be interested in this work prior to exposure to these leaders.

I guess the interest started probably back in about, in Elizabeth Kübler-Ross' times . . . I remember seeing a program on TV about her . . . I thought, this is bizarre, I'm actually finding this interesting, I must be sick . . . And then I heard of this workshop by

TABLE 3. PHASES IN THE EXPERIENCES OF LONG-TERM PALLIATIVE CARE WORKERS

<i>The Awakening</i>	⇒	<i>Making the Connection</i>	⇒	<i>Committing to the Philosophy</i>	⇒	<i>Reaping the Rewards</i>	⇒	<i>Soldiering On</i>
Interest Charismatic leaders Personal values Awareness leading to a point of no return		Comparison with other health care experiences Exposure Opportunity Personal experiences A better way Seeing the value		Involvement with family and patients Involvement with the team A discovery of honesty Personal growth		Making a difference A privilege Lessons from dying patients Positive outcomes		Economic considerations Restructuring Change Changing attitudes Impact on staff

Joy Brann, so I went along there, and it was six or eight weeks just once a week. And I really enjoyed it. And she was a wonderful presenter.

Participants reflected on some of the conflicts they were having with their work at that time. They identified aspects that conflicted with their personal values. They implied that an increased awareness of palliative care also brought about a realization of conflicts with personal values in the workplace.

I think I realized that what was happening out there in the nursing world—I didn't know that I wanted to do a lot of that . . . I didn't feel that the care given to the patients was up to my standards . . . I wanted to be in a patient's home and make some decisions on my own instead of having to listen to other people and fit in with how other people saw things.

Developing awareness of the complexities associated with care of terminally ill people was described as a turning point, a point of no return, for participants.

I was a solo general practitioner . . . at about the time that the hospice program was starting . . . The patient that sticks out in my mind is a chap who lived across the road from the surgery . . . It was really that patient and his wife that led to my understanding of some of the complexities involved in actually caring comprehensively for a patient and the wife . . . One day, busy surgery in the morning, bolt down a sandwich, go over there, see him, deal with pain problems, spent pretty well an hour there, and the surgery packed and waiting for me, and as I was going out, stopped in the doorway, and saying something to the wife like, you know, how are you coping? And she just dissolved in tears. And the terrible dilemma that I had of knowing that I really couldn't walk out on her. I needed to stay and deal with that then and there, as opposed to the demands of going back and doing the job that I was really getting paid for . . . That one patient . . . was a turning point for me.

The Awakening phase was brought about by participants' realization that the care needs of terminally ill patients and their families were different, that conventional approaches may not meet these needs, and that this new concept of palliative care could possibly meet these needs.

Making the connection

The next phase of the participants' experiences was identified as a period of Connecting. Participants were able to Make the Connection between the abstract concepts of palliative care and how they might be applied to the real world. This realization occurred gradually, often with comparison of other health care settings.

When I was working in the children's hospital in the oncology unit, a friend of mine who was . . . looking at hospice care, enlightened me about the better way there was of caring for dying people . . . She was really curious about the pediatric scene and thought that it would be much better than adult care. And it wasn't. There were the same conspiracies of silence, the same sort of struggles.

Accounts were given about seeking further information, sometimes through activities that were occurring within the communities, through media exposure, and through publications about palliative care. Establishment and growth of palliative care services in the local communities provided opportunities for participants to further connect with palliative care by seeking employment within these new services.

I saw an advertisement for this position, which I showed to my wife and she said, go for it, and I said I'll never get it.

Participants were also starting to hear accounts about people who had used palliative care services, sometimes reports from overseas where palliative care services were more established. The personal nature of these accounts served to strengthen the connection with palliative care.

I had a friend die at 29 . . . That perhaps more than anything shaped my attitude towards death and spirituality, because he

was someone who was able to stay in control, very much in control of what was happening to him, and able to offer the support . . . [He] was able to stay in control . . . [It was a] pretty significant event about what it means to be given the right to be yourself, as you're dying. To not be swamped within a system.

In various ways, participants described their connection to palliative care. One participant, although not criticizing the care his mother had received when she was dying, acknowledged the empathy that the experience afforded him in connecting with others in similar situations.

My mother died . . . of cancer . . . in a small hospital in a country town where we lived. And I was not to my knowledge aware of any inadequacies in her care . . . there's no memories that I have of that, that are particularly traumatic, except that you know I was perhaps 20 . . . So, I still feel a bit of a twinge sometimes when I'm talking to someone who's around 19, 20 or 21, and their mum's dying, and I sort of think well, yeah, I know a bit how you're feeling . . . People say . . . well that's why you're in palliative care. I can't actually see that myself.

Another participant viewed palliative care as a better way of dying than she perceived the experience had been when her father was dying.

Perhaps because my father died in great pain and isolation . . . I thought, it just felt wrong. And here was a set of principles that just worked so brilliantly.

Although participants made their connections with palliative care in various ways, all reported some personal aspects that made an impression on them and further encouraged their involvement in the area.

Committing to the philosophy

The stories related by participants in their interviews clearly identified that their continued involvement with palliative care strengthened their commitment to the work. This next phase of experience was interpreted as Committing to the Philosophy of palliative care. The concepts were

embraced and participants were able to describe their experiences of working with patients and families alongside colleagues in interdisciplinary palliative care teams.

Participants discussed the philosophy of palliative care as something that was shared with colleagues.

[What's kept me here] . . . Probably more than anything else, a commitment to what we do. To the philosophy of palliative care I think, and to seeing that practically worked out in the lives of our patients and families. That along with working with a great team of people . . .

I like working with other disciplines. And it's one area of health care where you do work with other disciplines. Where, although it doesn't always succeed, there is a philosophy for multidisciplinary care, holistic care.

Some of that philosophy was described as participants' own experiences of relating to patients.

I guess people let you in closer . . . all the guards have dropped and you're kind of really relating as just two people. Normally, we don't see any of that in our normal day lives. Just relate on a superficial level.

Reflecting on these experiences, participants expressed the feeling of personal growth they believed had occurred within the palliative care environment. The personal growth was expressed, not only as satisfaction with the positive outcomes for patients and families, but also on a more personal level.

[Before joining palliative care] . . . I never thought about a lot of these things. I never thought about my mortality. I just thought I'd be here for years. But, and I think it's probably an evolving thing, because I've noticed as I've got older, it worries you less and less.

Reaping the rewards

The satisfaction of working in this area was evident throughout the participants' accounts. Rewards were sometimes small, and perhaps not

immediately identifiable, but all reported Reaping the Rewards over time. Satisfaction was felt daily in meeting the immediate needs of patients and supporting families; however, the cumulative rewards included feelings of achievement and growth, and a sense of privilege associated with the work.

I feel quite comfortable talking to patients about difficult areas, of dying . . . Again I just keep getting back to that word rewarding, because you actually feel that you're achieving something by letting someone feel comfortable . . . in opening up with such personal things.

I think also you're interacting with people at a very unique period of their lives. Again, both for the patient and for the family. And, that's a privilege in a lot of respects.

Some of the differences that were made to patients' lives were clearly identified.

All those little things: the lady who wanted to go on a helicopter ride before she died; just taking somebody for a drive down to the park . . . being able to make things; being able to talk . . . Those sorts of things. To be a part of that is such a wonderful privilege for me.

There was also acknowledgment that satisfaction flowed not only from doing things for patients, but the experiences of caring for patients contributed to the personal growth of professionals working in palliative care.

It was just a lovely experience . . . Not just for the patient or for the family, but how the team were able to be engaged in something, that either changed our way of thinking a bit, or brought us to an appreciation of what was happening for a family. An appreciation of the coping of this patient.

It's the lessons in your own life. To live now, to live fully, to tell people that you love that you love them, and all of those things, and you strive for that.

The positive consequences of working in palliative care were reported to outweigh the diffi-

culties or sadness of working among people who were dying. Participants clearly identified rewards they experienced, despite the commonplace reactions of people outside the area.

That's what I mean it's rewarding, because you're actually achieving the goals that you've set yourself, to manage pain, manage symptoms, improve some quality of life, give some meaning to the dying process.

I mean a lot of people ask how you keep managing to deal with it . . . the standard thing . . . you work in palliative care, how depressing . . . The response is . . . well, it's sad sometimes, but actually it's much more rewarding than anything else I've ever done.

Soldiering on

The current phase for participants in this study was identified as one of Soldiering On. Participants have continued to work in palliative care, although they expressed frustration and regret at what they perceived to be a decline in funding and support for palliative care services. Many of the changes occurring within palliative care were related to economic factors in health care generally, and to restructuring of services.

Maybe it's indicative of the health system per se, at the moment . . . budget, finance, the way accountability is being structured . . . Things like staff support, and, you can parallel it sometimes to psychosocial support for patients. It's not always a priority when the other pressures are on.

I've been a little disillusioned since those early years, because I've seen some dreadful tensions, political rivalries and jealousies, and you know . . . competitive tendering, the forced amalgamation of services, the destruction of programs that were working.

Participants' experiences of change were reported as challenging.

I know change has to happen . . . I've seen lots of changes and some I agree with and some others I don't agree with. I think that change for funding sake without actually reviewing where you've been before is something that administration hasn't addressed

... It's part of the health system thinking ... maybe the system can be improved, but they need to make sure they don't cut off their noses in spite of their faces.

Some participants suggested that managing the changes was impacting on the ability to provide services.

I certainly realized with 70 patients on the program, that you had to prioritize, and had to spread yourself thinly, and use volunteers for tasks and responsibilities that were probably more the realm of the professional. But because we just didn't have the resources, we couldn't do what the families really needed us to do. It hasn't always been like that.

Further concern was expressed that the impact of limited resources was changing underlying attitudes towards patients and families.

This might sound so idealistic, but I don't like the way that patients and families are treated as objects rather than subjects who are really driving the process. It's just not empowering, and I don't think it's as supportive as it needs to be ... Even in that area of bereavement follow-up, where their needs are discounted, their suffering is minimized and trivialized. It appalls me.

The impact was also reported as affecting the people working in the area.

People are burning out at the same rate as they were burning out in the acute care sector ... I know people have left palliative care ... as a result of those changes.

However, while acknowledging these difficulties, the participants had cause to remain working in the area. For this participant, the passion for the work remained.

I've been a little disillusioned since those early years ... But I don't think that's dampened my enthusiasm for hospice ... Because I'm still quite passionate about bereavement services.

Some common themes emerged regarding participants' reasons for continuing their involvement with palliative care work. One theme was about the intrinsic reward of helping other people to gain some meaning from the dying process. Not only was the work viewed as a privilege, it also gave a sense of achievement. Participants expressed a sense of worth and a feeling of being energized.

You really feel like this is what's really important ... A lot of the other guff that goes on in life doesn't count for much at all, but just this being able to spend this time with this person ... You hear all those clichés about getting back what you put in. And it's true.

Another theme that emerged from asking participants what kept them working in palliative care was working in an interdisciplinary team. The experience of this was described as providing a sense of camaraderie, of mutual respect and support.

The fact that you actually work in an interdisciplinary team, you actually get an opportunity to develop some expertise and to have input into the daily assessment of ongoing care ... Knowing that ... you're actually an important part of the team ... I think that you're more recognized in palliative care as an expert ... and you're respected for your skills and your ability ... I also think too within palliative care that you actually are better supported amongst your colleagues.

Several participants also commented on the interest generated by the advances being made in palliative care.

I actually find that it's exciting because in a sense you are on the leading edge of new discoveries, on how to manage pain, the mechanisms of pain [for example] ... The technical side is interesting and exciting and moving forward at a rapid pace, so that satisfies that side of me as well.

Psychological areas were also seen to be providing opportunities for further professional development.

The whole area of grief and loss is an area that I continue to have an interest in. I think it's an area that still has a lot of growing to be done, discovery. So with that scope there's always new stuff to be looking at.

In summary, the trajectory of experience described by these long-term palliative care workers began with an awakening to the concept of palliative care, leading to a connection and commitment to the philosophy. Personal rewards were identified from continued involvement in the work. The rewards continue, and participants soldier on despite feeling pressured by external forces.

DISCUSSION

Participants in this study described a common trajectory of experience that attracted them to and has sustained them to work in palliative care services. They described a process of commitment that included a personal connection with the philosophy of care. The commitment to the work appeared to have developed over a period of time and exposure to the area.

As previously stated, staff stress in palliative care tends to be lower than in other areas of health care. Not only has this been attributed to appropriate staff support strategies, but it has also been mooted that the satisfaction experienced by some people may balance the stress associated with working in palliative care.¹⁷ Participants in this study appear to have achieved such a balance through finding personal meaning as well as achieving significant outcomes for patients and families.

The perceived pressures of working in the area of death and dying have prompted several studies that have identified both professional and personal aspects of palliative carers' roles, and the tensions between these aspects. For example, palliative care nursing roles have been examined by Davies and Oberle¹⁸ who described a central dimension of "preserving own integrity" and an overarching dimension of "global valuing" Both were seen as personal concepts but both were integral to the professional role of supporting palliative care patients and families. Rasmussen and colleagues,¹⁹ who also studied palliative care nurses, identified two themes; "pursuing mean-

ingful hospice care" and "pursuing spiritual integrity." The latter theme was concerned with personal issues such as "keeping one's energy flowing," which was associated with experiences such as feeling de-energized by exchanges with patients and families, and being strengthened by perceiving that their care was meaningful.¹⁹

Results from the current study suggest that participants also experienced a balance between de-energizing and energizing factors. For example, situations that were identified as sad and potentially stressful were balanced against the satisfaction of work that was described as "more rewarding than anything else I've ever done." Furthermore, although participants were only interviewed at one time point, they were required to reflect on their experiences over the time they had been involved in palliative care. Their stories suggest that the balance may have developed over time as the process of committing to palliative care intensified. Previous studies have not commented on the time period in which these experiences occur.

Palliative care services in Australia were in their infancy when some of the participants in this study commenced working in the area. Redpath²⁰ traces the beginnings of modern palliative care in Australia to the early 1980s. Services have expanded significantly in this short time. Participants' stories may mirror the evolution of palliative care in Australia, and it may be that their stories are unique to them and others who were involved during this period of palliative care development.

On the other hand, the process of working in a specialty area over several years, involving an Awakening, Connecting, Committing, Reaping Rewards, and Soldiering On, may be common to many people who seek a particular area of employment and decide to stay in that work for a period of time. However, the participants in this study clearly expressed a high degree of commitment to the area of palliative care, despite the fact that working with dying people is regarded as being stressful.

Occupational stress of participants in this study was not measured. However, the participants acknowledged the role of colleagues and the value of a team approach, which has been noted in the literature as being a significant factor in coping with stress related to palliative care work.²¹ Participants also clearly expressed frus-

tration in relation to organizational changes, which was in stark contrast to the satisfaction recounted in relation to the work itself. Some authors have discussed similar trends, noting that organizational factors such as work overload and administrative and management issues can be greater stressors of palliative care workers than issues related to caring for dying patients and supporting their families.^{22,23}

Nonetheless, these participants continue to remain committed and working in palliative care in a climate of economic uncertainty and significant organizational change. Therefore, the findings in this study have implications relevant to managers seeking to sustain a committed work force, and suggest that organizations should incorporate strategies to retain experienced staff. Consideration should be given to programs that encourage experienced staff to mentor newer staff members, and to maintain an appropriate mix of expertise within work units. Furthermore, although participants in this study did not express significant stress related to the work, it remains important that managers endorse both formal and informal staff support systems and embrace the importance of the team as a support in palliative care work.

The findings may also be of help to palliative care educators to assist health professionals to learn to work in this specialty area. Commitment to palliative care work may well be a developmental process that needs support and integration at various stages of an individual's career. Educational programs that account for this type of developmental process may be more helpful in ensuring that palliative care health professionals remain committed to the field.

LIMITATIONS

The experiences of the participants are reported and interpreted in the findings of this study. Similarity of experiences allowed the description of a trajectory of experiences working in palliative care. Other long-term palliative care workers may have different experiences, or indeed more recent workers in palliative care may have the same experiences. Other motivating factors, such as antecedent events, sentinel events in the workplace, or personal characteristics, may influence individual commitment to a profession or workplace.

It also should be noted that in the description of this trajectory of palliative care experience, par-

ticipants were required to reflect on their experiences over time. This type of cross-sectional study is therefore prone to the inaccuracy of recall of the individual, memory likely to be influenced by a multitude of subsequent events. Therefore, a longitudinal study would be helpful to more precisely capture the process of working in palliative care over an extended time period.

Subsequent work is also needed to confirm these phases with people at different stages in their palliative care experience. Further studies investigating these factors, the degree of commitment to the work, the satisfaction derived from it, and the relation to the time spent working in services may prove worthwhile. In addition, examination of individuals leaving palliative care and the stages at which they exit the workforce would be of interest.

CONCLUSION

This study has described the experiences of long-term palliative care workers. Their experiences of personal growth and professional satisfaction have sustained their commitment to working in this challenging area. Implications for managers relate to valuing and nurturing this commitment.

Reporting these findings also validates the experience for this group of palliative care workers and hopefully acknowledges the value of the work they do, and of others that might identify with their experiences.

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APPENDIX D

Participant Information

Information Sheet for Staff, Patients and Visitors to the Research Settings.

INFORMATION SHEET

Research Project: Understanding palliative care: an ethnographic study of three Australian palliative care services

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Faculty of Communications, Health and Science

School of Nursing and Public Health

THE RESEARCH PROJECT

The research project "Understanding Palliative Care" is currently being undertaken within this ward. The researcher conducting this study is Judi Webster, a registered nurse with experience working in palliative care, and who is currently a full time PhD student at Edith Cowan University, Perth. This study forms part of the work towards her PhD thesis.

OFFICIAL APPROVAL

This project has been approved by the Edith Cowan University Human Research Ethics Committee, and by (*this hospital's Ethics Committee*). However, participation in this research is entirely voluntary and in no way forms part of the care delivered by the hospital, nor is there any obligation on staff of the hospital, patients or visitors to participate in this research. There is no penalty for not participating in the study: there is no expectation that staff should participate, and patient care will in no way be affected by not participating.

WHY THIS PROJECT

The aim of the research is to add to the understanding of palliative care by observing palliative care settings, the people involved in those settings, including staff, patients and visitors, and the activities that occur in those settings.

WHAT IT WILL INVOLVE

The researcher, Judi Webster, will be observing what happens in the ward, and recording her observations. During this time, she will be assisting the staff with activities around the ward, which may include (*direct care within the boundaries set by the hospital*). From time to time, she may seek clarification about what she is observing, and ask questions of the people involved.

The research will be conducted to cause as little disruption to the routine of the ward as possible. Staff will not be observed in regard to clinical competence, or any other form of quality assurance. Management of the care of patients and their families/ friends will not be undertaken by the researcher, and any requests for clinical advice will be referred to the appropriate staff members.

WHO IT WILL INVOLVE

The study will involve all members of staff in the ward, including clerical and hotel staff, consultants to the ward, and patients, relatives and friends of patients. Confidentiality for all persons will be maintained. Records of the observations made will not include personal details that would allow identification of any particular person. Any publications resulting from the research will also not allow identification of any of the participants.

TO FIND OUT MORE

Any questions you may have regarding the research can be directed to Judi Webster (*contact details*), her academic supervisor Professor Linda Kristjanson (*contact details*), the hospital ethics committee representative (*name and contact details*), or (*staff member within the unit - and contact details*).

IF YOU DO NOT WISH TO BE INVOLVED

Any person wishing to be excluded from this study may decline by either notifying (*staff representative*) who will inform Judi, or by notifying Judi directly. Whilst it will be impossible to be present in the ward and not observe these people, the activities in which they participate will not be recorded for inclusion in the study, and these people will not be approached to discuss issues arising from the research. Exclusion from the study may occur at any time within the period of observation.

FURTHER RESEARCH

Later in the research, Judi may ask permission from particular people to discuss issues at length. Agreement to participate in these interviews will be negotiated individually and separately from the observation and informal talks described in this information sheet.

Statement of Disclosure for Formal Interviews.

STATEMENT OF DISCLOSURE

Research Project: *Understanding palliative care: an ethnographic study of three Australian palliative care services*

Researcher: *Judi Webster, RN, Cert Onc, BSc (Health Sciences), PhD (Nursing)
Candidate*

Edith Cowan University

Faculty of Communications, Health and Science

School of Nursing and Public Health

I am currently enrolled as a PhD Nursing student in the School of Nursing and Public Health at Edith Cowan University, Perth. I am a registered nurse, and have been involved in palliative care for many years. I was employed by Silver Chain Hospice Care Service from 1983 until 1997. As a full time student, I am not affiliated with any particular service provider, yet I remain committed to furthering issues within palliative care through research.

My current research study proposes to look at the understanding of palliative care amongst people who are involved in palliative care services, including staff, patients, and families or friends of patients. An increased understanding of the meaning of palliative care will provide direction for educational strategies to raise awareness of palliative care. The benefits of this will be to increase community support for palliative care, giving individuals more informed choices for care, and allowing politicians and funders to make more informed decisions about health care options.

Currently I am observing and participating in the activities within (*the service*). During this time, I have observed that you may be able to provide further information to assist with my research. I am now asking you for further involvement in my research. I would like you to participate in a face to face interview with me, in private, at a place and time of your choice. This session will last approximately one hour. I may also ask you to take part in further interviews, or I may later ask you to help clarify some of your comments once I have reviewed the initial interview.

The interviews may be tape recorded and later transcribed for analysis. I will give you the opportunity to view the transcriptions of your interviews, and you may request that I remove any information that you wish. You may also request that the tape recordings are erased, or you may wish to keep the tapes yourself.

I will also ask you to provide some brief personal information such as your age and how long you have been involved with a palliative care service. You may choose not to give these details if you wish.

Confidentiality will be maintained at all times. Each person will be assigned a code number and only that number will appear on any of the data collection forms, the interview tapes or the transcripts. It is possible that research colleagues will be asked to assist with coding of the data and will have access to the transcriptions of the interviews. However, these documents will only be coded by number. Only my supervisor, Professor Linda Kristjanson, and I will have access to the original tape recordings and to the list of code numbers and names of participants.

(for patients only)

I may also wish to review your patient case notes to compare written notes with the activities that I have observed and the things that you have discussed with me. The purpose of this comparison is to further describe how people understand aspects of palliative care, and whether it is the same for different people. I will not record any personal details from your record, and all information I obtain from your notes will remain confidential. You may agree to being interviewed without agreeing to give me access to your patient records.

The final research may be published, and any names used will be fictitious. Every effort will be made to protect the identity of all participants. It is possible that the palliative care services participating in this study will be identified, and people with knowledge of the particular services may be able to recognise participants by association with those services.

It is a requirement of the research that all data be kept in a secure and locked place for a period of five years, after which they are destroyed by shredding or incineration. Data will be stored at the university in locked offices allocated for research archiving purposes.

It is also a requirement of the research that any risks to participants be fully disclosed. During the interviews, talking about your experiences may cause some feelings of sadness or anxiety. Such reactions will be treated sensitively. It may be appropriate to consider seeking support from members of the palliative care service, and I will help with this if you wish.

Of course, there is no obligation whatsoever to participate in this study. If you do agree to participate, you may choose to withdraw at any time without penalty. Your decision not to participate, or to later withdraw, will in no way affect

(for staff) your role within the *(name of service)*.

(for patients) the care you are receiving.

(or for families/friends) the care your relative / friend is receiving.

I shall be contacting you within the next day or so to discuss your willingness to participate in interviews related to this project. If you agree, I will arrange a meeting at a time and place convenient for you. In the meantime, should you have any questions concerning the project *Understanding palliative care* please contact me, Judi Webster *(contact details)*, my academic supervisor Professor Linda Kristjanson *(contact details)*, the hospital ethics committee representative *(name and contact details)*, or *(staff member within the unit - and contact details)*.

If you agree to participate, it is necessary that we complete a Consent Form, which contains the same information as this Statement of Disclosure.

(For patients) There are two aspects of consent to consider; the first is agreeing to participate in interviews with me, and the second is giving permission to view your patient records. You may agree to one or both.

Thank you for taking the time to consider this request.

Yours sincerely

Judi Webster

Consent Form for Formal Interviews.

CONSENT FORM

Research Project: *Understanding palliative care: an ethnographic study of three Australian palliative care services*

Researcher: *Judi Webster, RN, Cert Onc, BSc (Health Sciences), PhD (Nursing) Candidate*

Edith Cowan University

Faculty of Communications Health and Science, School of Nursing and Public Health

Participant:
(PLEASE PRINT NAME)

Researcher: Judi Webster, PhD Nursing Candidate, ECU School of Nursing and Public Health

This current research study proposes to look at the understanding of palliative care amongst people who are involved in palliative care services, including staff, patients and family or friends of patients. An increased understanding of the meaning of palliative care will provide direction for educational strategies to raise awareness of palliative care. The benefits of this will be to increase community support for palliative care, giving individuals more informed choices for care, and allowing politicians and funders to make more informed decisions about health care options.

Currently I am observing and participating in the activities within (*the service*). During this time, I have observed that you may be able to provide further information to assist with my research. I am now asking you for further involvement in my research. I would like you to participate in a face to face interview with me, in private, at a place and time of your choice. This session will last approximately one hour. I may also ask you to take part in further interviews, or I may later ask you to help clarify some of your comments once I have reviewed the initial interview.

I will also ask you to provide some brief personal information such as your age and how long you have been involved with a palliative care service. You may choose not to give these details if you wish.

The interviews may be tape recorded and later transcribed for analysis. I will give you the opportunity to view the transcriptions of your interviews, and you may request that I remove any information that you wish. You may also request that the tape recordings are erased, or you may wish to keep the tapes yourself.

(*For patients only*) I may also wish to review your patient case notes to compare written notes with the activities that I have observed and the things that you have discussed with me. The purpose of this comparison is to further describe how people understand aspects of palliative care, and whether it is the same for different people. I will not record any personal details from your notes, and all information I obtain from

your record will remain confidential. You may agree to being interviewed without agreeing to give me access to your patient records.

The final research may be published, and any names used will be fictitious. Every effort will be made to protect the identity of all participants. It is possible that the palliative care services participating in this study will be identified, and people with knowledge of the particular services may be able to recognise participants by association with those services.

It is a requirement of the research that all data be kept in a secure and locked place for a period of five years, after which they are destroyed by shredding or incineration. Data will be stored at the university in locked offices allocated for research archiving purposes.

It is also a requirement of the research that any risks to participants be fully disclosed. During the interviews, talking about your experiences may cause some feelings of sadness or anxiety. Such reactions will be treated sensitively. It may be appropriate to consider seeking support from members of the palliative care service, and I will help with this if you wish.

Of course, there is no obligation whatsoever to participate in this study. If you do agree to participate, you may choose to withdraw at any time without penalty. Your decision not to participate, or to later withdraw, will in no way affect
(for staff) your role within the (name of service).
(for patients) the care you are receiving.
(or for families/friends) the care your relative / friend is receiving.

If you have any queries concerning this project *Understanding palliative care* please contact me, Judi Webster (contact details), my academic supervisor Professor Linda Kristjanson (contact details), the hospital ethics committee representative (name and contact details), or (staff member within the unit - and contact details).

If you agree to participate in interviews related to this project, it is necessary that we complete this Consent Form, which contains the same information as the Statement of Disclosure.

(For patients) There are two aspects of consent to consider; the first is agreeing to participate in interviews with me, and the second is giving me permission to view your patient records. You may agree to one or both.

I have read the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in the study **Understanding Palliative Care: An ethnographic study of three Australian palliative care services**, and understand my role as participant. I agree to be interviewed and to have those interviews tape-recorded. I agree that the research data gathered for this study may be published provided I am not identifiable. I also understand that I may at any time withdraw from the study without penalty of any kind.

Participant's Signature: Date:

Investigator's Signature: Date:

ADDITIONAL CONSENT TO ACCESS PATIENT RECORDS

I further agree that the researcher may review my case notes providing that all information obtained from these records remains confidential.

Participant's Signature: Date:

Investigator's Signature: Date:

NB: IF THE PARTICIPANT DOES NOT SIGN THIS SECTION, THE RESEARCHER IS NOT AUTHORISED TO ACCESS THE PARTICIPANT'S RECORDS.

APPENDIX E

Ethics Committee Approvals



7th September 2000

Human Research Ethics Committee

Ms Judith Webster
[REDACTED]

Dear Ms Webster

Code: 00-137
Project Title: *Understanding palliative care: An ethnographic study of three Australian palliative care services*

This project was reviewed by the Human Research Ethics Committee at its meeting on 6th September 2000.

I am pleased to advise that the proposal complies with the provisions contained in the University's policy for the conduct of ethical research, and your application for ethics clearance has been approved.

Please note that your research proposal must be approved by the Research Students and Scholarships Committee before you commence any data collection. The Graduate School will inform you in writing as soon as your research proposal has been accepted.

Period of approval: From 7th September 2000 To 31st December 2001

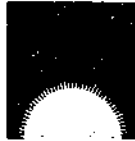
With best wishes for success in your work.

Yours sincerely

ROD CROTHERS
Executive Officer

Attachment: Conditions of Approval

cc. Professor Linda Kristanson, Supervisor
Mrs Karen Leckie, Executive Officer, Graduate School
Mrs A Stevenson, Administrative Officer, HDC



HOLLYWOOD PRIVATE HOSPITAL

February 7, 2001

Ms Judi Webster
[REDACTED]

Dear Ms Judi Webster

Re: **Hollywood Private Hospital - Research Ethics Committee Application**

REFERENCE NUMBER: HPH093

Understanding Palliative Care. An Ethnographic study of three Australian Palliative Care Services.

I am pleased to advise you that at the Hollywood Private Hospital Research Ethics Committee meeting held on February 6th, 2001, formally ratified the interim approval given for this study on 8th January, 2001. The approval includes:

- Research Proposal
- Information Sheet
- Report Request
- Statement of Disclosure for Patients/ Family members and Friends of Patients / Staff
- Consent Forms for Patients / Family members and Friends of Patients / Staff
- Demographic Data Form for Patients/ Family members and Friends of Patients / Staff

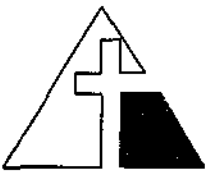
The Hollywood Private Hospital Research Ethics Committee operates in accordance with the NH&MRC National Statement on Ethical conduct in Research involving humans. In accordance with the *NH&MRC National Statement on Ethical Conduct in Research Involving Humans (June 1999) monitoring requirements*, the committee requires that annual reports be submitted for all approved projects. In addition, the committee must be advised in writing immediately in the event that any of the following circumstances arise:

- Proposed changes or modifications that are made to the original protocol or attachments
- Serious or unexpected adverse effects on participants enrolled in the trial
- Unforeseen events that may affect continued ethical acceptability of the project

Please quote the project reference number (**HPH093**) in all correspondence addressed to the committee. On behalf of the committee, I wish you well with your project. Please contact me on [REDACTED] or at robtt@ramsayhealth.com.au if you have any queries.

Yours sincerely

TANYA ROBB
Research Facilitator



BETHLEHEM HOSPITAL INC.

THE SISTERS OF THE LITTLE COMPANY OF MARY

476 KOORYONG ROAD
CAULFIELD
VICTORIA 3162
Tel: (03) 9596 2853
Fax: (03) 9596 3376

Registered No. A0011233X
ABN 55 836 187 048

5 April 2001

Ms Judi Webster



Judi
Dear Ms Webster

I am pleased to advise that at its meeting held on Thursday 5 April 2001, the Research and Ethics Committee of Bethlehem Hospital granted approval for the conduct of your study titled - "*Understanding palliative care*".

For reference purposes please note the following number, which is to be quoted on all communications regarding this project - 01040502.

In addition please note the following standard conditions that apply when such ethics approval has been granted by Bethlehem Hospital -

1. Ethical approval is granted for a two year period effective from 5 April 2001;
2. Immediate notification to Bethlehem Hospital's Research & Ethics Committee of any adverse affects on human subjects;
3. In the reporting of all adverse events, the Chief Investigator shall be required to explain in their opinion the significance of the event(s) being reported;
4. The immediate notification to Bethlehem Hospital Research & Ethics Committee of any unforeseen events that may affect the continuing ethical acceptability of the project;
5. Approval to be sought from Bethlehem Hospital's Research & Ethics Committee of any proposed modifications to the project; and

6. Submission of report at the completion of the project, with an interim report being provided at the expiration of the first 12 months and each 12 month period thereafter should the study be in excess of one year's duration.

Please note that the consent form ought to contain contact details for the Secretary of the Edith Cowan University Ethics Committee as well as also mentioning contact details for the Secretary of Bethlehem Hospital's Research and Ethics Committee (03 9595 3290 or ceo@bethlehem.org.au).

If you have any queries regarding this approval please do not hesitate to contact me.

Yours sincerely _____

PATRICK B GALLAGHER
Chief Executive Officer

PBG:ml

WESTERN SYDNEY AREA HEALTH SERVICE
HUMAN RESEARCH ETHICS COMMITTEE

Research Office, Clinical Sciences,
Westmead Hospital
Westmead NSW 2145

Telephone: 02 9845 8183
Facsimile: 02 9845 8352
Email: researchoffice@westgate.wh.usyd.edu.au

In reply please quote:

HS/TG HREC2001/6/4.7(1245)

Committee Secretariat:

Professor Stephen Leader
Chairman
Professor of Public Health &
Community Medicine

Dr Howard Smith
Secretary
Medical Graduate -
Endocrinologist

Committee Members:

Mr Leonard Burney
Layman

Dr Michael Cole
Neonatal Paediatrician

Dr Peter Eilla
Forensic Pathologist

Mrs Patricia Fa
Clinical Trials Pharmacist

Ms Jillian Gwynne Lewis
Patient Representative

Dr Vivien Lane RN
Nursing Professional
Development Unit - Research

Father Laurence McNamara
Minister of Religion

Dr Geoff Shead
Medical Graduate - Surgeon

Rev Janine Steele
Chaplain

Mr John Watts
Lawyer

Miss Freda Whillam AM
Laywoman

13 September, 2001

Mrs Judi Webster
School of Nursing and Public Health
Edith Cowan University
Pearson Street
CHURCHLANDS WA 6018

Dear Mrs Webster

Research Proposal: 'Understanding palliative care: an ethnographic study of three Australian palliative care services'

Receipt is acknowledged of your letter dated 30 August 2001 enclosing copy approval letter together with letter of support of your study from Ms Kathleen Thorpe, the Nurse Unit Manager.

As the Committee's ethical concerns have now been satisfied, confirmation of approval of this study is given. The Committee wishes you well with the study and looks forward to receiving a progress report in due course.

Yours sincerely

Dr Howard Smith
Secretary
Western Sydney Area Health Service
Human Research Ethics Committee