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## Rural palliative care nursing: A modified grounded theory study

Ruth McConigley  
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**RURAL PALLIATIVE CARE NURSING: A MODIFIED  
GROUNDED THEORY STUDY.**

by  
Ruth McConigley R.N., BSc(Nursing).

A thesis submitted in Partial Fulfilment of the  
requirements for the award of  
Master of Nursing

At the Faculty of Communications, Health and Science  
Edith Cowan University  
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## USE OF THESIS

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

## ABSTRACT

This paper presents the findings of a study of rural palliative care nurses in Western Australia. The numbers of rural centres in Western Australia offering palliative care services are increasing; however at present there is little empirical data available about the roles of the nurses involved. This study was undertaken to begin to correct this deficit. The study examines basic social processes associated with the role of rural palliative care nurses, and identifies issues that affect the nurses' professional practice.

A modified grounded theory approach was used to form a conceptual framework that describes rural palliative care nursing. Theoretical sampling techniques were used to identify the six palliative care nurses working in rural Western Australia who participated in this study. Data was generated using in-depth interview and participant observation techniques.

Constant comparative analysis of the data was employed to allow concepts to emerge from the data. The central theme that developed from the data *Living Palliative Care* describes the all-consuming nature of the rural palliative care nurses' role. Three related categories, *Wearing Many Hats*, *Being the Expert* and *Surviving in Palliative Care* are also discussed.

This research has explored issues that rural palliative care nurses feel are relevant to their professional practice, and it describes the basic social processes inherent in the rural palliative care nurse's role. Recommendations for nursing research, education, administration and clinical practice are presented.

## **DECLARATION**

**I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education; and that to the best of my knowledge and belief it does not contain any material previously written by another person except where due reference is made in the text.**

## **ACKNOWLEDGMENTS**

Firstly I would like to express my gratitude to the nurses who participated in this study. Your generosity in sharing your professional lives, and often your homes too made this research possible. Meeting you all has been a privilege, and the work you are doing is truly an inspiration.

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## **LIST OF ILLUSTRATIONS**

<b>FIGURE 1</b>	
<b>Diagrammatic representation of the conceptual framework</b>	<b>57</b>



## **LIST OF TABLES**

<b>TABLE 1</b>	
<b>characteristics used for theoretical sampling in care settings</b>	<b>42</b>
<b>TABLE 2</b>	
<b>Professional characteristics of participants</b>	<b>43</b>
<b>TABLE 3</b>	
<b>Definitions of the themes and categories related to the conceptual framework describing rural palliative care nursing</b>	<b>58</b>

## **TABLE OF CONTENTS**

Use of thesis	i
Abstract	ii
Declaration	iii
Acknowledgments	iv
List of illustrations	v
List of tables	vi
Table of contents	vii
<b>CHAPTER ONE</b>	
<b>Statement Of The Problem</b>	
Introduction	1
Research Aim	2
Purpose of the study	3
Background and significance	4
Palliative care in Western Australia	4
Rural Western Australia	6
Rural healthcare	8
Rural nursing practice	9
Palliative care service provision in Western Australia	11
Rural palliative care nursing	13
Conclusion	14
<b>CHAPTER TWO</b>	
<b>Review Of The Literature</b>	
Introduction	16
Providing rural palliative care: The perspectives of patients and their families	17
Rural palliative care nursing: The nurse's perspectives	23
Palliative care service provision	30
Conclusion	34

<b>CHAPTER THREE</b>	
<b>Research Methodology</b>	
<b>Introduction</b>	<b>35</b>
<b>Paradigm</b>	<b>35</b>
<b>Methodology</b>	<b>36</b>
<b>Conceptual framework</b>	<b>39</b>
<b>Sample</b>	<b>39</b>
<b>Characteristics of participants</b>	<b>41</b>
<b>Fieldwork</b>	<b>44</b>
Participant observation	44
Interviewing techniques	45
<b>Analysis</b>	<b>46</b>
<b>Trustworthiness of the research process</b>	<b>48</b>
<b>Ethical considerations</b>	<b>52</b>
Confidentiality	52
Informed consent	53
<b>Conclusion</b>	<b>54</b>
 <b>CHAPTER FOUR</b>	
<b>Findings</b>	
<b>Introduction</b>	<b>55</b>
<b>Discussion of findings</b>	<b>55</b>
<b>Living Palliative Care</b>	<b>56</b>
Going the Extra Mile	62
Socialising	64
<b>Wearing Many Hats</b>	<b>65</b>
Just Being A Nurse	69
Caring For All People	72
Working Together For Our Patients	74
Serving Many Masters	77
Maintaining Confidentiality	79
Being Creative With Funding	80

Planning For the Future	83
Being Other Places Too	86
Being the Expert	88
The Steep Learning Curve - Starting Out in Palliative Care	92
Caring For Colleagues	95
Surviving in Palliative Care	97
Joining Together - Finding Country Colleagues	99
Making City Connections	100
Getting Support From the Community	102
Finding Rewards	105
Conclusion	107
CHAPTER FIVE	
Discussion	
Introduction	108
Methodological issues	109
Theoretical issues	112
Clinical issues	114
Recommendations	117
Research	118
Education	118
Administration	119
Clinical Practice	120
Conclusion	120
REFERENCES	122
APPENDIX A	
Letter of introduction	131
APPENDIX B	
Fieldnote guide	134

**APPENDIX C**

**Interview guide**

**136**

**APPENDIX D**

**Letter for verification of data**

**139**

## **CHAPTER ONE**

### **Statement Of The Problem**

#### **Introduction**

Rural palliative care is a relatively new specialty area in health care. Only a few years ago people living with a terminal illness in rural areas of Western Australia simply had to cope as well as they could. There were few, if any, dedicated hospice facilities close by and little support could be obtained from existing medical services. As palliative care has evolved as a medical and nursing specialty, palliative care knowledge has been gradually disseminated into rural areas. Rural palliative care is now a developing component of the Western Australian health care system, in response to the needs of terminally ill residents in country areas. However, to date, there has been a paucity of research directed toward rural palliative care nursing (Western Australian Hospice and Palliative Care Association [WAHPCA], 1996). Despite an increase in the number of nurses providing palliative care in rural Western Australia, there is little empirical data regarding this professional role.

Rural palliative care nursing remains a largely under-funded service, and as such existing services are under-resourced to respond to increasing demands for palliative care (Freundenberger, 1991). Furthermore, few nurses practicing rural palliative care have educational opportunities to develop and advance their knowledge of palliative care (Bushy & Kost, 1990). The purpose of this research was to describe the role of rural palliative care nurses in Western Australia, to

examine the basic social processes associated with this role, and to identify issues that affect their professional practice.

This section provides background information regarding provision of palliative care services in Western Australia, and the extension of these services into rural areas. The need for research into rural palliative care nursing is explained, and the specific objectives of this research are described.

### **Research Aim**

There is a notable bias in the available literature towards the difficulties associated with medical practice in rural Australia. Little research has been undertaken to examine the role of rural nurses (Bell, Daly & Chang, 1997) or palliative care nursing in rural Australia. Western Australia's size and isolation, relatively small population, and the diversity of cultures within the population, make it unique in terms of health service needs. Australian rural palliative care issues have been poorly researched, and in fact there is little Australian research on rural nursing issues. There appears to be a predominance in the literature of humorous anecdotes about "nursing in the bush", but few research papers. The WAHPCA (1996) emphasises the need for immediate priority to be given to research into rural palliative care issues. Therefore, the aim of this research was to gather empirical data about the professional life of rural palliative care nurses in Western Australia, which will add to the small body of knowledge currently available. As palliative care in rural areas continues to grow, information will be needed by funding providers, health care planners and nursing educators to make

informed decisions about the future of this nursing specialty. This study attempted to begin to correct this knowledge deficit.

### **Purpose of the Study**

The purpose of the study was to gather empirical data about rural palliative care nursing in Western Australia. A qualitative research method was chosen due to the lack of empirical data available. Quantitative research may presuppose participants responses by offering limited responses in an instrument (Patton, 1990); whereas qualitative research can provide a wealth of data unfettered by the preconceived ideas of the researcher. Qualitative research allows the words of the participants to guide the study. A grounded theory methodology was chosen because it allows examination of "the richness and diversity of human experience" (Struebert & Carpenter, 1995, p. 145). Grounded theory is a particularly useful method of developing theories of nursing practice which have been overlooked as research topics in the past (Chenitz & Swanson, 1986). The time and budget constraints associated with this project, and the limited scope of Master's level research necessitated the grounded theory methodology be modified, so that the goals of this project were realistic and achievable. The specific modifications are discussed in the methodology section in chapter three of this report.

The specific objectives of this study are as follows:

- to describe the role of rural palliative care nurses in Western Australia
- to examine the basic social processes that occur in rural palliative care nursing



- to begin to develop substantive theory about rural palliative care nursing that can be substantiated by further qualitative research.

Consistent with grounded theory, these objectives were made as broad as possible, letting the words of the participants guide the direction of the study.

### **Background and Significance**

This section presents information related to the stated research aim and purpose. Issues examined are: palliative care in Western Australia, rural Western Australia, rural health care, rural nursing, palliative care service provision in Western Australia and palliative care nursing.

#### **Palliative Care in Western Australia**

Hospice/palliative care began in London in the 1960s when Dame Cecily Saunders opened St Christopher's Hospice, to provide care for patients dying of a terminal illness (Woodruff, 1993). Since then palliative care has developed a considerable body of knowledge and is now acknowledged as a medical and nursing specialty (Doyle, Hanks & McDonald, 1993). The Australian Association of Hospice and Palliative Care [AAHPC](1994) defines palliative care 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 provides physical, psychological, emotional and spiritual support for patients and support 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. (p.i)

For the purpose of this report the terms *palliative care* and *hospice* are used interchangeably.

In recent years public awareness of hospice/palliative care has increased. Reasons for the increasing profile of this medical specialty are varied. An increase in mortality associated with malignant disease has meant that more people are aware of the needs of the terminally ill, because they have had a personal association with someone with cancer (Twycross, 1995). The "euthanasia debate", centred around proposed legislation in Oregon in the United States of America and the Northern Territory of Australia has also underscored the needs of people with a terminal illness, particularly in relation to the difficulties people have accessing services that provide effective symptom management. The emotive nature of the euthanasia debate has resulted in extensive coverage in the popular media, and has thus increased the general public's knowledge about end stage malignant disease (Eccleston, 1997). The euthanasia debate has also led to nurses and other health professionals calling for a higher calibre of palliative care services being available, and for an increase in accessibility of palliative care services (McLean, 1997).

The role of palliative care is expanding to include people with non-malignant terminal illnesses (Saunders, Baines & Dunlop, 1995). Most notable in this category are people with HIV/AIDS, whose complex symptoms in the terminal stages require expert professional care. The incidence of individuals suffering from the symptomatic effects of AIDS in Western Australia continues to rise, and an increasing number of these reside in rural areas (Western

Australian Communicable Diseases Bulletin, 1995). It then follows that as these people become terminally ill there will be an increasing need for services offering high quality palliative care (Carwein, Sabo & Berry, 1993). Other people, such as those suffering from motor neurone disease, end stage heart disease, renal failure and pulmonary disease are increasingly being admitted to palliative care services for control of symptoms related to a terminal illness.

Western Australia has followed the lead of England, and has a well established network of hospice facilities. A free-standing 30 bed hospice was opened in 1987 (Oliver, 1992), and inpatient palliative care services are available in most general hospitals in the Perth metropolitan area. There is also an extensive network of community care available throughout the metropolitan area (Smith & Yuen, 1994). In recent years hospice facilities have become available in rural areas, and thus palliative care is a growing area of specialisation for rural health practitioners. The incidence of cancer diagnoses in Western Australia is expected to increase by 45% by the year 2001 (Threlfall, 1997). It is expected that the requirement for palliative care will be commensurate with this increasing cancer mortality.

### **Rural Western Australia**

The population of Western Australia has increased rapidly during the last 10 years, and is presently more than 1.5 million people. The state of Western Australia covers a vast area, posing unique problems associated with the distance of health care services from rural consumers. Western Australia is the largest and

most isolated state in Australia, being more than 2,400 km from north to south, and 1,600 km from east to west, and including over 7,000 km of coastline. The southern coastal areas are temperate and densely populated. Northern coastal regions are tropical and there are several large towns scattered on the northern coast. Central Western Australia is predominately desert with small isolated communities, that are generally either mining towns, or indigenous communities (Webster Publishing, 1996).

Perth, the capital city of Western Australia, is the centre of commerce and industry. Two thirds of the Western Australian population are found in the Perth metropolitan area. The remaining population is to be found in rural areas, most especially in large settlements in the Southern and Mid-West coastal regions. The population in rural Western Australia has shown a proportionally larger growth since 1986 than have urban areas. This is an unusual trend in western countries, but is related to the development of tourist resorts and retirement communities in coastal rural areas, increased mining interests, the increasing popularity of hobby-farming in the rural-urban fringe, and an increase in the numbers of long distance commuters who travel to urban centres for employment reasons (Shu, Goldlust, M<sup>c</sup>Kenzie, Struik, & Khoo, 1996). In total, approximately 570,000 people live in rural Western Australia (Webster Publishing, 1996).

## **Rural Healthcare**

Rurality is a difficult concept to define. Definitions of rural, particularly when supplied by government departments, often define rurality according to the number of residents per square kilometre (Lee, 1991). However, when discussing health and healthcare provision in Western Australia this quantifiable type of definition is inadequate because it does not take into account the availability of healthcare resources and the difficulty experienced accessing health care. Even larger regional centres with populations of 10,000 people or more may have limited healthcare resources (Australian Institute of Health and Welfare, 1998). All people residing in areas 100 km or more from Perth would be expected to experience some difficulty in accessing healthcare resources, regardless of the population of the area in which they live. Therefore, for the purpose of this study, rural will be defined as being more than 100 km from Perth.

For the purposes of this study a distinction is also made between regional centres and rural towns. A regional centre is an arbitrary title given by government bodies to a town in rural areas which has a high concentration of public services (e.g. a regional hospital and a senior high school; Australian Institute of Health and Welfare, 1998). A rural town is any town in a rural area not designated as a regional centre.

Rural people experience difficulty accessing health care facilities because most of the Western Australian health care infrastructure is located in Perth. There is often limited choice of health care practitioners and facilities available to rural communities, and care must be sought at large urban healthcare facilities,

that are often long distances away. Complex diagnostic procedures and treatment of illness generally occurs in the large metropolitan teaching hospitals because there are few specialist medical services available in rural Western Australia. There are vast inequities in the Australian healthcare system, particularly when examining differences between rural and urban healthcare infrastructures (Humphries & Nichols, 1995). Resources and funding are limited in rural areas, with most healthcare funding being allocated to large urban health centres. The cost of increasing healthcare infrastructure in rural areas is high, and population increases in rural Australia are not often matched with increased service provision (Shu et al., 1996). Services supplied to rural areas may in many cases be inappropriate, because planning is generally undertaken in urban areas with little input from rural consumers (Harvey, Sandhu & Strasser, 1994).

### **Rural Nursing Practice**

Health and healthcare are social phenomena. Both health and healthcare provision are closely linked with social organisation (Russell & Schofield, 1986). In particular, social stratification and family structure have a large impact on health beliefs and practices (Bond & Bond, 1986). Nurses must work within accepted cultural norms to provide appropriate and effective healthcare for the community in which they practice. The sub-culture of rural populations will impact on the role of the rural nurse. Individuals living in rural communities may have different health beliefs and definitions of health, and different values related

to personal health. The diversity of rural populations is a particular consideration for rural health nurses (Malone-Rising, 1992).

Many Western Australian towns have large immigrant populations, as well as high numbers of Aboriginal people (Hugo, 1996). Migrant groups often have health beliefs and health practices dictated by the culture in which they originate (Gifford, 1991). Aboriginals in Western Australia have complex health beliefs that are related to traditional health practices and to current social and environmental disadvantages suffered by this group (Gracey & Veroni, 1995). The beliefs and practices of both of these groups may differ greatly from the social norms of the society in which they are now a part. To provide culturally appropriate care for Aboriginal and migrant groups in the population, nurses must be aware of the specific needs of each group (Williamson, 1996). This increases the expectations placed on rural nurses.

Nursing in rural areas is acknowledged as being much different from nursing in large urban teaching hospitals (Long & Weinart, 1992). Rural nurses have a unique approach to giving care, which is a product of working conditions far different from those of their urban counterparts. Most rural nurses are expected to be generalists, providing healthcare for all community members. Rural communities often expect that nurses will always know what to do, and be capable and competent in any situation. Nurses are expected to be available on demand and to give their time selflessly. Rural nurses are also generally well known in the community and have little chance of retaining their anonymity and privacy (Thornton, 1992). The increasing cost of maintaining the healthcare

infrastructure in rural areas has led to increasing demands being placed on nursing staff. There are insufficient numbers of medical practitioners available in rural Australia, requiring nurses in these areas to assume increased responsibilities. Nurses in rural areas are often expected to fulfill multiple roles, such as pharmacist, physiotherapist, general practitioner and dietitian (Hegney, 1996).

### **Palliative Care Service Provision in Western Australia**

In 1995 there were more than 1600 rural Western Australians who were known to have a cancer diagnosis (Threlfall & Thompson, 1997). There were also more than 670 deaths directly attributable to cancer in rural areas. Mortality rates from cancer were proportionally higher in the Perth metropolitan area, possibly because people were forced to move to urban areas to access health care (Threlfall, 1997). The number of rural people dying annually with a terminal illness should be a significant consideration when planning resource allocation. However, Threlfall stated that there is insufficient evidence available at present upon which to base planning of rural cancer services. The needs of rural cancer sufferers are slowly being recognised, as an increasing number of rural health services offer palliative care to the communities they serve. In 1993 the directory of Hospice/Palliative Care Services in Australia listed four services in rural Western Australia that were providing palliative care (Brown, 1993). In 1997 that number had risen to 14 (AAHPC, 1997). Some larger regional centres in Western Australia offer both community and inpatient specialist palliative care



services. Smaller towns have designated palliative care beds in the local hospital, and some may also offer limited community support as well. Financial support for these services has been minimal and uneven. Maintenance of rural palliative care services relies largely on the volunteer sector and the interests of dedicated health professionals in rural communities (WAHPCA, 1996).

Many rural people wish to remain within their own community when ill to be close to their friends and families. This is particularly so when people are diagnosed as terminally ill (Williamson, 1996). Readily available community nursing support is a vital component of a competent and viable palliative care service. However, lack of funding prohibits 24 hour home care in country towns. The lack of community nursing services leads to more inpatient palliative care services being used by people who are not able to cope at home without professional support (Sach, 1997). Unfortunately, inpatient palliative care services may not be readily available when required.

The Health Department of Western Australia [HDWA] (1998) in a discussion paper stated it's goal with regard to providing improved services for people with a cancer diagnosis as:

all Western Australians with a cancer diagnosis must have access to high quality care delivered promptly and with humanity. In all cases care should be provided as close to the patient's home as is compatible with high quality...treatment in keeping with the expressed views of consumers and carers. (p. 84)

The HDWA also expressed the need for appropriate palliative care services to be available. The Commonwealth Department of Health and Family Services [CDHFS] committed increased funding in the 1997-1998 budget for rural

healthcare. Particular areas targeted included provision of more flexible models of health care for rural communities to meet the diverse needs of different communities, and provision of funding for both medical and nursing training in rural healthcare. Palliative care funding was also increased in the same government budget statement. The increased palliative care funding was provided to ensure that palliative care service provision is equitable and easily accessible for all Australians, and to develop further community based palliative care resources (CDHFS, 1998a). Sach (1997) underscored the urgent need for trained palliative care staff in rural Australia and suggests that recruitment and training be considered a priority for rural health care planners and funding providers.

### **Rural Palliative Care Nursing**

Palliative care is an acknowledged specialty area for nurses, requiring specific education and training and extensive knowledge and skills. Specialist Registered Nurses are more likely to be found in larger regional hospitals because smaller centres do not have the staffing numbers or funding to provide specialist care (Hegney, 1996). Even nurses who are labelled “specialists” are generally expected to perform generalist tasks. For example, a palliative care nurse may be required to be a cancer generalist, providing care and support through diagnosis, surgical treatment, chemotherapy, and palliative care (Curtiss, 1993).

Palliative care nurses in rural areas may face unique challenges in their professional life. Social and professional isolation is common for nurses working

in rural Australia (Hegney, 1996), and the lack of healthcare resources in rural areas poses additional dilemmas for rural palliative care nurses. The little research data available about rural palliative care nursing is either from England or the United States of America [USA], and findings may not be applicable to conditions in Western Australia.

Curtiss (1993) discussed the burden to patients of cancer treatment such as radiotherapy being available only in larger centres, necessitating travelling over 60 miles from home to receive treatment. In Western Australia, most diagnosis and treatment is available only in Perth, and people living in the North-West of the state may have to travel distances of 3,000 km or more for treatment. Curtiss also stated that most rural health facilities offer some cancer care, such as surgery and chemotherapy. Many small rural hospitals in Western Australia do not offer these options, and in fact may not even have a medical practitioner available on a full-time basis. The size and isolation of rural Western Australia make palliative care nursing a unique and challenging occupation.

Australian rural palliative care issues have been overlooked in the past, in terms of both funding and research (WAHPCA, 1996). Little research has been conducted on any rural palliative care problems, and the little data that does exist has been generated primarily in the United Kingdom and North America, making it difficult to generalise results to the far different conditions in rural Australia. Funding for rural palliative care has been largely provided by the institution offering palliative care services, because no specific rural palliative care funding has been made available. Public donations are a necessary but uneven source of

palliative care funding for rural service providers (Sach, 1997). The 1997-1998 Australian Commonwealth budget statement appears to make some attempt to rectify the lack of funds, with Government expenditure increased in the areas of rural health and palliative care (CDHFS, 1998b, 1998c). However, with little empirical evidence of the characteristics of this sector of the healthcare system, there is a possibility that inadequate or inappropriate services will be provided.

### **Conclusion**

This chapter has outlined the reason for undertaking a study of rural palliative care nursing. The field of rural palliative care is new, and growing in popularity, with ever increasing numbers of health services in rural areas offering hospice services. To date there has been little research about this nursing specialty, resulting in a lack of empirical data to guide decisions that affect rural palliative care nurses. Funding providers, health service development planners and nurse educators are some of the people who require such data to make informed decisions which will ultimately impact on palliative care nurses in rural areas. This qualitative study has elicited detailed descriptive data about rural palliative care nursing which may prove helpful in planning rural palliative care nursing services.

## **CHAPTER TWO**

### **Review of the Literature**

#### **Introduction**

Traditionally, grounded theory method requires the researcher to enter the field without extensive knowledge of the phenomena under examination.

Therefore, a review of the relevant literature would be conducted as part of the data generation process (Strauss & Corbin, 1990). However, the aim of this literature review was to identify areas that were possibly relevant to rural palliative care nursing, and would thus serve to guide sampling and the initial stages of fieldwork. To this end, a literature review was undertaken using the CD-ROM databases of CINAHL, Medline and Healthstar, and the electronic databases OVID and UNCOVER. A manual literature search was also conducted using the reference lists of related articles. This search revealed a paucity of empirical data related to rural palliative care nursing. Therefore, the scope of this literature review was expanded to include related areas with relevance to rural palliative care nursing.

Three relevant themes emerged from this literature review; studies of rural palliative care from the perspective of cancer patients and families, research related to rural nursing, and reports of models of palliative care service provision used in rural areas.

## **Providing Rural Palliative Care: The Perspective Of Patients And Their Families**

Literature describing rural palliative care from the view of cancer sufferers and their families was included in this section. As well, studies that document the health beliefs of rural people were reviewed, to provide a broader context within which to embed knowledge of rural palliative care perspectives.

A basic tenet of health care planning is the importance of defining health from the perspective of rural populations, so that healthcare is planned and implemented appropriately for the specific needs of the communities (Lee, 1991). To date there is no empirical data available from rural Australia that describes health beliefs of rural populations. The literature that does exist comes primarily from studies of Northern American rural communities. Bushy (1991) and Weinart and Long (1991) both discuss health beliefs of rural North American populations. In these studies rural people are characterised as slow to accept change, tending to maintain more traditional values, such as the stereotypes of men as the "breadwinners", and women as the "nurturers and housekeepers". These differences shape the health beliefs of the community, and impact on health professionals in the community. For example, nurses may be viewed as doing "women's work", which is unimportant.

A study of the health beliefs of rural elders found that most participants viewed ability to actively contribute to the community as the major determinant of health status (Craig, 1994). The elders valued the ideal of reciprocity with others, including healthcare professionals. Furthermore, healthcare choices such as which medical practitioner to consult were generally related to feelings of

relationship. That is, elders preferred to consult healthcare professionals with whom they felt they could have a good relationship. Choices were often made based upon recommendations of family and friends, and elders tended to “shop around” before approaching health professionals.

A major assumption made when researching rural health is that rural people have more difficulty accessing health care than do urban populations (Sach, 1997). Guidry, Aday, Teleki and Winn (1995) conducted a qualitative study comparing cancer sufferers in rural and urban Texas, to discover the factors that rural people perceived as barriers to accessing necessary cancer treatment. Costs, transportation difficulties, lack of social support, and insufficient communication and information sharing with health care professionals were the barriers that rural respondents reported as limiting their access to treatment. The urban group also reported that the financial cost of treatment was a deterrent, but did not name transport as a barrier. Individuals in the urban group also did not have as a great a need for reassurance as did the rural participants, perhaps because the urban group had access to more formal support networks, such as cancer support groups and counselling services. The findings from this study are limited by the small sample size ( $n=42$ ); however, these results suggest that innovative methods of health care delivery in rural areas may provide some relief from the perceived barriers to healthcare.

Wilkes and White (1998) studied the needs of palliative care patients and their families in rural New South Wales, Australia. Needs were identified by the patient, the family/caregiver, and by palliative care nurses working in the region. The most important areas of concern identified were the availability and

accessibility of appropriate services, the need for information, and the need for guidance and support throughout the illness trajectory and the bereavement phase. The authors noted that palliative care resources were unevenly distributed throughout the state, and were not always reflective of the needs of the rural community. This research highlights the contributions of rural palliative care nurses in providing direct patient care to cancer sufferers in their community. Rural palliative care nurses were included in the sample of this study, however, as the focus of the study was the support needs of patients and caregivers in rural areas, little data relating specifically to the experiences of rural palliative care nursing was sought. Although the researchers focused primarily on the needs of rural patients and their caregivers, the scope of this study did extend to allow the nurses to comment on aspects of their role that have a direct effect on the support needs of patients and families. Findings suggest that rural palliative care nurses work with the limited health care services available in their community to provide the best possible care for patients and families. Funding limitations often determine the extent of support offered to terminally ill people in rural areas. The research also reflects upon the relationship between rural palliative care nurses and General Practitioners in the community, and the effect that this may have on the quality of patient care. The researchers do not focus directly on the experiences of rural palliative care nurses, and therefore do not examine the specific needs of this group of nurses.

Another Australian study again conducted in New South Wales compared the adequacy of support systems of paid and unpaid carers for terminally ill people living in a regional area (Pincombe & Tooth, 1996). The study found that



unpaid carers placed great value on social support and family unity, suggesting that the role played by informal support systems may be more significant in this regional area. However, the authors do not comment on the degree of rurality associated with the sample, therefore it is difficult to apply these results to other rural populations.

Buehler and Lee (1992) conducted a grounded theory study into the availability and adequacy of formal resources provided to cancer sufferers and their families in rural Montana. They found that the resources available to rural communities were often limited and inadequate, which impacted greatly on the caregivers, necessitating major role changes to facilitate coping. The more isolated the area in which the caregiver lived, the more limited were the resources, and thus the greater the caregiver burden. Buehler and Lee coined the term "making do" to describe the coping strategies of rural participants, because rural families tended to be self sufficient and adapt to the changed situation as well as they could. Results of this study point to a need for an extension of existing support services into rural areas. However, the small number of participants (n=10), and the lengthy illnesses of the cancer sufferers (8 out of 10 had a long dying trajectory characterised by increasing debility and dependence) suggest that these results may not be generalisable to other rural populations.

Burman and Weinart (1997) studied specific concerns of rural cancer sufferers and caregivers in rural Montana. Results showed that a significant proportion of both cancer sufferers and caregivers reported marital difficulties and social isolation and feelings of "aloneness", suggesting that there are inadequate resources to meet their psychosocial and interpersonal needs. Interestingly, a

number of participants noted that health care professionals, including nurses, were insensitive to their needs, and 15% of participants in this study felt that their information needs were not adequately met. These results are similar to those of Silvera and Winstead-Fry (1997), who conducted a study of physical and psychological needs of rural cancer sufferers and their lay caregivers (family or friends). Personal care needs, involvement in their own health care, and interpersonal interaction needs were rated by both rural cancer sufferers and caregivers as very important. Although there were no urban comparison groups in either study, the results are similar to those found by Longman, Atwood, Sherman, Benedict and Shang (1992) in a similar study with a metropolitan based sample. However, the rural cancer sufferers and caregivers identified more informational requirements than the metropolitan sample. The authors suggest that rural participants are likely to have a greater need for independence than people living in metropolitan areas, hypothesising that the need for information may be a result of inadequate patient education.

Morgan (1997) describes patient teaching as vital in rural palliative care, because it increases the person's feelings of control and self-efficacy. Furthermore, Morgan asserts that providing appropriate information for rural cancer sufferers and caregivers promotes trust and respect in the relationship with the rural palliative care nurse. There is a strong suggestion in the literature that providing for information needs of rural people is a vital part of the rural palliative care nurse's role, however the extent to which the educational aspect of that role is supported and practiced does not appear to be empirically documented.

Few of the research studies cited specified the phase of illness of the cancer sufferer. The study by Burman and Weinart (1997) states that 90% of participants described their health as good, despite their cancer diagnosis. Therefore, results may over-represent cancer patients at earlier stages of the illness continuum, or patients who are less debilitated. It is probable that the needs of rural cancer sufferers and caregivers will increase as their illness progresses. This is supported by Buehler and Lee's (1992) findings that a longer dying trajectory and greater physical deterioration increased the burden placed on the rural caregiver and that resources available to meet caregivers needs were considered inadequate. However, because these studies do not focus specifically on the needs of rural people with terminal illnesses, they may understate the degree of support from rural palliative care services required at this phase. Furthermore, the majority of the studies cited have been conducted in the United States, and although they indicate some of the difficulties experienced by cancer sufferers and their families living in rural areas, results may not apply directly to conditions facing Australian rural populations. These study limitations have implications for rural palliative care nurses, who look to the literature for information to guide their practice.

Palliative care nurses play a vital role in providing support and meeting the needs of the terminally ill, and thus need to be fully aware of the needs and expectations of the community in which they work. The literature reviewed in this section suggests that palliative care nurses in rural areas are a primary source of support and information for palliative care patients and their caregivers. However, the research also suggests that available palliative care resources in

rural areas are limited and often inadequate. How the palliative care nurses cope with meeting the needs of their patients, and the burdens that this places on them are not examined.

### **Rural Palliative Care Nursing: The Nurse's Perspective**

No literature was found focusing directly on rural palliative care nurses, their role in rural communities, or the impact of the palliative care role on the nurse. Therefore, literature that described the experiences of rural nurses was contrasted with information regarding palliative care nursing in metropolitan areas. Literature detailing the experience of general practitioners involved in delivering palliative care in rural Australia was also examined.

Literature pertaining to palliative care in metropolitan areas was examined briefly to determine major themes that might be appropriate to consider when examining rural palliative care practice. Several qualitative studies have been conducted to determine the issues that oncology and palliative care nurses consider important to their roles. Rasmussen, Norberg and Sandman (1995) interviewed staff (n=19) in a newly established hospice in Sweden to describe the lived experience of being a hospice nurse, and to determine the reason that these nurses chose to pursue a career in palliative care nursing. The phenomenological study revealed that the nurses could cope with the stressful aspects of hospice nursing as long as they felt that they were providing good terminal care, and that their work had meaning. Nurses interviewed described the following points as being important in palliative care nursing:

- working in a setting that acknowledges death and dying,

- developing a close relationship with patients and their families,
- giving holistic care without the restrictions imposed in more institutionalised settings,
- being able to provide the “personal touch” when giving care,
- being in a supportive work environment.

A follow-up study in the same setting (Rasmussen, Sandman & Norberg, 1997) looked at the same nurses views of palliative care nursing 13 months later, when the hospice in which they worked was more established. The results were similar to the earlier study, but did suggest that further experience had emphasised the rewarding aspects of delivering palliative care, such as building relationships with patients and families. The value of a supportive work environment was underscored by the nurses as the most important factor in assuring job satisfaction. Maintaining good working relationships with colleagues was considered an integral part of being a good palliative care nurse. Also, personal and professional growth was an important part of palliative care nursing.

Another phenomenological study (Rittman, Paige, Rivera, Sutphin & Godown, 1997) examined the skills used in giving palliative care, the experiences nurses had giving palliative care, and the meanings that sustained palliative care nurses. The small sample size (n=6) and the use of only written narratives limit this study, however, the themes developed from the data support the findings of Rasmussen et al. (1995), and Rasmussen et al. (1997).

Two articles (Cohen, Haberman & Steeves, 1994; Cohen, Haberman, Steeves & Deatrck, 1994) report a phenomenological study of oncology nurses understanding and descriptions of their work, again with results similar to those

previously mentioned. Rewards of oncology nursing included the relationships established with patients and co-workers, working in a team environment, and gaining new skills leading to increased professional confidence. Difficulties associated with the role of oncology nursing included coping with angry patients, unpleasant death scenes, relationships with co-workers which were negative and involved unwarranted criticism, and difficulty finding help.

All of the studies mentioned above found results that were similar to the four themes that Dobratz (1990) noted in a review of literature pertaining to hospice nursing. These themes were:

- intensive caring (clinical skills, compassion, providing psychosocial and spiritual care)
- collaborative sharing (working within an interdisciplinary team)
- continuous knowing (having an extensive knowledge base)
- continuous giving (selfless care and compassion for others).

However, all studies were conducted in metropolitan areas making it difficult to ascertain how applicable the results might be to rural palliative care nurses. In particular, the importance of working as part of a team and having collegial support is stressed in each of these studies, however this support may not be available to rural nurses. A study by Bell, Daly and Chang (1997) found that rural and remote nurses in Australia felt that professional isolation experienced by rural nurses was an issue that required research. This finding suggests that professional isolation, and lack of collegial support may be a problem for rural nurses.

Problems associated with conflict within the interdisciplinary palliative care team may be less important to rural palliative care nurses.

A study of rural General Practitioners in New South Wales (n=133) who were actively involved in providing palliative care in the community in which they practiced found that 55% of those surveyed cited a lack of opportunity to debrief about their work as a problem, and 36% identified professional isolation as a difficulty (Trollor, 1995). It is possible that similar issues may arise for all health professionals providing palliative care in rural areas, although no empirical data is available for nursing or other allied health professionals.

The provision of rural health care poses unique challenges to health care professionals. An Australian study (Harvey, Sandhu & Strasser, 1995) surveyed health professionals who were either practicing in rural areas or who were involved in certain aspects of rural health care provision, such as educators (n=317). Issues of particular concern were: inadequate and/or inappropriate health service delivery, staffing issues such as recruitment and retention, and provision of adequate staff development. The study noted that issues of recruitment and retainment of staff were cause for concern because people working in understaffed rural areas experience a heavy workload and high levels of work related stress and dissatisfaction. Staff development was affected by the problem of understaffing, because there were no staff available to relieve others attending education and training sessions. Access and cost were further issues that prevented many rural health professionals from attending staff development courses. Unfortunately, this paper presented only preliminary findings of the study conducted, and did not present a full account of the methodology used to complete the research. Therefore these results must be viewed cautiously. However, this study does indicate that rural health professionals may work in

conditions that are far from ideal, and may face stressors that are unique to rural practice.

Hanson, Jenkins and Ryan (1990) conducted research with rural nurses (n=167) in Georgia (USA) to ascertain the factors that contributed to rural nurses' job satisfaction, and factors that may influence them to resign and seek other employment. The participants surveyed cited being useful and having a challenging position as important factors related to job satisfaction. Nurses listed lack of autonomy as their main cause for concern in the workplace. Nurses stressed the need to be included in decision making which would directly affect themselves. Lack of autonomy was strongly associated with nurses reported efforts to look for another job ( $r=-0.42$ ;  $p<0.01$ ), and nurses intention to resign ( $r=-0.46$ ;  $p<0.001$ ). No urban comparison was used in this study, therefore it is difficult to ascertain if the variables listed as impacting on the rural nurses job satisfaction are directly related to rural practice. It is difficult to generalise these results to Australian rural nurses, as a literature review pertaining to rural nursing in Australia (Hegney, 1996) suggests that many nurses in Australian rural practice work alone, and are often expected to assume expanded roles in the absence of trained health professionals. The making of decisions in complex situations for which nurses are not adequately trained is a problem for rural nurses in Australia, but lack of autonomy may be less important. Instead, the issue of concern may be a lack of support and preparation for an extremely autonomous role.

Rural nurses are often expected to be generalists, and to fulfill various roles as required (Hegney, 1995; Thornton, 1992). Thornton suggests that fulfilling the generalist role may be difficult for nurses, resulting in role conflict if



expectations cannot be met. Samarel (1989) examined the experiences of nurses who are required to care for both terminally ill patients and those requiring acute care, to ascertain the degree of role transition and role conflict they experienced. The findings suggest that providing care for two very different types of patients did not cause role conflict for the nurses, primarily because the nurses reported that the caring role had unified their work. Nurses provided reassurance, education and support to all patients, regardless of diagnosis. The author of this paper did not provide an adequate description of the acute care offered (e.g. acute oncology, general medical, surgical) making it difficult to judge the appropriateness of these results in other care settings. However, the differing views of Thornton and Samarel with regard to role expectations of nurses suggests that different groups of nurses should be viewed separately, and conclusions about role conflict in rural palliative care should not be drawn from literature that is not specific to rural palliative care nursing.

The literature regarding the education needs of rural nurses, and of rural palliative care professionals suggested that this is an area that may also be of significance to rural palliative care nurses. A review of relevant medical literature (Charlton & Ford, 1995) found that, in general, health care professionals are ill-prepared to provide palliative care. This paper only reviewed medical literature, and so does not offer insight into the specific educational needs of nurses. Redman, White, Ryan and Hennrikus (1995) studied the professional needs of palliative care nurses in New South Wales (n=108), and found that 42% of participants mentioned the need for further education in palliative care. However, due to the small sample, comparisons between the education needs of

rural and metropolitan based participants were not made. Armstrong, Clark and Stuppy (1995) studied the motivation of rural and urban registered nurses to obtain tertiary education qualifications (Bachelors Degree), and found that both rural and urban nurses had similar motivation in seeking further education. However, the study found that rural nurses had an increased need for professional knowledge than their urban counterparts ( $t=2.18$ ;  $p=0.03$ ). This may be related to an increased need for self reliance in rural areas, where little professional support is available. The authors also suggest that rural nurses may feel a greater sense of community than do urban based nurses, and may seek further education to provide more effective health care for the communities in which they work.

A paper by Kristjanson, Dudgeon, Nelson, Henteleff and Balneaves (1997) outlined a pilot programme to provide interdisciplinary training in palliative care for rural health care practitioners in Northern Canada, and evaluated the effectiveness of the programme. The evaluation found that the programme improved the clinical knowledge of the participants, and that knowledge was retained. Attitudes to death and dying were found to be more open and accepting after the education programme, and practitioners were found to be more confident and innovative when providing palliative care. This paper demonstrates the value of providing access to palliative care education for rural health care practitioners. Interestingly, the authors note that several participants had trouble finding replacement staff for the period they were attending the course. This reiterates Harvey et al's (1995) finding that access to staff development can be a problem for rural health care professionals. As adequate staffing levels and centralised education centres are a problem in Western Australia, it is possible that rural

palliative care professionals will have similar difficulties accessing educational opportunities.

While the literature reviewed in this section did not specifically examine the role of the rural palliative care nurse, it does suggest some areas that are potentially problematic. These include social and professional isolation and a lack of educational resources.

### **Palliative Care Service Provision**

Literature related to models of palliative care service delivery in rural areas was reviewed because the structure of the health service within which nurses work could be expected to have a direct impact on the rural palliative care nurses in these services. Styles of palliative care services which are appropriate in city areas are not practical in areas with much smaller populations and much larger catchment areas. Different palliative care settings may provide different amounts of social and professional support, educational opportunities, or facilities which provide client services. The literature regarding palliative care service models in rural areas is limited.

Sach (1997) conducted a study of palliative care service provision in rural Australia, using qualitative and quantitative methods to assess service delivery models in rural areas in the states of Victoria, South Australia, New South Wales and Queensland. His findings contradict a long held myth of rural health care delivery, namely that most of the rural populations in the areas studied did not live in isolated towns, as is the popular conception of outback Australia. Instead, most of the rural population was found in what Sach terms "provincial cities".

with only the minority being found in the "rural hinterland". Sach stated that the standard of palliative care delivered was high, contrary to his expectation, with community members being very satisfied with the care received. Sach suggested that palliative care services be tailored to the needs of individual communities. Larger rural communities should provide both inpatient and outpatient services to residents, including a full range of services catering for the psychosocial needs of patients and their families. Smaller communities may offer limited services that provide the opportunity for rural residents to access palliative care facilities close to home. Designated beds in small country hospitals could provide some inpatient services to smaller populations. Sach stresses the importance of maintaining a local focus when planning for palliative care service provision. This study does not examine the issues of palliative care in Western Australian rural areas, and does not provide any insight into the specific roles of health care professionals working in rural areas.

A report compiled by the North West Aboriginal Health Strategies Unit (Willamson, 1996) suggested that palliative care in the North West of Western Australia needs to be available to small communities in the area. The report suggests that existing palliative care services in the region form a decentralised network, pooling resources and offering extended services in the region. This study focuses specifically on the palliative care needs of the Aboriginal population in the North West of Western Australia, and stresses the need for culturally appropriate services to be provided to cater for the large Aboriginal population in the region. Despite the focus on Aboriginal issues, this paper offers suggestions that will benefit the entire community. The service structure

suggested is particularly appropriate for a region with a small population in a very large area. However, the demands and stresses of working in a decentralised service are not known, and the experiences of health care professionals working in a service like this have not been documented.

Providing an appropriate service for a region is a difficult choice, and is dependent on issues such as funding and availability of resources. Several innovative models of palliative care provision are mentioned in the literature as being appropriate for use in rural areas with small populations. Desch, Smith, Kane, Simonson and Breindel (1992) describe a cancer outreach programme developed in rural Virginia (USA), between a large teaching hospital and several small rural hospitals. The outreach programme encouraged a close working relationship between rural staff and urban based specialists, so that optimum care was provided in the rural community. Desch et al underscored the importance of assessing the needs of the rural community, and providing appropriate services. Smith et al (1996) provided details of an evaluation conducted of this rural cancer outreach programme, suggesting that treatment provided close to home offered a viable alternative for rural cancer sufferers. The study also looked at palliative care delivery before and after commencement of the outreach programme and measured the total morphine used in the rural oncology service. The authors found that morphine usage had increased between 500 and 700%. The authors suggested that increased morphine usage indicated more effective palliative care was being delivered. However, morphine usage is not an adequate indicator of the level or quality of palliative care services being offered, and this measure should be treated with caution. Patient, caregiver and staff satisfaction with the

outreach services were not measured. Despite the limitations of these papers, the research suggests that rural cancer outreach programmes can provide adequate professional support and educational opportunities for rural palliative care professionals.

Clarke and Neale (1994) presented two case studies detailing innovative community based hospice programmes in rural Great Britain. Both of the hospice teams experienced difficulties establishing community based hospice services, as community members were more interested in developing more traditional inpatient palliative care facilities. The initial resistance from the communities and funding providers lessened as the services became more familiar. The small community based organisations provided care previously unavailable to the rural communities in their own town, but maintained affiliations with larger palliative care service providers in towns close by. The findings of this study highlight the need for palliative care professionals working in rural areas to remain sensitive to community needs.

The literature regarding provision of palliative care services in rural areas focuses primarily on innovative, non-traditional methods of service provision. There is little empirical data documenting service provision models more common in Western Australia, such as hospital based palliative care units, or small community nursing groups who offer palliative care services. Therefore, it is difficult to ascertain the extent to which the literature regarding rural palliative care provision may be relevant to Western Australian rural practitioners. Furthermore, although the literature cited details service provision models and

evaluates their effectiveness, it does not examine the effect of these models on staff working in the services, or on the quality of services they are able to provide.

### **Conclusion**

This literature review has examined rural palliative care from the perspectives of rural communities, rural nurses, and health care providers. In summary, this literature has highlighted the following themes related to palliative care:

- health beliefs of rural populations may have a direct impact on the delivery of nursing care
- palliative care nurses in rural areas may often have similar experiences to their urban counterparts
- social and professional isolation are potential problems for rural palliative care nurses
- rural palliative care nurses are likely to have difficulty accessing adequate educational opportunities
- innovative models of palliative care service provision may be utilised to provide appropriate, financially viable services to isolated communities.

To date, there is no empirical data that proves or disproves these suggestions when considering rural palliative care nurses. The lack of literature directly relating to the roles of rural palliative care nurses underscores the need for research to be conducted that will provide information to illuminate this area.

## **CHAPTER THREE**

### **Research Methodology**

#### **Introduction**

This chapter details the methodology employed to conduct a study of rural palliative care nursing. The choice of a qualitative methodology is discussed, and details of a modified grounded theory study are offered. Measures to maintain the trustworthiness of the research process are examined. Ethical considerations related to the research are also detailed.

#### **Paradigm**

There is minimal empirical data available about palliative care nursing in rural settings. In areas that have been poorly researched in the past, qualitative methods have definite advantages over more traditional quantitative research. Quantitative research requires the researcher to decide upon appropriate variables to examine prior to the commencement of the study. Given the large diversity in the demographic composition of country towns in Western Australia, it is difficult to pinpoint specific variables which require research (Malone-Rising, 1992). Quantitative research relies heavily on instruments, often using a questionnaire type format, that offer limited response choices to participants. Questionnaires contain predetermined categories of responses devised by the researcher to test the hypotheses of interest (Patton, 1990). In the area of rural palliative care nursing, where there are few hypotheses to be tested, and little preliminary



research upon which to design a questionnaire, qualitative research methods offer an appropriate choice.

Qualitative research is a non-interventionist method. The method involves observation of people in their natural settings. Qualitative researchers enter the field with no a priori hypotheses about the area under investigation, and thus can search for concepts that have meaning to the participants of the study. Data collected is not subject to control and standardisation, as in quantitative research, but reflects the complexity of the social setting (Strauss & Corbin, 1990).

Qualitative researchers look for trends, patterns and styles of behaviour that are not easily assessed in a quantitative manner and attempt to understand, rather than to explain human relationships (Fontana & Frey, 1994). This study proposed to interpret phenomena in terms of the meanings ascribed to them by rural palliative care nurses. This type of research design allowed participants to recount their experiences freely in their own words, which were reported by the researcher without bias (Denzin & Lincoln, 1994). A qualitative study also allowed the researcher to verify meanings and interpretations given to the data with the participants themselves, thus increasing validity of the findings (Lincoln & Guba, 1985).

### **Methodology**

Grounded theory was chosen as the method with which to research rural palliative care nursing. Grounded theory is a useful qualitative methodology for

examining areas which have not been widely researched in the past, such as rural palliative care nursing (Chenitz & Swanson, 1986; Stern, 1980; Strauss & Corbin, 1990). A grounded theory approach allowed the researcher to commence the study with an open mind, and let theory develop from the data (Morse & Field, 1996). The researcher using grounded theory does not set out to prove or disprove an existing theory, but develops theory grounded in the data collected. Strauss (1987) asserts that theory that is not grounded in empirical data can be considered speculation only. When researching an area such as rural palliative care nursing, where there are no existing theories in the literature, it is inappropriate to use a research methodology which relies on the testing of identified variables, as there is nothing in the nursing literature on which to base such a study.

Grounded theory attempts to provide explanatory models of human behaviour, by examining the basic social processes inherent in human interactions (Morse & Field, 1996). Grounded theory techniques were developed from the ideas of the "symbolic interactionists", sociologists at the University of Chicago in the 1930s. These sociologists believed that seeing the world from another's viewpoint could enhance understanding of human interaction (Schwant, 1994). Symbolic interactionists believe that people's actions are related to meanings derived from previous social interactions. These meanings are established and modified via interpretive processes. People are considered to be active participants in their environment, who assess and interpret ascribed meanings and temper their reactions accordingly (Craib, 1984).

Grounded theory research methods allowed a wide variety of sources to be utilised when collecting data (Baker, Wuest & Stern, 1992). Interviews, informal

discussions, participant observation, organisational manuals and current professional literature were all sources of data examined during the data generation process. Using such diverse sources provided a more comprehensive and in-depth study. The flexibility associated with grounded theory allowed the researcher to seek data from any source that would contribute to the developing conceptual framework (Strauss, 1987).

Grounded theory is an appropriate method for researching many nursing questions, because the method permits study of human experiences, providing theory grounded in empirical data (Streubert & Carpenter, 1995). Grounded theory is also helpful to nurse researchers because it can be used to identify and track solutions to problems in much the same manner as the nursing process (Stern, 1985). Strauss (1987) stressed the complexity of grounded theories, suggesting that they mimic the complexity of social phenomena. A grounded theory study can begin to develop understandings of the many concepts and variations inherent in the social world of rural palliative care nurses.

The design of this study was specified as a *modified grounded theory* method because of the time and scope limitations associated with Masters level research. Ideally a grounded theory study involves theoretical sampling until saturation of data is reached. That is, until no new or relevant information is obtained during data generation (Strauss & Corbin, 1990). Ongoing interviews and extensive participant observation are conducted until a core category is identified in the data. However, given the boundaries of this research project, a modified grounded theory method was employed, with an artificial time limit placed on the project, thus limiting the depth and breadth of analysis. Theoretical

sampling of five care settings occurred. Specific characteristics of care settings sampled for were size, age, location and model of service provision. Participant observation was limited to a maximum of two working days, and interviews were approximately 90 minutes long, with follow-up interviews conducted by telephone as required.

### **Conceptual Framework**

Grounded theory methodology suggests that delineation of a conceptual framework prior to commencing a study is not appropriate. Instead, a conceptual framework was constructed using themes that emerged from the data collected throughout the study (Stern, 1985). Sandelowski (1993) suggested that when a researcher chooses to use a qualitative research method, the adoption of the theoretical basis of that method is implicit. Therefore, symbolic interactionism, the theoretical orientation of grounded theory methodology, provided an orientation for the researcher during the data generation process.

### **Sample**

Sampling in grounded theory studies is theoretical, in that the sample is chosen based on concepts appearing in the data which appear particularly relevant (Strauss & Corbin, 1990). Grounded theory methodology dictated that the researcher begin data collection with no preconceived ideas of the direction the study would take. The researcher was at first unaware of what to sample for, and allowed the words of the participants to serve as a guide. As data was coded throughout the data generation process, the sample was chosen to provide

information which would fill gaps in the emerging conceptual framework (Glaser, 1978), or to further elaborate on often repeated concepts in the data (Strauss & Corbin, 1990).

For the purpose of this study, participants were sampled according to the type of palliative care service with which they were affiliated. Characteristics sampled were: location of service (regional centre versus rural town), maturity of service (developing versus established services), and model of palliative care provision (e.g. single nurse practitioner versus interdisciplinary team). A total of five palliative care settings were included in the sample.

The sample was drawn from the list of rural hospice agencies listed by the WAHPCA (1996, pp. 11-26). Helen Walker, Nurse Educator at The Cancer Foundation Cottage Hospice - Rotary Palliative Care Education Centre, Shenton Park, Western Australia assisted with sampling. Ms Walker has extensive knowledge of rural palliative care services in Western Australia gained while providing palliative care education for health professionals in this area. Six rural palliative care nurses were selected using the theoretical sampling process. Each individual was sent a letter outlining the proposed research project, and asking if they would be willing to participate (see Appendix A). The nurses were asked to sign the attached consent form and return it in the provided stamped envelope if they were willing to participate. The resulting sample consisted of six rural palliative care nurses. All of the nurses have a professional title that includes their palliative care role, for example "Clinical Nurse Specialist - Palliative Care".

The sampling procedure was guided by the data collected, therefore it was impossible to specify the number of participants at the commencement of the study. Sampling continued until redundancy of data was obtained. There was evidence of redundancy of data after conducting four interviews, and the final two were used to verify themes which were apparent in the data. Although a more extensive theoretical sampling method may have elicited some additional information, within the boundaries of this sample and the limits of a Master's research plan, redundancy of exemplars was achieved.

### **Characteristics Of Participants**

Participants in this study were chosen according to the model of palliative care service in which they worked. Five care settings were sampled. The characteristics of these are presented in Table 1 (p. 42). Four of the five care settings were regional centres in Western Australia, the fifth was a rural town. The care settings in this study were chosen in part because of the diversity of location. The communities in which the rural palliative care nurses who participated in this study practice were located in towns that ranged in distance from more than 1,000 km from Perth, to less than 200 km from Perth. Another determining factor when sampling was the length of time that the service had been established. One service had yet to be officially opened, another has been providing palliative care services for more than ten years. The difference amongst care settings was judged to be adequate to ensure that the data generated encompassed a range of rural palliative care experiences, and did not present a unilateral viewpoint.

**TABLE 1****Characteristics used for theoretical sampling in care settings**

CHARACTERISTICS SAMPLED	VARIATIONS WITHIN CHARACTERISTICS	n
Model of palliative care service	<ul style="list-style-type: none"> <li>• dedicated palliative care unit in local hospital</li> <li>• free standing hospice unit</li> <li>• community based nursing organisation</li> <li>• community and hospital based organisation</li> <li>• integrated palliative care service</li> </ul> <p>N.B. Some participants were involved in more than one palliative care service in the community</p>	<p>2</p> <p>1</p> <p>2</p> <p>1</p> <p>2</p>
Community in which palliative care service is based	<ul style="list-style-type: none"> <li>• regional centre</li> <li>• rural town</li> </ul>	<p>4</p> <p>1</p>
Distance of community from Perth	<ul style="list-style-type: none"> <li>• Less than 200 km</li> <li>• 200 - 499 km</li> <li>• 500 - 999 km</li> <li>• More than 1000 km</li> </ul>	<p>1</p> <p>2</p> <p>1</p> <p>1</p>
Population of community	<ul style="list-style-type: none"> <li>• 5000 - 9 999 people</li> <li>• 10 000 - 19 999 people</li> <li>• more than 20 000 people</li> </ul>	<p>2</p> <p>1</p> <p>2</p>
Length of time palliative care service established	<ul style="list-style-type: none"> <li>• Currently developing</li> <li>• Less than one year</li> <li>• One to five years</li> <li>• More than five years</li> </ul>	<p>1</p> <p>1</p> <p>1</p> <p>2</p>

This table describes the characteristics of the rural palliative care settings sampled for this research project, and the number of each specific characteristic sampled.

**TABLE 2****Professional characteristics of participants**

<b>PROFESSIONAL CHARACTERISTICS OF PARTICIPANTS</b>	<b>VARIATIONS IN PROFESSIONAL CHARACTERISTICS</b>	<b>n</b>
Years in nursing	<ul style="list-style-type: none"><li>• Less than five</li><li>• Five to ten</li><li>• More than ten</li></ul>	0 1 5
Years working in palliative care	<ul style="list-style-type: none"><li>• Less than one</li><li>• One to five years</li><li>• More than 5 years</li></ul>	1 3 2
Professional title	<ul style="list-style-type: none"><li>• Clinical Nurse Specialist - palliative care</li><li>• Clinical Coordinator - palliative care</li><li>• Clinical Nurse Manager - palliative care</li><li>• Clinical Nurse - palliative care</li><li>• Nurse Manager</li></ul>	1 1 2 1 1

This table describes the professional characteristics of each of the rural palliative care nurses who participated in this research project.



A total of six rural palliative care nurses were participants in this study (see Table 2; p. 43). Two participants worked in the same community, in different health care organisations. All nurses sampled had a professional role that included at least a proportion of time allocated to palliative care service provision. Three of the nurses worked solely in palliative care, the other three had a range of professional commitments. The six rural palliative care nurses had widely differing lengths of experience in palliative care nursing. One nurse had been working in palliative care for only six months, while the most experienced had been practicing in the palliative care field for 15 years. Again, the diversity in the backgrounds of each of the nurses served to ensure that a well rounded view of rural palliative care nursing was presented.

### **Fieldwork**

This study used participant observation and in-depth interviewing methods to obtain empirical data about rural palliative care nursing. Further information was obtained from organisational manuals and policy statements, professional colleagues, and the nursing literature.

### **Participant Observation**

Participant observation necessitated the researcher becoming involved in the social world of the subject (Schwartz, 1994), to view that world as the participants see it. Participant observation provides the researcher with an understanding of the meanings given to interactions, as well as a description of the interactions themselves. Participant observation is a non-interventionist

approach to qualitative research, that allows observation in a natural setting (Adler & Adler, 1994). Four of the five care settings were observed for two working days per setting. Patton (1990) suggested that researchers employ a "sensitising framework" to assist the researcher to become sensitive to the environment. To this end a brief guide was made to assist with the writing of fieldnotes (see Appendix B). Extensive field notes were made throughout the observation period. Notes were written either at the end of the day, or in quiet times, so as not to seem obtrusive. Patton (1990) warned that the writing of field notes can be distracting to people being observed, and can affect their behaviour.

### **Interviewing Techniques**

In-depth interviewing was used to provide rich detailed data that facilitated understanding of the experiences and ascribed meanings of the participating rural palliative care nurses. Undertaking an in-depth interview demonstrated an appreciation of the worth of the stories of others (Seidman, 1991). Fontana and Frey (1994) suggested that an interview will be more honest and provide more sound data if it is conducted as a conversation, rather than using a formal interview type format. Therefore, the interviews were conducted in an informal manner. An interview guide was used to provide direction for the interviews; (see Appendix C) however, it was not rigorously adhered to. The words of the participants guided the direction that each interview took. As the research progressed the interview guide was altered to elicit answers to more specific questions which clarified previous data, or expanded developing themes. Each interview took approximately 90 minutes, with follow-up interviews being

conducted by phone to clarify any points if necessary. Data was also clarified using electronic media (email) if available.

### **Analysis**

All of the interviews conducted throughout this study were tape recorded. The tapes were transcribed by myself as soon as possible after completion of the interview. For the purpose of this study, data management was aided by use of QRS NUD\*IST software. As each interview was transcribed, it was coded using NUD\*IST, along with accompanying field notes. This software allowed the researcher to move data as required during the coding process, and encouraged fluidity throughout the coding process (Pateman, 1998).

A modified grounded theory technique required that data collection and analysis occurred concurrently so that the subsequent data collected verified earlier findings (Strauss & Corbin, 1990). This constant comparison method allowed themes that capture the essence of the data to emerge, thus developing a conceptual framework related to rural palliative care nursing. Constant comparison also guided the process of theoretical sampling, so that emerging themes were expanded upon. Analysis, or "coding", is discussed below as a three stage process. It is important to note that the coding process was not always sequential, as the constant comparison method dictated that the data be continually re-examined.

The initial phase of the coding process involved identifying words and phrases which appeared to capture underlying themes in the data. Glaser (1978) calls this "open coding". Interview transcripts and field notes were analysed line

by line to identify concepts in the data. Concepts that emerged from the data were labelled and similar concepts grouped together into categories (Strauss & Corbin, 1990). Fifty two concepts were identified during open coding. Each was reexamined and grouped with similar concepts, forming a total of nine categories, and numerous sub-categories.

The next step, axial coding, necessitated intense analysis of each category separately. Data was re-examined, and connections made between categories and sub-categories (Strauss & Corbin, 1990). The data was analysed using what Strauss (1987) termed the "coding paradigm". This involved examining the data for conditions, interactions between people, strategies and tactics employed, and consequences of actions. Axial coding resulted in basic social processes being identified. Basic social processes link action and interaction to demonstrate how particular phenomena are managed. Examination of data for basic social processes allowed conceptualisation of events, explaining how and why problems occurred (Strauss & Corbin, 1990).

Finally, selective coding was employed to develop themes in the data. Continuous re-examination of the emerging categories, and consultation with research colleagues resulted in a central theme and three related categories being identified. The ultimate aim of grounded theory is to generate a core variable, that is, a variable which is central to the themes that emerge from the data (Strauss, 1987). The limits imposed on this research project prevented a core category being identified. However, a central theme *Living Palliative Care* was developed from the data, and together with associated categories and

subcategories, forms the basis of a conceptual framework which describes rural palliative care nursing.

Throughout the research procedure, memos were kept detailing the theoretical thinking of the researcher. Glaser (1978) stressed the need for memos to be comprehensive. The reasons for making memos included noting ideas as they arise, allowing the freedom to write ideas/hypotheses without having to use "correct" writings styles, providing a "memo fund" of ideas that were developed further at a later date, providing sortable data that was arranged and rearranged at will, and finally, memoing slowed down the coding process, encouraging deeper thought about data. The memos were also managed using NUD\*IST software, and assisted in the formation of the central theme and associated categories presented in the following section.

### **Trustworthiness Of The Research Process**

Qualitative research is not subject to the checks of validity which govern quantitative research, because the naturalistic style of qualitative data collection and analysis do not lend themselves to such checks (Lincoln and Guba, 1985). In the interest of demonstrating that a qualitative study conforms to the ideals of "good science", Lincoln and Guba suggested four tests of the reliability of qualitative research. These are truth value, applicability, consistency and neutrality.

The first test of trustworthiness, truth value, refers to the credibility of the research. Spending an adequate amount of time in the field, so that a well rounded, balanced view of the phenomena in question was gained demonstrates

credibility. For the purpose of this research eight days of participant observation were undertaken, as were six interviews with rural palliative care nurses, each one to one and a half hours in length. Peer debriefing is another method that was used to ensure truth value. Open coding was done in part by my principal supervisor, who coded several interview transcripts to verify the completeness of the open coding process. Frequent meetings with supervisors, as well as telephone and email contact, allowed discussion and verification of the categories that emerged from the data during the coding process, and resulted in data being re-examined and reflected upon. The categories which emerged from this process were again examined by myself and my research supervisors, and diagrams and conceptual maps were drawn to identify the relationships between categories in the emerging conceptual framework. Furthermore, the categories developed from the data were also verified with participants. A copy of the themes developed, along with a definition and exemplar of each were sent to each participant for clarification of the truth value of the findings (see Appendix D). The participants verified that the conceptual framework that was developed accurately reflected their professional role as a rural palliative care nurse.

The applicability of a study is demonstrated if the findings of the research are found to have relevance in similar settings. Good qualitative research presents descriptions and interpretations of phenomena that readers can relate to their own experiences (Sandelowski, 1986).

To demonstrate consistency the research process must be auditable, that is, all decisions, choices and thoughts that govern the direction that the researcher takes were clearly documented. Throughout this study memos were made that

documented all theoretical decision making. These memos serve as a record of the research process.

Finally, a qualitative research project must demonstrate neutrality. Neutrality demands that the research be free from bias. During the data collection and analysis process a diary was kept so that the I could note any preconceptions and ideas about a palliative care service, and reflect on them. This was of particular importance because of my familiarity with some of the care settings sampled, and with several participants.

Patton (1990) stated that the importance of triangulation of data should not be discounted as a way of demonstrating methodological rigor. Use of multiple methods of data collection (e.g. interviews, participant observation, and literature review) constituted triangulation methods. Ensuring that various different sources of data were used is also effective triangulation. Using only one source of data would have presented a skewed view of the phenomena under observation. Therefore varied participants and care settings were sampled, and varied perspectives of rural palliative care nursing were obtained. Using triangulation methods when generating data eliminated unnecessary bias in the study (Mathison, 1988).

The qualitative researcher is considered the research instrument, and should thus demonstrate any personal biases, preconceptions and the degree of personal involvement with the study (Sandelowski, 1986). Patton (1990) suggested that if this information is available to the reader, they make their own decisions regarding the credibility of the researcher. The literature revealed differing views of the effect of a researcher having prior knowledge of the area

being studied. Patton (1990) cautions that pre-existing knowledge may cloud the researchers view, and thus impose personal biases on the data collected.

However, Cotterill (1992) suggests that involving friends and colleagues in a research project may enhance the quality of the data generated, because the participants may be more willing to “open up” to a known researcher. During the data generation and analysis processes associated with this thesis, every attempt was made to discount personal preconceptions and instead to report the words of the participants.

A journal was kept for the duration of the study so that all personal thoughts were recorded and reviewed for the effect they may have on the research process. This was particularly important as my own experiences in rural palliative care nursing meant that I could not enter the field free from preconception. Entries made in the journal while visiting participating services illustrated that my preconceptions were generally false. For example, prior to commencing the fieldwork for this study, I believed that rural palliative care nurses worked in isolated communities where they would be expected to work as a generalist, with palliative care being a minor part of their workload. Furthermore, I believed that geographical isolation would severely limit the amount of palliative care information available to rural palliative care nurses, thus limiting their specialist palliative care knowledge. Neither of these beliefs proved to be correct, and were quickly discounted upon spending time in the rural palliative care services. Also, the possibility that personal knowledge of both the care setting and people working in that setting would lead to my personal bias affecting the data generation process when visiting a community that I had lived



and worked in were acknowledged. However, careful examination of my own bias, and diligent journal keeping while visiting this setting ensured that personal biases were minimised, and that the data generated reflected the views of the participant, rather than of myself.

### **Ethical Considerations**

When conducting any research involving human subjects, it is vital that ethical considerations be taken into account. The research proposal for this study was subject to examination by the Edith Cowan University ethics committee. In particular, the areas of confidentiality and informed consent were addressed prior to commencement of data generation. This is a low risk study; all participants are familiar with discussion about patient care, and may have benefitted from the opportunity to discuss their role. The key to conducting ethical research in this type of design is respecting the interviewee, and the adherence to participant confidentiality. Both were maintained throughout this study.

### **Confidentiality**

Every attempt has been made to guarantee confidentiality of participants in this study. No names or specific demographic details were noted which could identify participants. All identifying data has been removed from sections of the interviews and field notes used to clarify specific ideas in this paper. Robley (1995) cautioned that the depth of detail required by qualitative research may be enough to identify participants. This was a problem for this study, because the total number of rural palliative care nurses in Western Australia is very small. It

was difficult to protect the identities of participants in such a small community (Punch, 1994). However, every effort was made to present results in such a way that individuals cannot be linked to data. To this end, exemplars from interviews and fieldnotes have not been ascribed any sort of code. Such a code may have provided a means to identify participants, and was thus judged to be inappropriate. As well, participants were given the option of withdrawing from the study at any time, and having all data generated by them destroyed.

Transcripts of the interviews were assigned a numerical identifier, and no personal information was recorded on the transcripts. All data is stored securely in a locked cabinet; interview transcripts and fieldnotes are stored separately from the participants' personal details. The data will be stored for a period of five years, after which time it will be destroyed by incineration, as per the National Health and Medical Research Council guidelines.

### **Informed Consent**

It is a requirement of Edith Cowan University that all human research subjects give their fully informed consent prior to the commencement of data collection. Participants were sent a letter explaining the purpose and method of the study, and asked to sign a declaration stating that they had read and understood this, and given their consent to participate. Raudonis (1992) points out that the dynamic nature of qualitative inquiry may necessitate changes being made to the study that may affect the participants' decision to contribute. As such, during this study informed consent was considered an on-going concern. The subjects' continued participation in the interview situation was considered to

constitute continuing consent. Asking participants to review a copy of the final draft of the research gave them another opportunity to withdraw if they felt compromised by the final results.

### **Conclusion**

This chapter has described the research paradigm and selected research method chosen to study rural palliative care nursing in Western Australia. The sampling and data collection techniques have been outlined. Data management and analysis methods are described. Methods to ensure the trustworthiness of the research process have been discussed. Finally, ethical considerations have been addressed.

## CHAPTER FOUR

### Findings

#### Introduction

This chapter presents the findings of this research project.

Conceptualisation of the central theme that emerged from the data *Living Palliative Care* is explained, as are the three associated categories, *Wearing Many Hats*, *Being the Expert* and *Surviving in Palliative Care*. Subcategories that relate to each category will also be examined. Examples from the interviews and fieldnotes are used to support the development of the central theme and associated categories.

#### Discussion Of Findings

The central theme discerned from the data generated throughout this study is that of *Living Palliative Care*. Three categories emerged that are related to the central theme, *Wearing Many Hats*, *Being the Expert* and *Surviving in Palliative Care*. The conceptual framework was developed through constant comparative analysis of interview transcripts, fieldnotes, memos and journal entries generated throughout the research process. The diagrammatic relationship between these components of the conceptual framework developed is shown in Figure 1 (p.57). Each of the three categories appear to overlap. However, the exact nature of the relationship between these categories is not fully apparent from this analysis. Rather, this modified grounded theory study has elicited the components of the rural palliative care nurse role. Greater understanding of the relationships

amongst the components of the conceptual framework developed in this study requires prolonged engagement and a larger sample using more complete theoretical sampling techniques.

The central theme developed in this study will be discussed, followed by each of the categories, and related sub-categories. Passages from interview transcripts and fieldnotes are used to demonstrate specific points. In the interest of maintaining participant confidentiality, the source of each exemplar has not been revealed, and no pseudonyms or identifying numerical codes have been used. Table 3 (pp. 58-59) provides a definition and exemplar of the central theme and associated components of the conceptual framework.

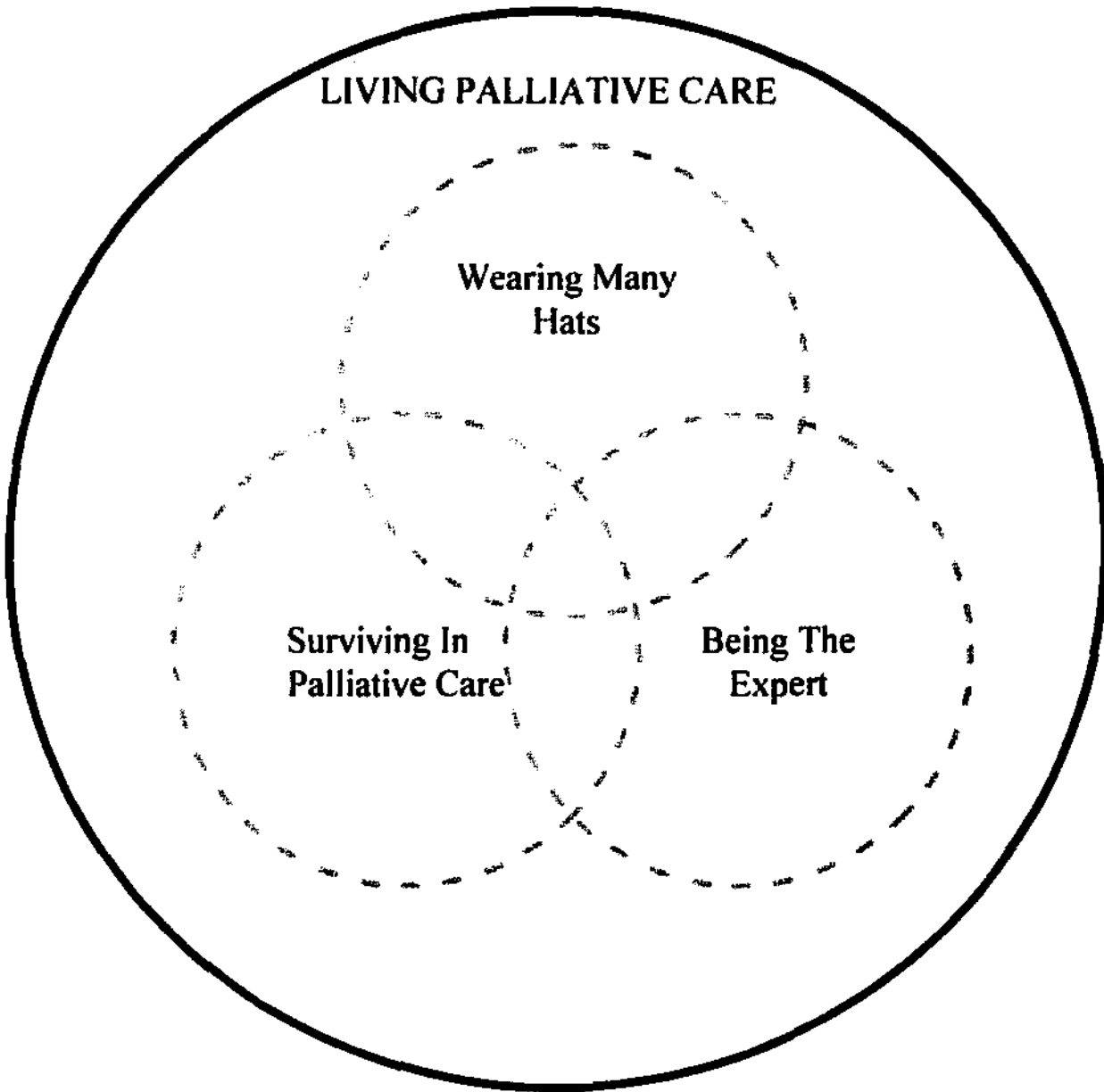
### **Living Palliative Care**

*Living Palliative Care* emerged as the central theme in the data during analysis. Concepts that described the time and effort rural palliative care nurses devote to their professional role, and concepts associated with the effect palliative care has had on the lives of the participants, were grouped together to form this theme. The central theme of *Living Palliative Care* explains the effect that being a palliative care nurse has on all aspects of a rural palliative care nurse's daily life. Significant sub-themes within this theme, *Going the Extra Mile* and *Socialising* will also be discussed.

From the point of view of the nurses who participated in this study, palliative care has become a way of life. They not only have long working days, and remain on call overnight for emergencies, they also attend community and fundraising events out of work hours as part of their professional role. As well,

**FIGURE 1**

**Diagrammatic Representation Of The Conceptual Framework**



This figure illustrates the conceptual framework developed during data analysis. The categories of *Wearing Many Hats*, *Being the Expert*, and *Surviving in Palliative Care* are illustrated as overlapping. The broken lines indicate the lack of data about the degree and strength of the relationships between these categories.

**TABLE 3**

**Definitions Of The Themes And Categories Related To The Conceptual Framework Describing Rural Palliative Care Nursing**

This table presents a brief definition of the central theme, associated categories, and subcategories, related to the conceptual framework developed from this research project that describes rural palliative care nursing. An exemplar from the interview transcripts and fieldnotes is provided to offer further insight into the meaning of each definition.

	<b>THEME</b>	<b>DEFINITION</b>	<b>EXEMPLAR</b>
1.	<b>LIVING PALLIATIVE CARE</b>	being a palliative care nurse affects all aspects of daily life	<i>I would work between 40 and 50 hours a week, at least. I'm trying to reduce that, because I know in my head it's not sensible.</i>
a	Going The Extra Mile	making a special effort to provide for patients and families, regardless of the difficulties associated	<i>...he had a wish, he wanted to go back to his original church and be baptised...and he had this ceremony and I took a photo, and ... when he died, and all of ... his last days in hospital he had that photo up on his bedside</i>
b	Socialising	how the rural palliative care nurse role affects the social life of the nurses	<i>... not being seen as being brash or brusque with any one, and sort of stopping a question or a conversation, just being very nice, diplomatic.</i>
2	<b>WEARING MANY HATS</b>	taking on a large number of different roles as part of the overall rural palliative care nurse role	<i>I manage the hospice and deal with the clinical programmes... I have to make sure the building is kept up to scratch and the grounds. I have an overview of the fundraising organisation, ...I have to do quite a lot of liaison work. And I am also the volunteer coordinator and educator. ...[And I] manage the clinical programmes which are run from the hospice.</i>
a	Just Being A Nurse	having the desire to work solely in the clinical sphere, and devote time primarily to patient care	<i>... my time is limited in how much I can give each person, but that time I can give them is dedicated time</i>
b	Caring For All People	providing care that is culturally appropriate, and takes into account the special needs of specific groups in the community	<i>So I feel like that is very special, we're building up that rapport there, and also nursing the Aboriginals at home. That's what they want. It's wonderful.</i>
c	Working Together For Our Patients	working with other health professionals to ensure that a high standard of palliative care is delivered	<i>We've worked on that since the beginning, of seeing things as a team. Some have strengths in areas that others don't have...</i>

d	Serving Many Masters	being responsible to more than one management body, having commitments to two or more palliative care services	<i>It's very difficult for myself because I really am serving two masters. I work for [the hospital], and I was trying to support the Palliative Care Service as well.</i>
e	Maintaining Confidentiality	retaining patient and family confidentiality in small towns is a particular challenge	<i>You can't do anything about that, and you just know that you're very confidential and hope it seeps through.</i>
f	Being Creative With Funding	searching for new and different ways of raising money to maintain the service	<i>I have to be creative with my funding. I'm not allocated any money, I run on donations from community groups</i>
g	Planning For the Future	making plans to develop and expand palliative care services in rural areas	<i>...one of my next developmental ideas is to get a volunteer coordinator. So I'm hoping that that's going to happen in the future...</i>
h	Being Other Places Too	having professional commitments in areas other than palliative care	<i>I have ... to work in different areas of the hospital...[and I] have to relieve in urgent care and ICU</i>
3.	BEING THE EXPERT	the expectation that the rural palliative care nurses will assume the role of palliative care specialist in the community where they practice	<i>And they ring you because you happen to have that role... "Oh my God, better get her over here".</i>
a	The Steep Learning Curve - Starting Out In Palliative Care	commencing in the rural palliative care nurse role necessitates acquiring large amounts of knowledge about palliative care service delivery	<i>And I really didn't realise at first how specialised it was. But that's not a problem.</i>
b	Caring For Colleagues	the expectation that the rural palliative care nurse, as the head of the palliative care team, will take responsibility for helping and supporting other palliative care staff who work in the service	<i>As you saw today, they will seek me out, and come and talk to me if they've got a problem or just ring me on the phone</i>
4.	SURVIVING IN PALLIATIVE CARE	looking for ways of debriefing, and getting support in a difficult and demanding role	<i>I do recognise that you can't keep doing it forever...and I have taken breaks... and have done something different.</i>
a	Joining Together: Finding Country Colleagues	sharing ideas with other rural based palliative care nurses	<i>You have to, you have to liaise with other areas in the same field. Because there have been no guidelines.</i>
b	Making City Connections	getting help from palliative care specialists based in large metropolitan health services	<i>No, they don't come to me. I know I can go to them. The [city] hospice, they send me all their regular handouts, like the courses they have on, but no, nothing. No talking or anything like that on the phone, like chit chat, unless I call them.</i>
c	Being Supported By The Community	receiving support from the local community, generally in the form of fundraising or as a volunteer workforce	<i>...it's very overwhelming, they are very supportive.</i>
d	Finding Rewards	being sustained by the rewarding aspects of palliative care nursing	<i>People are just so grateful for the little things that you do. The gratefulness far outweighs the little bit that you did.</i>



the nurses generally have a high public profile in their community, and this can affect the way they live their lives. The nurses commit a large amount of their time to palliative care, whether that be direct patient care, associated work, or attending fundraising or education events. All of the nurses that I spoke with worked substantially more than their paid hours:

I theoretically work 30 hours a week...but I would work between 40 and 50 hours a week, at least. I'm trying to reduce that, because I know in my head it's not sensible. But I'm also uncomfortable never having everything finished. In terms of administration. Because the people come first.

Another nurse spends much of her out of work time concentrating on fundraising:

I've been guest speaker at Rotary twice now, guest speaker at Soroptimists, they are a local group of professional women. I've been to quiz nights, and this is all out of hours, it all comes out of my private time. I've been to schools, baby shows, fundraised there.

Several of the nurses stated that because of the multiple roles that they are required to play, they take work home. As sole practitioners, or as the leader of a palliative care team, there is often no one else to take on the day to day chores that make the service run smoothly. Only one of the nurses had office support, and this came only as a result of sacrificing some of her paid working hours. Taking paperwork home allows the nurses to concentrate on their patients first, and complete less urgent tasks later. However, it does mean that for these nurses palliative care can become a seven day a week job. Although the nurses are aware of the need to have time away from work, they find it difficult to leave tasks undone. One nurse explained:

I mean I have taken on more than I ought to have done, and my head has been aware of it. And I determined right from the beginning that I wasn't going to do it. But then because I cannot bear to have everything unfinished all the time I sort

of get a spurt on and say I'll work this and this and this time and then I'll be straight, but it never happens.

Being a rural palliative care nurse in a small town, with few or no other palliative care nurses as back up means that often the nurse carries the responsibility for patients all of the time. Several of the nurses are on call constantly, whilst others have an on call roster and may work only part of the week on call. However, all accept that they will get phonecalls at home from time to time, either from colleagues seeking advice and reassurance, or from patients requiring help:

I have most weekends on call. But I have a few nurses now who can run the hospice so every so often they have the phone for two or three days.

This level of commitment to work is tiring, and this nurse acknowledged the need to have time away:

...it started off being one weekend every two months, and now I've got it down to once a month, and now I'm going to make it alternate weekends and involve more people.

However, despite the stresses associated with being available for patients 24 hours a day, the nurses feel that it is essential to be seen as approachable:

I try not to show my patients I'm busy. I always have time for them.

The constancy of being available for patients at all times enhances the relationships that rural palliative care nurses develop with their patients.

There was a suggestion from one nurse that perhaps as caring professionals, rural palliative care nurses take on a greater volume of work more readily than others may:

Well that's been the trouble with the caring professions hasn't it? Getting the right balance. All along. That's not new.

Another nurse comments that wanting to always be there was very typical of nurses:

And that's another thing you know, it's all conditioning. You're preconditioned to be there, like a Florence, you want to rush in and make things better.

However, one nurse is very disparaging of the need to take on so many roles:

I don't think we have to be everything. I think this is a specialty like any other specialty is. And I don't see why it can't be properly funded so that it can be like everything else. You don't have this nonsense in coronary care or maternity.

The suggestion that rural palliative care nurses would not have to shoulder such large burdens if funding were adequate was expressed by a few nurses. Others had a large group of volunteer workers who took some of the burden from them, leaving them more time to concentrate on patient care issues.

### **Going The Extra Mile**

This section examines the effort that rural palliative care nurses make in the care of patients and families, regardless of the personal sacrifices that may be associated. Rural palliative care nurses also add caring touches that can make a difference to someone who is dying. The amount of care that nurses devote to their service is what makes them so special. One nurse told a story of providing breakfast for a family of seventeen, who had travelled some distance to see a

dying relative. Another nurse told of the effort that all of the palliative care team made to help a man go home one last time, to see his house:

...it was wonderful, because we liaised with the St John's Ambulance and they brought in volunteer drivers, and we got in the ambulance, and we got him home, and he saw his house for the last time, and he went into his shed, we wheeled him into his shed, and [his wife] was just so excited, I mean she had afternoon tea there for everyone. And the neighbours came in. He was only out for about an hour or so. And his old neighbour walked over...

Another nurse described arranging a service for a man who wished to be baptised:

...he had a wish, he wanted to go back to his original church and be baptised. We got our chaplain involved, and we had a little ceremony in the home. The chaplain came round and ...our casual RN [registered nurse] came round, and I came round. And I took around flowers and [another nurse] made a cake, and I took a frame and I had my camera... And he was so happy, he got a suit on, except it was about 20 sizes too big for him, he had last worn it 20 years ago, and his wife got all dressed up. And it was almost quite bizarre that in this shell of a house that was so run down, and he had this ceremony and I took a photo, and to me it was just fascinating. And we had one of us together. But when he died, and all ... his last days in hospital he had that photo up on his bedside.

Each nurse participating in this study told similar stories to these, illustrating the caring and compassion they devote to their patients.

Not only do rural palliative care nurses "go the extra mile" for their patients, they often quite literally extend the area in which they practice, so that outlying smaller towns also receive the benefit of their services. This willingness to help other towns in need, and their nursing colleagues who work there is extremely generous, particularly when you take into account that some of these nurses are still working on developing their own services. A nurse describing her plans for extending her service said:

...at that stage we were talking about the need to reach out to the smaller communities, and that there were many people in those places who when they are diagnosed with a terminal illness they actually relocate to a larger centre such as [X] or Perth, and we felt that if we could reach the already rich resource of volunteers within these communities, Red Cross, CWA [Country Women's Association] and the like, and provide appropriate education and the like, when the need came those people might have the opportunity to be supported in their own home throughout the time...[and] at least give them the opportunity to stay at home with extra supports. Red Cross were very interested in that, but of course without the funding, [we] can't do that, we would just have to say enough's enough.

Unfortunately, as in the above example, nurses' willingness to extend their services is hampered. However, many do offer education, bereavement services or advice and support to others. Much of this work is done out of normal working hours, and is given to the community free of charge.

### **Socialising**

This section examines how the rural palliative care nurse role affects the social life of the nurses. The social cost of being a palliative care nurse in a rural area is apparent not only in the lack of leisure time available, but also in having to maintain a public profile as a representative of the palliative care service. One nurse described how she feels she is always "on duty":

...and not being seen as being brash or brusque with any one, and sort of stopping a question or a conversation, just being very nice, diplomatic, you know what I mean?

Another aspect of living in a small town, where you have a high profile, is the difficulty interacting with other community members, especially for nurses who are new in town. A nurse said:

...I don't have any personal friends, or I do, I'm friends with a lot of the volunteers, but because we also work together

what I'm saying is that relationship is different...and I haven't really had a chance to interact with anybody, any group that's not to do with the hospice. Because the whole town, from everywhere, has got somebody on the volunteer panel.

For others, the difficulty lies with knowing everyone in town, which must inevitably lead to having to nurse a friend or family member who is dying:

...they are issues that you have to deal with, and invariably you always know these people, or their family.

Living and working in a small community is often fraught with issues such as these. For rural palliative care nurses the difficulty lies with finding a balance between giving everything to the town in which you work, and having time out to relax in anonymity. The aspect which possibly makes obtaining this balance more difficult for rural palliative care nurses is the sensitivity of the area in which they work, and the special needs of people whom they meet in the course of their work.

*Living Palliative Care* describes the total commitment that rural palliative care nurses give to their profession, and the way it becomes an all-encompassing part of their lives.

### **Wearing Many Hats**

The category of *Wearing Many Hats* was formed from combining numerous smaller categories that deal with specific aspects of the rural palliative care nurse role. *Wearing Many Hats* is defined as taking on a large number of different roles as part of the overall rural palliative care nursing role.

Subcategories within this category that will be discussed are; *Just Being A Nurse*, *Caring For All People*, *Working Together For Our Patients*, *Serving Many*

*Masters, Maintaining Confidentiality, Being Creative With Funding, Planning For the Future, and Being Other Places Too.* Each of these subcategories describes one specific role, or “hat”, that rural palliative care nurses wear.

Having to wear many hats is a comment made frequently by rural palliative care nurses. Rural palliative care demands that the nurses running these services be “multiskilled”. Frequently the rural palliative care nurse is the only person employed in the health service, or in the town as a whole, to provide palliative care. Thus, the nurses must assume all of the duties required to run a health service. One nurse described the palliative care roles she fulfills:

I manage the hospice and deal with the clinical programmes, so I have to make sure the administration is up to scratch, and I employ an office manager to do that. I have to make sure the building is kept up to scratch and the grounds. I have an overview of the fundraising organisation, because we rely very heavily on fundraising. I’m not involved, no, but all the messages and everything that people leave all come through here, so I have to do quite a lot of liaison work. And I am also the volunteer coordinator and educator. I represent the hospice in the palliative care service, so now we are coming back into my clinical role, which is to manage the clinical programmes which are run from the hospice.

Other roles accepted as part of the rural palliative care nurse role include providing grief and bereavement support, organising and chairing team meetings, planning capital works projects (e.g. building new hospice buildings), providing education for other staff, supporting nursing staff through difficult situations, raising community awareness of palliative care by giving talks and speeches, attending fundraising events, and liaising with the media. Many of these tasks are taken on by the rural palliative care nurse because there is no one else available, or willing, to take them on.

Rural palliative care nurses have to be, in effect, a palliative care “generalist”, often performing all or many of the functions of a interdisciplinary palliative care team. One nurse discussed the need for nurses to be able to perform allied health duties, as often there are no allied health professionals available in the town to provide care:

So I guess nursing staff will pick up on that, if there is any specific physiotherapy treatment to do, we'll be taught. They know they are going to be away for four days, they'll be educating us what to do, so we'll be picking up that role.

Another nurse listed the many roles that she plays in the community in which she works. She not only runs the palliative care programme, but is also involved in many of the acute oncology programmes in the community. This same nurse runs the breast cancer support group, the partners support group, is a Cancer Foundation Resource Nurse, has been instrumental in the regional hospital commencing chemotherapy clinics for people in the area, and organises education sessions for the other staff on oncology issues. There are many other ways the rural palliative care nurses' role could be extended, however, finding time for more tasks can be problematic, as one nurse explained:

...as you know a nurse in the country wears many many hats, and because I'm known to be a grief counsellor, guess what, I'm overwhelmed with requests and referrals to see people, and unfortunately I cannot, I have to say look no, I cannot do this, this is not part of my job, and I would love to be able to but I cannot stretch myself. My priority is my palliative care patients and my hospice bereavement patients, which I'm really finding I'm having difficulty keeping up with.

The amount of time the nurses spend on work and work related issues every day is large. This is in part because of the number of different tasks that are



seen to be the responsibility of the rural palliative care nurse. However, the nurses were generally philosophical about having to take on so many roles:

... just the fact that you've got to slip out of palliative care mode, into full medical or surgical mode, and then back again. But that's the difficulty of being in a small hospital. That's what happens, you've got to accept that. Yes it's frustrating at times, but you've got to accept it.

However, the changing of hats is not always easy. When asked if she felt she would continue her work in palliative care one of the rural palliative care nurses replied:

I don't know, I'm not sure. I can't answer that. I guess, well, I would like to do palliative care, it's all the other roles, the hats we have to wear. That makes it very very difficult. Because of your mindset, you know, you're for ever switching from one role to another role, it's very very mentally draining, and quite stressful. Very stressful. And I guess that relates to the fact that I've had three lots of the flu. Well, it's got to be something. I'm normally a healthy person, and in the [time] I've been doing this job I have not been well. And that's one thing people have noticed. Because I'm never sick. And I guess we get run down, we don't look after ourselves the best, and there's always paperwork and other issues to deal with. Not always to do with palliative care. You know, there's the meetings, there's all sorts of other things we've got to do.

Overall, the demands of multiple roles is a frequently identified stressor in rural palliative care nursing.

Most of the nurses feel that having to wear so many hats detracts from what they feel is their most important role, giving patient care. One nurse said:

...well I am first and foremost a clinical nurse and I enjoy nursing. One of my disappointments... is that I can't do more of it. I'd like to be a nurse, a real basic nurse.

The commitment to their patients first and foremost was very evident when observing all of the palliative care nurses, and is the reason why nurses are

willing to take on so many other chores that they do not find rewarding or interesting. Asked what was the least rewarding part of her palliative care role, one nurse replied:

Having to spend so much time on lobbying, making submissions, politicising, worrying about money. It's taken so much time and energy, that's been the most disappointing.

This nurse stresses that her main focus is on patient care, and anything else is an unwelcome distraction.

### **Just Being A Nurse**

This subcategory examines the rural palliative care nurses' desire to *Just Be A Nurse*, that is, to have the opportunity to work solely in the clinical sphere, and devote their time entirely to patient care. Providing the best possible nursing care for a patient and family is the ultimate aim of all of the rural palliative care nurses who participated in this study. Several nurses stated that in recent years advances in medical technology have led to them having to spend more of their time involved in the less human side of patient care. The nurses in this study all stated that one of their reasons for wanting to become involved in a palliative care service was to be able to provide "hands on" nursing care:

...well, I was asked if I was interested in doing it, and I just thought that I'd love to do it...I just thought yeah, because I'm a good nurse, I'm caring, and I thought yeah. I knew I could do a good job.

There is a strong feeling among rural palliative care nurses that they can improve upon accepted standards of care for terminally ill people. Several nurses tell stories about unpleasant experiences they have had with dying patients in the past. This nurse explained that:

...having seen poor symptom control in people who are dying. I know there's a better way, I've learnt there's a better way, and that's what keeps me going. I know that these people could die with better symptom control, and live to the end...

Although all of the nurses were concerned about providing good pain and symptom relief, all also expressed their belief that providing emotional and spiritual support is a crucial part of their role:

...the time spent with the person, and listening to the situation with them is such a vital component of the job.

With this aim in mind, the more established rural palliative care services are beginning to establish programmes to address not only basic symptom control, but also the more complex psychological issues of the terminally ill and their families:

I'm only just now starting to do something different, to develop services like the recollections, and cosmetic care and things like that. And bereavement drop in is going to happen next January.

One nurse described the most rewarding part of her job as knowing she had provided the best possible care for a patient and their family:

I feel like I did everything I could to make their time easier than it was. And you know, even though I just sat there and said nothing, that was what they wanted.

A nurse who had previously worked in a metropolitan palliative care service felt that the caring side of their role was something that she had been able to focus more on in rural practice:

Even though certainly my time is limited in how much I can give each person, but ... time that I can give them is dedicated time. Just looking at metro services, the time that they have is getting more scarce, ... I have the luxury up here of still having that dedicated time, and prioritising.

Another nurse pointed out that the caring ethos is an historic tenet in palliative care, and one that should not be overlooked. People who visit her service are referred to as “guests”, as opposed to the more commonly used term “patients”. She explained that this is because:

... the word hospice is from the hospitality and host ideas isn't it? So that's what it's always been and that's what it will stay.

However, taking the time to “just be a nurse”, and spending extra time with patients can be a contentious issue, causing ill-feelings among other staff not directly associated with palliative care. One nurse said:

They see their nursing as going to do a physical thing, and if they haven't got to do a physical thing like put that person to bed then they don't go. They don't see it as providing support for the whole situation.

The lack of understanding on the part of other professionals about the demands on the nurse's time that providing quality care requires is a cause of stress for some nurses. There is feeling that little appreciation is shown by other health professionals for the standard of care upon which rural palliative care nurses pride themselves.

Making sure that patient care needs are met is the goal of all rural palliative care nurses, and despite their often hectic professional lives, it remains their focus. Caring for terminally ill people is the reason that these nurses wanted to practice in palliative care, and it is the reason that they persevere amidst often difficult work conditions.

## **Caring For All People**

Working in small communities, rural palliative care nurses express a concern that all groups in their communities receive adequate palliative care when required. This subcategory examines the efforts made to ensure that the palliative care service is accessible to all community members, and that care is appropriate to the individual's specific needs. Several of the rural communities have large ethnic populations, including Eastern European groups such as Poles and Ukrainians, Vietnamese and other Asian cultural groups; and indigenous Australian groups. These groups present specific challenges to rural palliative care nurses, and during participant observation periods it was noted that the participants in this strive to provide a high standard of palliative care to these often marginalised groups. Describing some of the difficulties encountered with a non English speaking patient, a nurse said:

We've got somebody on the ward right at the minute, who is from a ... [non English speaking background], the family dynamics are quite poor, and they have to translate for their father...

The nurses have difficulty accessing professional translator services, and have to rely on family members or staff members who speak the same language. In rural areas there are also the associated problems of providing care in small close knit community groups, where conflict may ensue from seemingly minor actions.

A number of rural towns, particularly in the North West of Western Australia have a high percentage of Aboriginal residents. Providing palliative care that will meet their cultural and spiritual needs is a continuing challenge for rural palliative care nurses. All of the nurses whose service provides care for Aboriginal people are diligent in respecting their choices. "Smoking" of hospice

facilities is a ritual that palliative care nurses abide by, to make the hospice environment acceptable to patients and their families. A nurse described this practice as follows:

...if they have an Aboriginal person die in a specific room that room has to be smoked. As in their traditional, their cultural procedures of smoking the room, getting rid of the bad spirits. Otherwise, no one, if they know about it will go into that room.... So I guess here, if we have an Aboriginal person die, it's a single room, they've got extended families they'll know about it. I guess the elders will come in and do the smoking process.

The hospice environment is also able to be adapted so that it is as comfortable as possible for Aboriginal patients and their families:

We've got the outside area there, we've got fold up beds, we've got whatever. If that's where they want to camp that's where they camp. They don't have to be treated in the formal bedroom.

The palliative care nurses feel a strong sense of satisfaction when they are accepted into the Aboriginal community in their area, and are able to provide palliative care as needed:

So I feel like that is very special, we're building up that rapport there, and also nursing the Aboriginals at home. That's what they want. It's wonderful.

Considerable effort goes into making sure that the palliative care service provides care for everyone in the town, and an extra effort is made for groups that are marginalised and hence may miss out on services, such as people from non English speaking backgrounds and indigenous people. The care and attention that rural palliative care nurses pay to learning about the culture, language and religious beliefs of groups in their towns is a fundamental component of their caring ethos.

## **Working Together For Our Patients**

Teamwork is acknowledged as an essential part of providing palliative care. The subcategory of *Working Together For Our Patients* is defined as working with other health professionals to ensure that a high standard of palliative care is delivered. The interdisciplinary team provides a range of expertise and experience that compliments the concept of providing holistic care for a terminally ill person. Although there is no doubt that rural palliative care nurses strive to provide holistic care, they may do so with an unconventional team approach. Some of the rural towns visited during this study did not have a wide range of medical practitioners and allied health professionals to form part of the palliative care team. One nurse, who works in a town where staff shortages are a way of life, bemoaned the lack of a stable palliative care team:

R: Can you see any weaknesses [in your team]?

N: Yes I do. Allied health in this community are so busy, and they are not always in town. It's ... access. Ongoing access and continuity. Even with the doctors. That's going to be the big thing. But I'm aware of those issues, so we'll just have to address them as best as we can. They are keen, you know, ... but once again they spend two or three days away, whether it be North South, East or West. There are [only] two physios, and there is just so much work.

Rural palliative care nurses do, however find ways to build teams that are perhaps not conventional, but that work effectively for them. A nurse working in an inpatient setting described her relationship with the domiciliary nurses in her community:

We work very closely, because they continue on the home care once the patient is discharged. And if there are any ongoing issues we liaise and discuss. And often the girls will come in, and I've got lots of education material, and I buy books. And we'll talk it through, talk about assessment, and try things, they are part of the team. Definitely. Couldn't be without them. And they couldn't be without us. Because

once they want to come in for respite, this is where they come. And then they can come in at any time and continue on their care too, if that is what the patient wants.

Despite the rural palliative care nurse's resourcefulness in building a team, there remain some barriers to organising a interdisciplinary palliative care team:

I think we need to do some team building. In terms of trying to find ways of working better together. Like some of the doctors don't like this business of "medicine by committee" as they call it.

Overall though, the rural palliative care nurses in this study were observed to have good working relationships with General Practitioners and other health professionals in their communities. One nurse said:

...but I have found in palliative care that the doctors are gaining more and more respect for your opinion, which is really wonderful. I'm noticing that now you know. ...And we're really getting that recognition from doctors and I think they are valuing our service now, and I think they are also recognising that we can help them. And you know a couple of times they might say "well what do you think?". That's really good to know, that you're working together now, as a team.

Rural palliative care nurses are positive in their comments about their teams, and the efforts that the teams go to to ensure that other team members are well supported, that patient care needs are met, and that the service runs smoothly. One nurse praises her other nursing colleagues, saying that they display:

... an incredible feeling I suppose of loyalty to where they are. Amazing the efforts that they will go to make sure that whoever is coming on has got as little [as possible] to do, everything is completely up to date. A lot of pride in documentation, making sure things are done properly, and really very keen on all following through the same way. We've worked on that since the beginning, of seeing things as a team. Some have strengths in areas that others don't have, and I suppose we've tended to work with that.



There is a feeling though, from the nurses who worked in larger organisations, that their managers have little concept of the palliative care nurse's role, and the immense workload rural palliative care nurses have. Management are often ostensibly part of the palliative care team, but are sometimes perceived to be unaware of the implications that their decisions may have on both the individual nurse practitioner and the palliative care team as a whole:

..it's just that there hasn't been that recognition of palliative [care], it's taken a real back seat. I'm feeling stronger about it, I do feel like we're starting to get more recognition.

A nurse manager who discussed her own experiences with palliative care says that the opening of a palliative care unit in her area represented a new experience for her. She admitted that when the unit was opened she had little knowledge of the needs of terminally ill patients, how skilled staff had to be and the demands placed upon them. Over time she has developed an increasing understanding of the need to provide adequate numbers of trained staff to work in the palliative care unit so that patients' needs can be completely met.

Even nurses who work as part of an established palliative care team appear to feel some degree of isolation, perhaps because they are generally the only dedicated palliative care staff in the community. Questioned about the most difficult aspect of rural palliative care practice, one nurses said that it is:

Working alone in palliative care. It's too much for one person, to have a patient load. I think there's got to be somebody for the lone palliative care provider. I don't mind it personally, I'm OK with it, but I've got opportunities to debrief, with relationships I've built up here. You know, professional relationships. But I think it's a much healthier approach if there can be two people because I do find there is a certain amount of dependence from patients when there is one person.

However, despite this recognition of the need for a team approach to palliative care delivery, funding constraints and only small numbers of terminally ill people requiring palliative care services in each community prohibit staffing numbers being greatly increased.

### **Serving Many Masters**

Rural palliative care nurses, when carrying out the myriad duties that are part of their job description, often feel torn between the different areas and/or health services of which they are a part. This subcategory, that examines the reality of rural palliative care nurses being responsible to more than one management body, and having commitments to two or more palliative care services, has been labelled *Serving Many Masters*. The nurses may be employed by a local hospital or domiciliary care facility, and also be an active member of an "integrated palliative care service" Although there is an expectation that they will serve on such committees, they are often not given dedicated time during their working day.

Several of the palliative care nurses discussed the implications of being a member of an integrated palliative care service, which consists of four or more different service providers combining to deliver a "seamless" palliative care service. Integrating with other service providers in this way is generally seen as a positive step. A nurse said of the integration of services in the community where she works:

I think that any group of service providers that get together to work at a unified project can only be good. Because everybody starts dropping down those parochial barriers, and we realise that we're not just pushing and shoving shoulders to try and get a better place in it. What we're all there for is

to provide better care for our clients. And it's really nice to see that happening. So you're not veiled in suspicion and concerned about whose turf you're on.

The nurses involved in this sort of service appeared committed to making it work effectively, and were observed devoting enormous amounts of time and energy to making the team function smoothly:

We were determined to make this work. Yes the difficulties ... still exist, but it's not antagonism like there was before... I think learning to take off your own hat, ... I had to really put aside my [hospital] hat to work within the service, ...[but] we felt that we couldn't stop what we were doing, we had to keep moving forward.

However, juggling the commitments of working for a paying employer, and continuing involvement in a voluntary palliative care service is difficult:

It's very difficult for myself because I really am serving two masters. I work for [the hospital], and I was trying to support the palliative care service as well. So there were some conflicts there and really you did more and more in your own time, because you couldn't justify doing it in work time. [The hospital] have been very supportive, and have allowed me some non clinical time.

Despite the support of their employees, two of the nurses report feeling uncomfortable spending paid work time doing tasks not directly related to the organisation for whom they work. The nurses find that they are compelled to do more and more work outside their paid working time, because they do not want to appear to be shirking their duties:

R: What's the hardest part of your role in palliative care?

N: Just trying to keep focused on palliative care. My role is not in palliative care anymore. [My employer] is very generous, in as much as they know I am involved in the service. They are concerned that it is taking up a great deal of my time, and that's why I insist on doing it after hours, so it doesn't impact, and [my employer] is not meeting the cost of my time in palliative care. But something has to give.

Another master that nurses were observed to be serving is “normal ward routine”. Nurses who work in a hospital setting feel it necessary to take on an extra burden, so that their palliative care role does not impact on the ward/hospital routine, and so that other nursing staff do not have an increased workload as well. A nurse explained:

I have to be really careful, because if we take a less load, what was happening was, and it stills happens, is the girls on the ward take more patients. So then you take more load to make sure your colleagues on the ward aren't overloaded.

For this reason, it is not uncommon for rural palliative care nurses to have one or two patients in the palliative care unit, and also have the responsibility of looking after six or more acute patients as well. There is still a culture of rural nurses having to “pull their weight”, and during participant observation periods it appeared that palliative care was viewed by non-palliative care staff as a position that allows a nurse to decrease the amount of work he/she does. Rural palliative care nurses are compensating for this view by increasing their own workload so that they may in fact do more work than their non-palliative care colleagues.

### **Maintaining Confidentiality**

In small towns, nurses find that maintaining confidentiality can become an issue. This section examines the challenges of maintaining confidentiality in a close knit community. Maintaining confidentiality is a particular issue for the rural palliative care nurses, who run a palliative care service and must make sure that confidentiality is maintained by everyone who works within the service.

A nurse with experience in both rural and metropolitan palliative care said:

I think really the biggest difference is people knowing everyone, and keeping confidentiality.

When everyone knows everyone else, it can be difficult to avoid others who want to ask questions. A nurse explained how she maintains patient confidentiality:

And I do find, in something like that, I do find it really easy to change the subject and just switch off. I don't wish to talk about my patients. So I don't really find that a problem, I can quite easily do that....Its happened to me once before too. I've been bailed up by someone;. "Oh this woman was a friend of mine...".

Maintaining confidentiality throughout the whole service can be a problem in small communities, and difficulties may arise when choosing staff and impressing on them the need for confidentiality:

...I mean Perth is a small country town when it comes to confidentiality, and this is a small country town anyway. You'd have to scrutinize and interview really very carefully.

In small towns it is inevitable that staff will know people for whom they provide care, or they may share mutual friends. As one nurse pointed out:

You can't do anything about that, and you just know that you're very confidential and hope it seeps through.

The rural palliative care nurse's role in maintaining confidentiality within the palliative care service can be a challenging one at times.

### **Being Creative With Funding**

This subcategory, *Being Creative With Funding* describes the responsibility rural palliative care nurses have for securing funding for their palliative care service, and discusses their search for new and different ways of raising money to maintain the service. Funding issues were the most often cited

irritation of rural palliative care nurses, and all nurses who participated in this study were observed spending a significant proportion of their work time (in several cases up to 25% of their working day) involved with funding related matters. Most services do not have recurrent government funding, and instead rely on funding supplied by grants from groups like the Lotteries Commission and Rotary, or upon donations made from community groups, sporting clubs and individuals. Securing funding is a significant issue for rural palliative care nurses, as their current precarious funding situation makes continuing high standards of service provision difficult.

One nurse described how the entire hospice unit she runs has been furnished by community groups:

...equipment has come from all community groups, whether it be service clubs, craft groups, individuals, a lot of it has come from individuals. They gave us [money] for that electric bed and that alpha x-cell (mattress). The syringe pump was donated by the Lions Club, they fundraised...which they do every year.... The sofas have come from community donations, everything, all of the tables and chairs are from community funding. The brick pavers were donated, the plants have all been donated. Carpet was donated by a private person, stereo was donated by a private person, TV video, microwave was donated by a private person. The curtains came from community funding, as did the slim line blinds. And all of the linen so far has been donated by individuals. Vases, plates, the whole bit. Every time I saw a need for something, I sent out a letter, a general community letter to a lot of places and they were very forthcoming... CWA donated money, the pensioners league donated the birdbath. Volunteers to rotary hoe, to prepare for the garden club to come and plant all of their gear.

Another nurse explained how the hospice building itself had been funded for the most part by community donations. All of the rural palliative care nurses

in this study were reliant to some degree on community funding to maintain palliative care services.

Although a great deal of money is raised for hospice/ palliative care by community groups, rural palliative care nurses still find themselves juggling funds to be able to pay staff wages, run cars and provide necessary equipment. One of the nurses described her funding practices as creative:

I have to be creative with my funding. I'm not allocated any money, I run on donations from community groups. I pay my RN's like that.

Even with community donations, there are times when rural palliative care nurses find it difficult to fund trained nursing staff to provide clinical palliative care services.

Other nurses discussed how they have to work within specified definitions to use the funding they are provided:

The funding is mainly for respite, so hopefully a little bit more or less respite will happen, but that's the only way to get funding, as a respite service.

Another nurse stated:

There has been some palliative care programme funds that increased last year. ...[but] that doesn't meet our needs seeing as we had 75 palliative clients last year....So we decided that those services provided during normal working hours could be deemed a normal service. Those occasions of service that occur out of normal working hours (i.e. a Saturday or Sunday, or night) they were not normal and that's what the extra funding would buy. And that gobbled up that [money] very quickly.

The nurses spent a lot of their time and effort attempting to secure funding. Some of the more unusual ways of raising funds include a sponsored

endurance horseride, a fishing competition, cake stalls, quiz nights and even baby shows.

Writing grant submissions to attempt to secure funding has become an accepted but disliked part of the rural palliative care nurse role. All of the nurses have recently received some government funding, but found grant writing something for which they had had little preparation, and for which they had little time:

...you [have to] go into another domain like an administrators role, which I haven't been trained in. If you're on a ward you know your forms and your paperwork, but this is something that you're going into that's completely different and really there are no guidelines. It's not written down that you have to have a report go out here, and you have a report coming out here, you put your submission in here. It's all really finding out as you go along.

Discovering possible sources of funding for palliative care happens in an ad hoc manner. Nurses hear from another colleague or see an advert in the newspaper and decide to submit an application "just to have a go". Seeking funding is crucial in that finances must be secured to ensure the continuation of palliative care services in rural areas. As such the rural palliative care nurses are all concerned with finding new and creative ways to generate funds.

### **Planning For The Future**

Making plans to develop and expand palliative care services in rural areas is the concept explored in this subcategory. Self care and reduction of workload is the primary aim of most of the rural palliative care nurses interviewed. There is a recognition amongst these nurses that the amount of work they have taken on



cannot be sustained, so they are planning to extend the staff numbers of their service if possible. A nurse explained her wish to delegate some of her workload:

...one of my next developmental ideas is to get a volunteer coordinator. So I'm hoping that that's going to happen in the future, and that the next [volunteer education] course will be developed and run by this person. And the volunteer support and rostering can be taken over by them which will reduce my hours. But also spread the work so that other people can do it all...

Other nurses have plans to employ more nursing staff to assist with patient care tasks, to get assistance with office and administration work, and to increase volunteer participation in services.

Securing regular education, for themselves and other health professionals is also planned by most of the nurses. Asked what she would most like to see in her palliative care service, one nurse replied:

... basically education. Just ongoing education. And offering and knowing about new procedures, new treatments, whatever's going. I guess it's just ongoing education. Being supportive, education to the staff, I'd like to see that be more.

This is more of an issue for the isolated nurses who participated; however, even the difficulty associated with accessing education when a community is less than 200 km from Perth can be considerable. Providing palliative care education in their own community is a priority for most rural palliative care nurses.

Rural palliative care nurses also feel strongly that increasing awareness of hospice/ palliative care, both among other health professionals and in the general community will be of great benefit to them. One nurse said her aim is to have:

...I think just more community awareness, and just everyone's awareness. Having a bit more recognition of palliative [care]. Maybe because it's such a short term care, and maybe also the fact that fortunately it doesn't touch many peoples lives and that's why it's not got that

recognition. I really feel that it needs more recognition, because it's not all doom and gloom like people might think.

The general expectation is that increased awareness will help to educate people that palliative care is a viable option for people with a terminal illness. This in turn will encourage more referrals to palliative care services in rural areas, and will also empower community members to request palliative care. The palliative care nurses also hope that increased awareness will attract more fundraising for their services, because without a reliable source of income the service will be jeopardised.

Two nurses identified the need for improved grief support services in their communities. Both stressed that unresolved grief was a frequently encountered problem in their experience. A nurse said:

I think that our government has no understanding of the pathology of unresolved grief. Especially in rural communities, where people just don't have access to even the basic counselling services. I think that that is something that must be looked at. Because I'd shudder to think of the total pathological picture that unresolved grief causes.

There are few adequate services to address this problem in rural Western Australia, however the problem is being tackled by several rural palliative care services. However, several nurses have plans to extend their bereavement services, and stress the need for services to examine the issue of non-hospice bereavements and other grief issues that affect rural communities.

Several palliative care services have plans to develop inpatient facilities as a part of their service, or to upgrade their existing inpatient palliative care facilities. Other services already have inpatient facilities, although to date one has

not been fully commissioned. The need for suitable inpatient services appears to be widely accepted:

The general manager, he's got his ideas of what he wants this developed to, the nurse manager has got her ideas, the DON [Director of Nursing] has got her ideas, and they're all conflicting, they've all got different ideas of what they want to see....But as far as setting up a palliative care unit, they are all very eager for that to happen.

For some, the planning of a new facility goes beyond merely needing a building, it also represents a chance to develop relationships with associated health services:

I think that that will enable us to do this work [together], because we'll be closer to one another geographically, and logistically it won't be so difficult. It will be easier for the nurses to pop in and see their patient...

Planning for inpatient facilities necessitates nurses taking on new roles, such as planning and commissioning buildings and arranging appropriate equipment and furnishings.

### **Being Other Places Too**

The subcategory of *Being Other Places Too* examines the stresses associated with having professional commitments in areas other than palliative care. Three of the nurses who participated in this study are not dedicated palliative care nurses. Each of them has responsibilities that requires them to work in areas other than palliative care at times. These nurses were observed spending their working day not only in the palliative care unit, but also in the casualty department, and in the labour ward. One told stories of having to help in

theatre and recovery, on the medical/surgical ward and in midwifery as well as caring for palliative care patients:

... quite often if you are short staffed, emergencies or whatever, you are taken ... no matter what you are doing, to work in that other area. So you have to be really versatile, and have a good knowledge of the overall running of the hospital.... it's hard, it's very very hard... Then I might add, amongst all of this, we carry a page, and are on the emergency system. So whenever our page goes we have to run.

Some of the nurses described feeling torn between their administrative and non-palliative care responsibilities and the needs of their palliative care patients and families.

I'm part of the team here, so I have a loyalty to the hospital to work in different areas of the hospital and to be supportive to what's happening in the hospital. And then just the fact that sometimes I may coordinate the hospital, but that doesn't happen as often because of the fact that I normally have to work in this one area, well, on this particular ward, so I'm not as involved with the acute side of things. To coordinate here you have to relieve in urgent care and ICU, and it's not something I relish.

Having to divide their work day up like this, and having to work in many different areas is problematic for the nurses. This is how one nurse described the difficulties she encountered:

R: How do you find changing between palliative care and the acute care?

N: Very difficult, very difficult, as you've seen today. I'm pleased that S is as stable as he is today, and the family. Because you have to prioritise and you've got to end up leaving your palliative patients.... We fought and fought to make people understand our workloads. It's very difficult when you've got someone in a terminal phase and you've got four other patients on the ward. Four or five. So changing hats, changing your thinking pattern is not easy.

Having to have a working knowledge of so many specialty areas is not uncommon among rural palliative care nurses. There is also a feeling that other nursing staff do not understand the demands of caring for a terminally ill person, and feel that palliative care nursing is a “soft option” that requires little expertise. Having to be a nursing generalist as well as a palliative care specialist is difficult for these nurses, because it requires having extensive knowledge and competence in many areas of nursing. It also necessitates balancing the demands of a specialist palliative care role with other commitments. This compounds the stresses associated with the rural palliative care nurses’ role.

The category of *Wearing Many Hats*, and the associated subcategories have examined the many separate roles that together constitute the rural palliative care nurse’s role. The time devoted to fulfilling all of these roles, and the stresses associated with being multiskilled undoubtedly impact on the life of the rural palliative care nurses, and contribute to the all-encompassing nature of their work.

### **Being the Expert**

This category examines the concept of *Being the Expert*, that is, of others having an expectation that rural palliative care nurses will assume the role of palliative care specialist in the community where they practice. Most of the rural palliative care nurses who participated in this study are sole practitioners, in the sense that they are the only dedicated palliative care provider in either the health service for which they work, or even in the town in which they work. Because of this, there is often an expectation that the nurses will act in a consultative role, that is, being the expert in palliative care. Related subcategories, *The Steep*

*Learning Curve-Starting Out in Palliative Care and Caring for Colleagues* will also be described.

Even the most recently employed rural palliative care nurses are looked upon as being knowledgeable in the field of palliative care, when they are in fact just beginners in this area. For most this is an accepted part of their role. All of the nurses make themselves available to other health professionals, including those from outlying towns, should they require assistance in providing palliative care. In general this is not a burden, but is actually a positive part of the rural palliative care nurse's role. This is how one nurse described her palliative care consultant role:

...there are the ones who ring you at the drop of a hat because there's a palliative care patient there. Nothing that they can't solve, even though I do like to know that they are there for the statistics....And they ring you because you happen to have that role... "Oh my God, better get her over here". And then there are the ones who are really good, and document a lot of stuff, and call you for advice...and if I come across and visit a patient, and I see something that probably could be improved I suggest that maybe we could try it this way and see how it goes. They are very receptive. Very pleased with the input. I make life easier for them and the patient.

Sometimes the consultancy role involves nurses offering advice to other health professionals, particularly General Practitioners. While this type of relationship between palliative care nurse practitioners and doctors sometimes presents a problem initially, the nurses work hard to maintain professional relationships that facilitate the sharing of ideas. The rural palliative care nurses who participated in this study found that the medical practitioners in their communities were very pleased to receive extra help:

I think it's just one of those things, if someone else can pick up on a bit of their workload, they're quite willing to pass it

on. ... If there is an issue, or if they want me to liaise with ... somebody out in the community... yeah, they are very good.

This reciprocal kind of relationship between the rural palliative care nurses and the doctors enhances the quality of patient care delivery by providing consistent information for the patient and the family.

However, the role of the palliative care expert can be a burden, particularly for nurses who also have commitments in clinical areas other than palliative care. One nurse described the difficulties she finds fulfilling her role as "expert":

I guess the hard thing for me, this is only for me personally though, is if they've got a palliative care [patient] on [the] ward and they are having problems, and I'm working in another area as a clinical nurse, they ring up and they want you down there now. And I've got my role to fulfill on the ward and I can't always leave that area and go and see the patient. And I'm frustrated at that because I can't go over and sort something out, and they are frustrated because I didn't go. It may be four or five hours before I get there and I find it very very difficult.

As well as staff having the expectation that the palliative care nurse will be available as needed, patients and relatives often have similar expectations, and want help from "the expert". This places extra demands on the palliative care nurse, and can leave her feeling dissatisfied when she is unable to fulfill all of her commitments to her own satisfaction. The caring nature of the palliative care nurses makes it hard for them to not provide care when requested.

Being the only expert in the town places extra demands on the rural palliative care nurses, as there is no one to take on this role when they are not available. One nurse lamented the lack of others to take on some of the burden of being the expert:

What would make it easier is having other staff who are able to, who are interested enough to attend education sessions like I did, going down to [the city], and then coming back, and working together. Because I'm it, I'm the only one....And it's always too easy for the staff to say oh, she's the palliative care specialist. I wouldn't say I was a specialist, it's just an interest, and I've gained a lot of knowledge. But I would by no means say that I'm a specialist in that area.

All of the palliative care nurses involved in this study were observed performing multiple tasks in their professional life. During participant observation, it was noted that the rural palliative care nurses had a sense that they were solely responsible for the completion of all duties, and that they must take on the ultimate responsibility within the palliative care service. Often the rural palliative care nurse is the only person in the community providing a palliative care service, and if the service is to continue they have to keep performing all of these roles.

So, you are fairly well a sole practitioner in this area. Very much so actually. It's when I look back I think "yeah, how did I do this?". And people you know, I've asked...for information, and they are too busy. It's very difficult.

Some of the nurses expressed hope that as more people became aware of the role they were playing and the needs of the community, they would no longer feel compelled to do everything required to maintain the service:

...there's just you. That will change a bit, and come with education, and people getting more confident. Hopefully it will anyway. I mean, I can't do it, and I accept that. I can't do everybody's job, because everyone is good at something, and you can't be good at everything. There are always other people who can pick up somewhere else. It's just making them aware that they can do it just as good.

At times the rural palliative care nurses also take on a more formalised "expert" role. They are often responsible for teaching other staff about palliative



care. This may involve teaching volunteers who work in the service, but several of the nurses also provide regular education sessions for other health professionals. One of the nurses now laugh about commencing the role of palliative care nurse, and having to prepare a volunteer training course immediately after beginning. The task was daunting, but it was completed, and now similar courses are run regularly. This educator role is one which often develops as the palliative care role expands, and the nurses' expert status gains credence.

### **The Steep Learning Curve - Starting Out In Palliative Care**

This section discusses how commencing in the rural palliative care nurse role necessitates acquiring large amounts of knowledge about palliative care service delivery. Several of the rural palliative care nurses who participated in this study had no previous palliative care experience, and started out with nothing but a great deal of enthusiasm. One nurse said:

And I really didn't realise at first how specialised it was. But that's not a problem.

Despite having little knowledge of palliative care, and indeed little knowledge of how to develop a new service, the nurses had been charged with the responsibility of providing palliative care to their community and were expected to deliver. Often they had no help from anyone:

There is very limited support, and very little input from anybody else, I've just been left to my own devices, to set it up the way I would like to see it. If there have been some curly issues I have sought advice but...there is no committee per se, to help, and I have just rung around to other places to get ideas and see what they have done, and what's in place, and things like that.

Despite the stresses of not always knowing what to do, and the pressure to perform, the nurses described their start in palliative care as a challenge and expressed satisfaction at a job well done:

...see this is all new, ... But there's nothing written, in concrete. So you're really thinking what would I change another time? I wouldn't change anything I've done.

One of the nurses was approached to set up a palliative care service, and was employed by a health service to do so. Despite this service wanting a palliative care nurse, there were no guidelines in place, and this nurse didn't even have a job description when commencing her role. In fact, one of her duties while setting up the service was to write her own job description.

Although the nurses are confident in the quality of the service they provide, they do bemoan not having other people to compare themselves to, and welcomed the chance to talk with someone else to get another perspective on their services:

It's good to get that feedback, because you've got no one to compare anything with.

Despite often only having limited palliative care experience when commencing in their role, educational opportunities are limited for palliative care nurses working in rural areas. The monetary and time costs associated with traveling to Perth for education are prohibitive, and causes the rural palliative care nurses to seek knowledge from alternative sources. Most of the towns in which the nurses in this study work have received one or more educational workshops from palliative care professionals based in Perth, who offer their services to country towns.

Holding these types of workshops is a costly option. Some of the services were able to access some funding from scholarship funds, and from businesses who sponsor educational events. This lessened the cost and makes these education sessions a viable option. There is also a yearly televised course in which nurses in rural areas can participate, again run by palliative care nurses in Perth. This link up is a valuable source of knowledge for rural nurses.

Although these education sessions are valuable, they are generally not aimed at the more experienced nurse practitioner. Because the numbers of rural palliative care nurses are small, it is impractical to hold seminars for them in the many towns throughout the state. This leaves the nurses the option of traveling to Perth for study purposes. However a nurse explained:

...it's costs, education costs, the distance, we're geographically isolated, it's the cost of getting to Perth.

Often, the nurses just learn what is needed as they go along, seeking appropriate literature and reading in their own time. Of course, there is also some difficulty associated with accessing professional literature, though the advent of electronic media such as the internet in rural towns is lessening this problem. It is interesting to note though, that some rural towns have only had affordable internet access since early in 1998, so this is a new option for some.

Opportunities to access palliative care education are limited by geographical isolation. Nevertheless, rural palliative care nurses are expected to have adequate knowledge to perform their clinical role competently.

### **Caring For Colleagues**

Caring is an acknowledged part of the rural palliative care nurses' role. This subcategory examines specifically the rural palliative care nurses' role in helping and supporting other people involved in the palliative care service, and the expectation that the rural palliative care nurse, as the head of the palliative care team, takes responsibility for caring for other palliative care staff who work in the service. The rural palliative care nurses' caring role includes not only palliative care patients and their families, it is extended to encompass colleagues and sometimes the wider community as well. One nurse described her perception of the importance of caring for other palliative care staff in her role thus:

... what I see as the most important thing is getting nurses on board, and getting a good rapport, and keeping them interested. Also getting the rapport with the hospitals, doctors, so there's an awful lot of networking as well in this role.

Several of the nurses appear to be a safe haven for other staff who are troubled, particularly if a death has been traumatic, or they have suffered a bereavement in their own life. One nurse said:

...PCA's [patient care assistants], to enrolled nurses to RN's [registered nurses]...as you saw today, they will seek me out, and come and talk to me if they've got a problem or just ring me on the phone...

Several nurses have offices that are quite isolated, so that staff feel comfortable seeing them if they require support. Providing this sort of informal support is an invaluable service for other staff members working within the palliative care service, but at times may impact on the nurses' already limited time.

Some other services have a more formal support network, where planned team meetings are used for debriefing:

I am part of the bereavement support group. ... And I am the counsellor on that group....So we meet once a month to support each other and review our practice and introduce new situations.

Another nurse supports her team members by assisting them with the initial patient assessment on admission. In this way she is not only aware of what is happening in the service, but has a working knowledge of a situation if someone needs to debrief, and can step in and complete clinical requirements if the staff need some respite:

But I feel that that's like a [part of my] role, you know, going in, seeing them, supporting the nurse on the first visit, ... and that's working fantastically as you can see. And then if it's getting heavy, I can be there as an extra nursing hand if that's what's needed.

The rural palliative care nurses that participated in this study showed great insight into the need to be supported when working in palliative care, an area that may be stressful and draining for staff. Although they may differ in the approach that they take to support their colleagues, all of the nurses are available to others who need help, and give their time willingly to help other palliative care professionals. A nurse, when discussing her support role said that she endeavours to:

...allow plenty of time to debrief, which often means staying back a little longer, and they'll ring me at home and stuff. Which is fine. You know at times you think "huh", and my husband says "it's work again", but often particularly for the enrolled nurses, they are there on their own, so if they'd rather ring me, and I'd rather they did that, and talk about what's happening. And then they are reassured.

Being available at all times for others demonstrates the capacity for caring and compassion that is a hallmark of the rural palliative care nurses in this study. However, at times the expectation that the rural palliative care nurses will be available for anyone who needs assistance is a burden, particularly as there is often no support for the rural palliative care nurses when needed.

*Being the Expert* places a burden on the rural palliative care nurses, as they strive to meet the expectations of others. The strain that this causes the nurses impacts on their daily life, as they devote increased time to completing all tasks related to their "palliative care expert" role.

### **Surviving In Rural Palliative Care**

This category examines the coping strategies that rural palliative care nurses use in their professional life, including seeking support in a difficult and demanding role, and finding rewards in palliative care. The category was developed from several concepts, identified during the coding process, that examined different coping mechanisms and sources of support for the nurses. The subcategories discussed within this category are: *Joining Together: Finding Other Country Colleagues, Connecting With the City, Being Supported By the Community and Finding Rewards.*

Few would doubt that working in an area such as palliative care can be demanding and emotionally draining at times. For palliative care nurses in rural areas the demands of the job are exacerbated by the conditions under which they work. These nurses generally work alone, or in small teams, and have considerable responsibility inherent in their position as a sole practitioner. These

potential stressors, for rural palliative care nurses, are combined with insecure and often inadequate funding, and often little preparation for their role. All nurses expressed the need for some support to be able to survive in palliative care.

Awareness of the need for support and understanding from those close to them is acknowledged by all of the participants in this study. However, the tendency to overlook this need, and to put others first is also acknowledged:

I think the one thing that we're not good at as nurses is [taking] time out, and recognising that we may also need some, not counselling, but, you know, we forget to look after ourselves basically. "We can cope, we can do it". It becomes very hard, very hard, very draining.

The need to take time out, and be away from the demands of palliative care is recognised by the nurses. One nurse described her approach to sustaining her energy in a job that regularly places great demands on her:

I do recognise that you can't keep doing it forever, and certainly the pace that most palliative care nurses work... and I have taken breaks... and have done something different.

The greatest source of support for the nurses in this study was their family. Having family members who understand the dilemmas faced living and working in a small community provides the succor that the nurses need to be able to "recharge" and continue their work. A nurse working in a small town discussed the support she gets from her husband when she is caring for a friend:

... well, he'll be understanding, but he knows when there is a family member who I know that is terminally ill, he accepts that, and he supports me that way. That's the only support that I've found you get. Occasionally you'll get staff saying you're doing a good job, or hang in there, you know, that kind of thing, but I think it's family that support you the most. It is very very difficult.

As well as family, other health professionals are cited as being supportive when needed. Interestingly, few of the people the rural palliative care nurses listed as being supportive work directly in the palliative care team. The support for the rural palliative care nurses tends to be more informal in nature, and is sought from friends in the workplace rather than palliative care colleagues.

The lack of professional support is an issue for some nurses. This seems to be particularly true for those who work for a larger organisation, of which palliative care is only one part. One nurse told of the difficulties of working in an environment where other staff members have little insight into the stresses she encounters in her work:

I know they would be supportive, but it's like being a, what's that, a chameleon? Can you see that? And I suppose it's my nature, I suppose it's something I should learn, that not everyone's like me. You know, because I'm very feeling and understanding of other people, I sometimes think I wish other people could be. But then they are coming from different directions. Everyone's doing their own thing.

It seems that a lack of understanding of the rural palliative care nurse's role on the part of non-palliative care colleagues possibly contributes to their inability to provide support.

### **Joining Together: Finding Country Colleagues**

The subcategory of *Joining Together: Finding Country Colleagues* is defined as finding other rural palliative care nurses with whom ideas can be shared, and frustrations discussed. Other country palliative care nurses are a valuable support network. Rural palliative care nurses feel that linking with other



palliative care colleagues is a vital way of gaining information, particularly when setting up a service. One nurse stated that:

You have to, you have to liaise with other areas in the same field. Because there have been no guidelines.

Connections with other rural nurses provide insight and ideas that have already proven to be effective in rural areas. One of the services I visited has a flourishing volunteer service, which was orchestrated with the help of another nurse who had already set up a service in her own town. The experienced rural palliative care nurse provided assistance with recruiting and training volunteer carers, who form a vital part of the palliative care service.

Unfortunately, like connections made with palliative care professionals in the city, connections with rural counterparts are made on an ad hoc basis. Often the isolation of towns, and the vast distances between them, prohibit nurses developing relationships with others. Opportunities for "networking" and social interaction are few for nurses in more isolated areas, limited by the prohibitive costs and time involved in travel.

### **Making City Connections**

The subcategory *Making City Connections* is defined as rural palliative care nurses seeking guidance from palliative care specialists based in large metropolitan health services. Having a connection with palliative care institutions in Perth is of great comfort and support to many of the nurses, particularly those who are beginning palliative care practitioners. None of the rural palliative care services have formalised links with metropolitan services, but most of the nurses have met city based palliative care professionals at conferences and workshops,

and make contact with them if they need information or clarification of issues. A nurse explained her connection with metropolitan palliative care services as:

...well I have a relationship with [a city palliative care service], and I go up there for 2 or 3 days every year to update myself. And so does one of the casual nurses, I send up one a year. And we also have a relationship with the [city hospice] in that we always get their videos and workbooks, and 2 people, a nurse and a volunteer always go up and do the [palliative care] course. And if there are any questions they want to ask I ring ... And they have also been helpful to me and the office manager in terms of trying to set up a sensible administrative structure. So they are helpful in that way as well. So we do have a link with them.

One country hospice has a reciprocal arrangement with a city palliative care professional:

... she comes down for 2 weekends a year, lives in one of the volunteers houses... for 2 or 3 days, and does a workshop in return. So she always does the last workshop of the volunteer course which I run twice a year.

This arrangement is undoubtedly satisfactory to all of the people involved, and provides an invaluable service to the rural community, as well as offering support to the rural palliative care nurse.

The lack of a formalised relationship with a metropolitan institution is lamented by some nurses, particularly those just establishing services in their communities:

No, they don't come to me. I know I can go to them. No, they never ring me. I get the palliative care brochure from the West Australian Palliative Care Association, and that keeps me a bit up to date with what is going on. The Rotary Cottage Hospice, they send me all their regular handouts, like the courses they have on, but no, nothing. No talking or anything like that on the phone, like chit chat, unless I call them.

The absence of regular support and assistance from experienced palliative care professionals makes the initial setting up of a palliative care service problematic at times, and the expertise of others would assist greatly in the early stages of developing a rural palliative care service. A city connection would also help beginning nurse practitioners gain confidence in their own decision making. Several nurses noted that not having anyone who they could "bounce ideas off" made them feel that they carried the burden of providing palliative care alone.

### **Getting Support From The Community**

This section examines how the rural palliative care nurses receive support from the local community, generally in the form of fundraising or as a volunteer workforce. The enthusiasm and willingness of rural communities to assist with hospice services in their town is a catalyst for the commencement of palliative care services, as this nurse explained:

... it's very overwhelming, they are very supportive. It's new, something new, and the people that are most interested are older people....Oh, they've heard about the Cottage Hospice in Perth, and that's where their friends go, and they have visited people there, so they've seen the setting, and they can see there's a need. There's a need here in [town] to keep their family members and their friends here as long as possible.

Many of the observed rural palliative care services are community funded, and run by a committee of community members. Several nurses discussed the apparent passion in rural communities for palliative care, and the commitment of rural people to the maintenance of services in their town. One nurse described the community's feelings about the hospice unit:

The willingness to learn and change, and again with the community...most people have had an experience with

hospice, it's very close to the hearts and there is a real ownership. Because we are not funded, basically our hospice is funded by the community, and so there is this ownership of it that I don't think you get in these really big funded type operations.

The rural communities visited during the data generation process seemed to embrace palliative care services as their own, and donate enormous amounts of time, effort and money to ensuring the success of these fledgling services. As previously noted, many of the rural palliative care services that participated in this study rely wholly or in part on funding generated from community sources. The efforts of community groups fundraising for a palliative care service were described by one nurse:

I was never advised about any funding, so then I saw that maybe community funding was the way to go. So I spoke at various groups. Each time [I] spoke to one group word passed around to another group and they invited me back. So I did lots and lots of speaking out of hours, and they were all willing to participate and fundraise very generously.

The willingness of the communities visited to back a hospice or palliative care service in their town helped to make the service successful, and to remain a viable health care option for these communities. Community support is also often an incentive for nurses to work hard at ensuring the service provides optimum care for community members. As a nurse pointed out about the service she works in:

Oh, it's definitely a community thing. In fact to be a part of that you have to embrace them as well....What I love particularly about being in a rural area is how resourceful people are. I love their attitude, and I find it very rewarding to assist people first of all like I said to live their life the way they want to as much as possible, but empowering people and their families to share in that, encouraging them to be a part of that, and making it a very special time. And I find that, in my experience again, rural palliative care people, certainly in this community are very keen to do that. I found

in [the city] that there was an expectation that, "oh we've got services here, so we'll use them". People, families, extended families, friends, relatives are too busy it's a ratrace. People up here they might be busy, they have to work, but they still find the time, and certainly I think their employers are a bit more understanding, everybody helps each other, and I think that ... they just take responsibility, and I find that very rewarding to be a part of.

This willingness to participate in providing community services, and to take on a caring role, was prevalent in all of the rural communities that I visited.

Considering the funding crisis in Australian healthcare, and the difficulties recruiting staff in rural areas, volunteers were observed playing a large role in staffing rural palliative care services. The role played by volunteer workers is invaluable, and the experience of working with volunteers is a positive one for these nurses:

...the volunteers we've seen come from all different walks of life, professional people rubbing shoulders with people who have been unemployed for many years. All working together in palliative care. A kind of family is formed. And the commitment of the volunteers, and the willingness to learn, and the support. It's just fabulous. And to get feedback from them just is amazing.

The support of the community in which they live and work is cited as vital by the participants in this study, because community support enables them to continue to provide care when needed. Not only is the financial and physical support a crucial part of maintaining an underfunded service, but the recognition and appreciation of their efforts go a long way in encouraging these nurses to persevere in what may sometimes seem a thankless task.

## **Finding Rewards**

This subcategory examines the way that rural palliative care nurses are sustained by the rewarding aspects of palliative care nursing. The rural palliative care nurses with whom I have spoken acknowledged that their chosen path is not always easy, and that at times the support they receive from others is less than optimal. However, all were quick to add that they love the work that they are doing, and would not want to work in another area. The caring component of the rural palliative care nurses' role is described by all of the nurses in this study as the most rewarding part of their role:

It's when you get in the room, and you close the door, and you're just in there making a difference to the patient, you're just in there giving the best care you can for your patient. And seeing families respond, and seeing people respond that have come in with symptoms out of control. Just knowing that you are doing it right. Not that you always get it right. The actual hands on nursing part is really rewarding.

Asked to describe what kept them going on days when things were difficult, the participants most readily identified the satisfaction of seeing a patient respond to the care that they receive:

People are just so grateful for the little things that you do. The gratefulness far outweighs the little bit that you did.

Another nurse described her reasons for staying in palliative care as being mixed:

I think it's a personal thing, it's something I set out to do, as I said I could see a need, and it was a big need. There was a deficit in the hospital situation, patients were coming in for respite, and it's a goal that I want to achieve, it's a personal goal. And also for the community. Because they are so supportive, and so behind it, and so enthusiastic. I just couldn't dampen their spirits. I just couldn't, even if I wanted to I wouldn't. You know, the support has been just incredible. Absolutely incredible.

Recognition of the role that they play in their respective communities is another thing that is an incentive for rural palliative care nurses. One nurse told a story about how her manager had a talk to her while doing a performance appraisal:

And it was really good for me, and I feel certain it was probably good for her. She said "Oh gosh, you've done so much", and she was really pleased to know. But no one notices. And you know I think nurses we're fairly "recognition people". We like recognition in some form. And with patients you get recognition by, you know, doing something and then you've made them feel better. And so you get that nice feeling. It's a feedback thing isn't it?

Rewards also came to the nurses from unexpected sources. One nurse told how satisfying it can be having student nurses spend time with her. This sharing of the hospice ideal is not only an indication of the dedication the nurses have to their chosen profession, but can also yield rewards too:

...I actually had a real reward the other day. [A student] rang up wanting me to give him a reference. But he also said "I'm really pleased I worked in hospice for those few months. I really got to know what basic nursing actually meant". And that was great. And he said about how you put love into it.

For this nurse such a simple tribute meant a great deal, and provided the inspiration to keep going in her demanding role. Rural palliative care nurses do not advertise their dedication widely, but do gain satisfaction from recognition and appreciation of the role that they play in their communities.

The category of *Surviving in Palliative Care* has examined the coping strategies that rural palliative care nurses employ to survive in their often challenging and sometimes stressful professional role. These strategies ensure that while the nurses may *Live Palliative Care*, they are able to cope with the stressors that such a demanding professional may entail.

## **Conclusion**

This chapter has presented the findings of this research project. The central theme that emerged from the data, *Living Palliative Care* is explained, as are the three related categories, *Wearing Many Hats*, *Being the Expert*, and *Surviving in Palliative Care*. Subcategories within each category have also been discussed. Exemplars from the interview transcripts and fieldnotes were used to clarify points.



## **CHAPTER FIVE**

### **Discussion**

#### **Introduction**

This chapter discusses the findings of this research project. The discussion will examine methodological considerations, theoretical issues, and implications for clinical practice. Recommendations for research, education, administration and practice will be presented.

This research has developed a conceptual framework that describes the basic social processes associated with rural palliative care nursing. The central theme *Living Palliative Care* discusses the all-encompassing nature of the rural palliative care nurses' role, and the effect that this professional role has on all aspects of the nurses' lives. Three related categories were developed from the study. The first, *Wearing Many Hats* examines the various roles that combine to form the overall rural palliative care nurse role. The category of *Being the Expert* discusses the expectations relating to the rural palliative care nurses' role as "specialist" in the community where they practice. Finally, the category of *Surviving in Palliative Care* examines the coping strategies employed by the rural palliative care nurses to lessen the stress related to their professional role. This category also examines the rewards the nurses identify in their role. These findings will be discussed in the context of the existing literature, and recommendations for nursing will be presented based on the findings of this study.

### **Methodological issues**

Three areas of methodological significance have been identified as having had an impact on this research project. They are limitations in the sampling procedure, issues associated with conducting research involving professional colleagues and personal friends, and the effect the researcher had on the care settings during the participant observation/data generation process.

In accordance with a modified grounded theory methodology, the sampling procedure followed for this study was theoretical in nature, recruiting participants who had specific characteristics that would enhance theory generation and provide data to fill in gaps in knowledge (Corbin, 1986). The time and financial constraints associated with accessing care settings in rural Western Australia, as well as the constraints of Masters level research limited the sample size to five care settings and six participants. However, this number of participants was sufficient for redundancy of information to be noted.

Sandelowski (1995) cautioned that sample size is not always representative of quality of data generated, and that "small is beautiful" (p. 179) in some situations. The data generated for this study was rich and dense, and as such it is considered suitable for the level of research being conducted, and was adequate to meet the stated research aims.

Conducting research with participants known to the researcher may be problematic and pose ethical dilemmas for the researcher (Ribbens, 1989). Several of the participants in this research were known to me prior to commencement of the sampling process, and I was also familiar with one of the

care settings, having lived and worked there myself. Despite concerns that personal preconceptions might possibly bias data generated when participants are known, the interviews with participants already known proved to be efficient at generating rich and detailed data, because there was no need to spend time developing mutual understandings and trust. Cotterill (1992) discussed the difficulties associated with interviewing friends for research projects, commenting on the problems of knowing whether information disclosed is done in a "friend to friend" manner, rather than as an "interviewer to participant". In this study information was at times disclosed that was not appropriate to be quoted in the text of this project. However, on each occasion the nurses concerned added a qualifying statement such as "I hope this won't be included". In these instances the specific passage of the interview was excluded from the coding process. However, the impressions generated by these comments were included in memos, and form part of the researcher's overall impressions of the setting.

Having prior knowledge and experience of the participants and settings proved to be an advantage to the research process. Patton (1990) noted the need for researchers conducting fieldwork to learn the "native language". Having had personal experience in rural palliative care nursing in Western Australia resulted in a deep understanding of shared meanings, and increased reciprocity in the interviewing process (Cotterill, 1992). Furthermore, the shared "black humour" of palliative care nurses noted by McNamara (1996) assisted in setting the conversational tone of the interviews, that in turn assisted in generating data that did not seem stilted and contrived (Fontana & Frey, 1994).

The final methodological consideration is the effect of the researcher on the care settings in the sample. The duration of participant observation for this study was limited again by time constraints, and may have contributed to a skewed view of the palliative care settings that were observed. Gerrish (1997) cautioned that be some distortion of any setting where a researcher is working is to be expected. In this study, several nurses "saved up" tasks that they considered more interesting for the days that the research was being conducted. This may have led to an over representation in the data of palliative care activities, particularly when participants had non-palliative care commitments in addition to their palliative care role. Generally, in anticipation of my visit, the nurses would plan to spend more time than usual on palliative care activities. Other nurses with a more palliative care focused workload may have over-represented the amount of time spent in the clinical area, as this is the part of their role that they feel warrants most attention. This distortion of the care settings may have been lessened by increasing the duration of participation observation, allowing the researcher to become a more accepted part of the environment (Patton, 1990).

In summary, the methodological issues of significance in this study are; the limitations of sampling related to time and access issues, working with research participants known to the researcher was also a consideration, although in this study it appears to have been a positive factor in data generation, and finally, the effect the researcher had on the research setting is accepted as being a contributing factor to possible inaccurate representation of care settings and the professional role of participants.

## **Theoretical Issues**

The major theoretical issue noted in this study is the need for further information relating to the degree of association between the categories identified from the data. The diagrammatic representation of the relationship between the central theme of *Living Palliative Care* and the related categories of *Wearing Many Hats*, *Being the Expert* and *Surviving in Palliative Care* represents the relationship between these elements of the conceptual framework developed in this research project with a dotted line, indicating a lack of data about the degree and strength of relationship between categories. Categories are also presented as inter-connected, but the degree of relatedness between categories was not clearly revealed in this study. For example, it was apparent that the categories of *Wearing Many Hats* and *Being the Expert* overlapped in the area of assuming the role of palliative care educator, which may be considered another “hat” that the rural palliative care nurses wore, and also a component of the palliative care “expert” role. Furthermore, *Wearing Many Hats* and *Being the Expert* overlap with the category of *Surviving in Palliative Care* when considering the educator/expert role, because assuming multiple roles, and meeting both personal expectations and the expectations of others required the rural palliative care nurses to develop coping strategies that would facilitate survival in an often difficult and challenging professional role. Other areas of overlap between the categories include: the relationship between the concepts of *Just Being a Nurse* and *Finding Rewards*, and the apparent connections between *Caring for Colleagues* and *Caring for all People*. However, despite some of the relatedness between the categories being apparent, the limits imposed on the theoretical

sampling procedure used in this research project may have prevented further data being generated that would have provided more detailed information on the relationship between the categories and the central theme.

The concept of palliative care nursing being an all-encompassing role is one that has not previously been identified in the literature. Hegney (1995) and Thornton (1992) both identified the social aspects of being a nurse in a rural community, including extended working hours, community expectations of constant availability, and loss of anonymity. However, while these two studies present the social cost of rural nursing as an often negative experience, the nurses in this study did not cite these areas as being of major concern. This is perhaps because the nature of palliative care nursing allows the nurses to find rewards in giving patient care. This idea is supported by McNamara (1996), whose research found that hospice nurses were sustained by the ideal of providing patients "a good death" in what has the potential to be a stressful professional role. However, the impact of living immersed in a demanding profession such as palliative care nursing requires further examination.

This study found that there was a need for rural palliative care nurses to develop coping strategies to facilitate survival in their profession. Other research has examined the relationships between the issues identified. Several studies have found that teamwork and collegial support is a major factor in relieving work related stress, and thus assists palliative care professionals to cope in their work environment (McNamara, Waddell & Colvin, 1995; McWilliam, Burdock & Wamsley, 1993; Vachon, 1986). However, the relationship between coping strategies and teamwork is not clearly established in the rural palliative care

setting. It seems likely that the coping strategies employed by rural palliative care nurses are focused more on family support, and the sustaining aspects of the palliative care nurse role. Teamwork is an identified stressor for some of the nurses, and poses challenges not noted in literature relating to metropolitan palliative care. However, some nurses also cited members of their team as a source of satisfaction and support. This seeming paradox suggests the need to further examine the relationship between the rural palliative care nurse's role and its associated stressors. The need to employ coping strategies to survive in the rural palliative care nurse role is also not fully examined in this study.

Furthermore, the effectiveness of the coping strategies employed is not explored.

Examination of related research suggests that the concepts developed that relate to rural palliative care nursing practice are unique, and further research is required to develop a conceptual framework that demonstrates the strength and direction of relationship between the central theme and associated categories.

In summary, the conceptual framework regarding rural palliative care nursing that was developed in this research emphasises the relationship between the central theme *Living Palliative Care*, and the categories of *Wearing Many Hats*, *Being the Expert* and *Surviving in Palliative Care*. However the degree and strength of the relationships is not fully understood. Therefore, research is required to further examine these concepts.

### **Clinical Issues**

Two clinical issues of importance to rural palliative care nursing have been identified in this study. Firstly, there is a clear need for palliative care

education to be more accessible to rural palliative care nurses. Secondly, the identified stressors and lack of adequate social and professional supports suggest that issues of self care are of importance to the well-being of rural palliative care nurses.

This research project has underscored the need for education to be made accessible to rural palliative care practitioners. Having to meet the expectation of being an expert palliative care clinician with inadequate educational opportunities is undoubtedly stressful at times. Glen and Waddington (1998) studied the transition between Staff Nurse and Clinical Nurse Specialist (CNS) roles, and found that role overload and role ambiguity are sources of stress for the new CNS. Role overload is described as occurring when "expectations and demands of the job are in excess of the ability, or perceived ability" (p. 287) of the nurses. Role ambiguity occurs when expectations of the CNS are unclear. Both role overload and role ambiguity were problems identified by the rural palliative care nurses in this study. Although all of the nurses in this study now feel able to perform their duties adequately, they did suggest that they felt inadequately prepared when commencing the role of rural palliative care nurse. More adequate preparation for this specialist role would improve standards of patient care in rural areas and decrease the stress associated with commencing the rural palliative care nurse role.

Furthermore, numerous studies into the support needs of palliative care patients and their families have found that information needs are ranked as extremely important (Harrington, Lackey & Gates 1992; Hileman & Lackey, 1990; Hileman, Lackey & Hassanein, 1992; Hull, 1989; Kristjanson, 1989;



Longman et al., 1992; Wingate & Lackey, 1989). Studies of rural patient and caregiver needs noted that rural people described their information needs as more important than people in metropolitan areas, perhaps because rural people are noted to be more self reliant (Buehler & Lee, 1992; Burman & Weinart, 1997; Morgan, 1998; Silvera & Winstead-Fry, 1997; Wilkes & White, 1998). Nurses are cited in these papers as being a main source of information for patients and caregivers. It is then imperative that palliative care staff be able to provide for these needs. Therefore, providing access to appropriate education for rural palliative care nurses about disease progression, pain and symptom control, psychosocial and spiritual aspects of death and dying and bereavement issues is a necessity if the support needs of rural people are to be met.

Several of the nurses in this study discussed the benefits of televised palliative care education which is currently available. However, it appears that the frequency of these televised sessions is inadequate to meet all of the education needs of the rural palliative care nurses who participated in this study. Several Australian universities now also offer distance education courses in palliative care, however these are predominantly for post-graduate students, and are therefore not available to nurses who have not completed an undergraduate qualification. Offering more frequent televised palliative care education, and providing distance education in palliative care related topics for undergraduates may help to alleviate the difficulties the nurses in this study experienced accessing appropriate education.

The findings of this research suggest that the role of rural palliative care nurse can be stressful, and that opportunities to debrief and support mechanisms

may be lacking for rural nurses. Saunders and Valente (1994) and Vachon (1998) underscored the importance of nurses working in the palliative care field caring for themselves, paying particular attention to grief and bereavement issues. Cramer (1995) found that grief reactions in remote area nurses in Australia are compounded by knowing patients who die. This was also identified as a stressor by the nurses in this study.

Another identified stressor was the necessity to “change hats”. This finding contradicts that of Samarel (1989), who found that nurses working in palliative care and acute areas concurrently did not encounter role conflict. Samarel proposed that this was because the nurses were adequately prepared for each role, and transition between the two roles was anticipated and planned for. Rural palliative care nurses do not always feel adequately prepared for the roles they are required to fulfill, therefore the transition would be expected to be stressful at times. Rural palliative care nurses need to be aware of the potential for occupational stress and burnout, and options that may lessen the impact of their stressful role require examination.

In summary, the clinical issues that have arisen from the study are the need for adequate preparation and ongoing education to be able to fulfill the role of palliative care specialist, and the need for rural palliative care nurses to practice self care techniques to minimise the stressful aspects of their role.

### **Recommendations**

This section presents recommendations for research, education, administration, and practice related to palliative care.

### **Research**

This study has underscored the need for more research to be conducted that studies issues related to rural palliative care nursing. A study which extends the conceptual framework developed in this study would provide further insight into the problems inherent in rural palliative care practice. Further research into the relationships between the central theme and associated categories developed in this study would provide information that can be used to improve the quality of palliative care services offered in rural Western Australia, and assist in developing the role of rural palliative care nurses as service providers. A more extensive grounded theory study with more complete theoretical sampling techniques may offer greater insight into these areas. Furthermore, research into palliative care nursing practice in differing rural locations may provide information about the effects of isolation on rural palliative care nurses. While there was some suggestion from this study that isolated rural palliative care nurses encounter more difficulty accessing educational and support facilities, this was not fully investigated. Research that examines the social costs of rural palliative care nursing, and stress and burnout among this group of nurses may offer insights into methods of assisting sole practitioners to cope effectively with the stresses associated with their unique place in the health care system.

### **Education**

This research underscores the need for education in rural areas that addresses the specific needs of rural palliative care nurses. Although the nurses

that participated in this study stated that the educational opportunities they have had access to in their locality to date has been excellent, their specialist role demands increasing clinical knowledge so that they continue to provide consultative services when required. The focus of the education needs to take the expanded role of rural palliative care nurses into account. Education on areas such as business planning, budget management, human resource management and writing grant submissions would better equip these nurses to fulfill all components of their professional role. Furthermore, the lone practitioner status of many of these nurses suggests that education regarding appropriate coping strategies, including self care techniques and reflective practice may offer some benefits.

There is a need for more funding to be made available for rural palliative care nurses to access education. The 1997-1998 budget statement allocated funds for palliative care education to be made available for rural General Practitioners (CDHFS, 1998b). However, the findings of this research suggest that rural palliative care nurses often take on a specialist consultancy role in the community, providing assistance to General Practitioners. Therefore it is necessary, in recognition of this role, that funding also be made available to upgrade the education offered to rural palliative care nurses.

### **Administration**

This study has demonstrated a need for administrators and health services managers to be fully conversant with the rural palliative care nurse role.

Recognition by these groups of the demands of a specialist palliative care role

would be beneficial if the stress associated with the multifaceted palliative care nurse role is to be alleviated to some degree. Education for administrative staff of specific management issues associated with rural palliative care practice may prove beneficial.

### **Clinical Practice**

Findings of this research have highlighted several issues related to rural palliative care practice. Firstly, there appears to be a need for a formalised support network to be introduced, to assist beginning rural palliative care nurses in their specialist role. Networking between rural palliative care services would be beneficial, and could perhaps be arranged through the state palliative care association. A mentoring arrangement between rural palliative care practitioners and metropolitan based palliative care services may also be beneficial. Although rural palliative care nurses currently access metropolitan services for advice if required, it is an ad hoc arrangement which can leave the rural practitioners feeling isolated. A more structured relationship may facilitate increased communication between rural and metropolitan palliative care services, thus providing much needed support for sole practitioners in rural areas, and facilitating improved clinical decision making.

### **Conclusion**

This thesis has presented the findings of a modified grounded theory study of rural palliative care nursing in Western Australia. A central theme *Living Palliative Care* was developed from the data, and details the all-encompassing

nature of the rural palliative care nurses' role. Three categories were developed within that theme. Firstly, the category of *Wearing Many Hats* describes the multifaceted nature of the rural palliative care nurse role. The category of *Being the Expert* discusses the expectation that the rural palliative care nurse is an expert in the field of palliative care, and will offer consultative services to others as required. Finally, the category of *Surviving in Palliative Care* describes coping strategies adopted by rural palliative care nurses, and examines the rewards and sustaining moments in the rural palliative care nurses professional role. The findings of this study have been discussed with relation to other literature, and recommendations for nursing education, practice, administration and research have been offered. The findings of this research have begun to develop theory in the area of rural palliative care nursing. Further research is required to build upon the conceptual framework that was developed from this research.

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**APPENDIX A**  
**Letter of Introduction**



Ruth M<sup>c</sup>Conigley  
13 Clifton Crescent  
PINJARRA WA 6208  
Ph. 08 9531 2678

DATE

Dear .....

I am a registered nurse, currently working at Murray District Hospital, in Pinjarra. My experiences of hospice nursing in country Western Australia have been vastly different from time spent working in Perth as a hospice nurse. I am currently undertaking a Master's Degree in Nursing from Edith Cowan University, and have elected to conduct a research project on the experiences of other rural palliative care nurses. The aim of the study is to highlight issues that you believe have relevance to your clinical practice, and to make rural palliative care nurses more visible as a group. It is hoped that this research may begin to impact on some of the difficulties you face in your professional role, by encouraging others to continue to research this area, and by making planners, funders and educators more aware of your role in rural communities.

I would like to invite you to participate in this research project. In order to contribute to this research, you will be asked to take part in an informal interview, approximately 1<sup>1</sup>/<sub>2</sub> hours long. I would also like to spend one or two days with you at work, to observe your palliative care service. Times for the interview and observation period will be arranged for your convenience.

All possible attempts will be made to guarantee your confidentiality. No names will be printed in the final thesis, and all raw data will be seen only by myself and my university supervisors, Professor Linda Kristjanson and Mr Adrian Morgan. You will be given the option of reviewing the transcript of your interview and you may request that any data supplied by you be removed if you

are not happy with it. You are also free to leave the study at any time, and all information you have provided will be destroyed.

If you would like to participate in this study, please sign the consent form below and return it to the address above. Alternatively, I can be contacted by telephone as above, or via email <xcvwsd@echidna.stu.cowan.edu.au>. If you have any future queries, please do not hesitate to contact me.

Yours sincerely,

Ruth M<sup>c</sup>Conigley.

.....

I, ....., hereby agree to participate in the study of rural palliative care nursing as outlined above. I agree that I have read and understood the outline of the study. I understand that the study may be published, but that my name will not be associated with the research.

Signature.....

Date.....

Contact phone number.....

**APPENDIX B**  
**Fieldnote Guide**

## **Fieldnote Guide**

This guide was used when writing fieldnotes during participant observation sessions. It was intended as a guide only.

### **Physical Environment**

- describe town
- describe buildings/office/patient care area etc.

### **Social Environment**

- describe palliative care team (members, structure)
- describe groups/ subgroups which are concerned
- describe characteristics of participants, & relevant team members
- examine interaction pattern within team
- examine communication pattern within team
- examine decision making process (who, how, why)
- find out history of palliative care role
- describe planned activities (meetings, classes, support groups)
- describe unplanned activities (informal teaching, socialising etc.)
- examine relevant documentation
- are there any obvious omissions in palliative care nurse role?

Developed from Patton (1990, pp. 216-219).

**APPENDIX C**  
**Interview Guide**

## **Interview Guide**

This interview guide was developed to offer some structure to what were otherwise informal interviews. The questions are deliberately broad, so that the words of the participants guide the direction of the interview.

1. What led you to become a palliative care nurse?
  - How did you get started?
  - Was it a formalised role?
  - Were you the only palliative care nurse here?
  - Did you chose this role, or is it part of your job?
2. How did your role develop?
3. What are your goals as a palliative care nurse?
  - Are they being met?
4. What are your goals as a service/programme?
  - Are they being met?
5. Palliative care is renowned for promoting an interdisciplinary team approach to care provision. Could you describe your team for me.
  - What are it's strengths?
  - What are it's weaknesses?
  - What would you like to improve about your team?
6. What part of your role has been most rewarding?
  - Can you describe a particularly good experience for me?
7. What part of your role has been most difficult or demanding?
  - Can you describe a particularly difficult time for me?

**What keeps you going when things are difficult?**

8. Are there any things which you feel may improve your role, or make it easier?
9. Are there any other areas which you would like to comment on?

**APPENDIX D**

**Letter For Verification Of Data**



**Ruth McConigley**  
13 Clifton Cres  
PINJARRA WA 6208

DATE

Dear.....,

Thank you for participating in my research project looking at rural palliative care nursing in Western Australia. I am now reaching the conclusion of the project, and have completed analysing all of the information that I obtained.

So that I can be sure that the findings of my research truly reflect the role that you have as a rural palliative care nurse, I would be grateful if you could examine the attached table relating to the findings of this study. The table presents the central theme and associated categories found in the data, and is used to form a theoretical framework about rural palliative care nursing. The information presented should represent what you see as the fundamental aspects of your professional role. However, please be aware that because other nurses also contributed to this study some of the themes may not be wholly representative of your ideas.

I would be very interested in hearing any comments or suggestions you may have relating to the themes presented in the table. I can be contacted by phone, fax or mail as above, or by email <xcvwsd@echidna.stu.cowan.edu.au>.

Again, many thanks for your contribution to this project, and I look forward to hearing from you.

Yours sincerely,

**Ruth McConigley.**