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**An investigation of palliative care nurses’  
perceptions and views of an extended  
hours community nursing service at the  
Northern Adelaide Palliative Service.**

Jane Grigson NPC

School of Nursing

The University of Adelaide

December 2014

## Table of Contents

<b>Index of Figures .....</b>	<b>iv</b>
<b>Index of Tables.....</b>	<b>iv</b>
<b>Signed Statement.....</b>	<b>vii</b>
<b>Acknowledgement.....</b>	<b>viii</b>
<b>Abstract.....</b>	<b>v</b>
<b>Chapter 1 Introduction.....</b>	<b>1</b>
Introduction.....	1
Background.....	2
Outline of the Study.....	5
Summary.....	6
<b>Chapter 2 Literature Review.....</b>	<b>7</b>
Introduction.....	7
Data bases and time span.....	7
Search Terms.....	8
Palliative Care.....	8
Description of models of care.....	15
Extended hours palliative care community services.....	26
Common Themes.....	34
The Australian Experience.....	35
Summary.....	41

<b>Chapter 3 Methodology.....</b>	<b>42</b>
Introduction.....	42
Purpose of this study.....	42
Quantitative versus qualitative? .....	43
Qualitative Foundation.....	44
Theoretical Perspective.....	45
Research Approach.....	46
Phenomenology.....	47
Grounded Theory.....	48
Ethnography.....	49
Summary.....	51
<b>Chapter 4 Methods.....</b>	<b>52</b>
Introduction.....	52
Design.....	52
Qualitative Data.....	52
Analysis of calls received.....	54
Setting.....	55
Study sample.....	56
Inclusion/exclusion criteria.....	56
Ethical considerations.....	56
Data Collection.....	59
The interview.....	59
Analysis of after-hours calls.....	60
Pilot Interview.....	61
Data Analysis.....	62

Issues of reliability and validity.....	63
Role of the Researcher.....	64
Summary.....	65
<b>Chapter 5 Results.....</b>	<b>67</b>
Introduction.....	67
Participant information and demographics.....	68
The interviews.....	68
Extended Hours of care- models identified.....	69
Extended Hours of care at NAPS- views, benefits and barriers.....	74
Current client group.....	77
The after-hours telephone calls.....	78
Summary.....	84
<b>Chapter 6 Discussion.....</b>	<b>86</b>
Introduction.....	86
Purpose of the study.....	86
Summary of the findings.....	87
The literature review.....	87
The interviews.....	90
The after-hours calls.....	91
Relationship between the literature review and data collected.....	92
Implications for practice.....	94
Study limitations and suggestions for further investigation.....	95
Reflections on the Research Process.....	97

Conclusion.....	98
<b>References.....</b>	<b>99</b>
<b>Appendix 1.....</b>	<b>105</b>
<b>Appendix 2.....</b>	<b>106</b>
<b>Appendix 3.....</b>	<b>107</b>

**Index of Tables**

Table 1 An overview of some differences in three methodologies.....	50
Table 2 Number of calls received versus reason for call.....	79

**Index of Figures**

Figure 1 Total number of calls received by time of day over a 30 day day period.....	80
Figure 2 Total number of calls received versus day of the week over a 30 day period .....	81
Figure 3 Total calls by symptom versus calls by symptom that CPC could respond to over a 30 day period.....	82
Figure 4 Total calls received versus calls CPC could answer by day of the week over a 30 day period.....	83
Figure 5 Total calls received versus calls that could be answered by the CPC by time call received over a 30 day period.....	84

## **Abstract**

### **Background**

Palliative care as a health specialty has undergone dramatic growth across the globe since the 1960's. With this growth has come an array of service models, providing palliative care in a variety of ways. The situation in Australia is no different, and the inequity of access to palliative care has been noted at both a commonwealth and state government level.

### **Purpose**

This study investigated the perceptions and views of the nurses into an extended hour's community nursing service at Northern Adelaide Palliative Service. The data obtained was intended to identify if there was any perceived need for a change in service delivery and any potential benefits to the current client group.

### **Methods**

This is a mixed method study, combining the collection of qualitative data from the current nursing staff and an analysis of the after-hours telephone calls to the service. Nursing staff were interviewed individually using a semi-structured approach. Telephone data reviewed was information already collected by Northern Adelaide Palliative Service, and all data was de-identified prior to review.

## **Results**

Data gathered from the interviews revealed that whilst there was support for the concept of an extended hour's community service in general, this support did not translate to the local setting. A lack of consensus existed between current nurses of Northern Adelaide Palliative Care Service in relation to both the need for an extended hour's service and the potential benefits to the current client group. The telephone data identified that nearly a third of all calls received could have been responded to by a nurse, with the majority of these calls being received after eight in the morning until ten at night.

## **Conclusion**

Overall the data obtained is not convincing in indicating either a desire or need for an extended hours community nursing service at Northern Adelaide Palliative Service. Despite this the management and care of the palliative patient in the after-hours period continues to be an area of concern. It would be beneficial to collect additional data from all users of the service to obtain their view on the effectiveness and accessibility of the service.

## **Signed Statement**

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution.

To the best of my knowledge, this work contains no material previously published or written by any other person, except where referenced within the text.

I consent to this copy of my thesis when deposited in the School of Nursing Library, being available for loan and photocopying.

Jane Grigson



## **Acknowledgement**

This thesis would not have been possible without the support and encouragement of many people and I would like to sincerely thank everyone who has encouraged me throughout my Masters study programme.

To my supervisors Dr Kate Cameron and Visiting Associate Professor Gillian Harvey, I am immensely grateful for your time and assistance throughout this year. You have provided me with advice, guidance and encouragement, and all with unerring tolerance and good humour.

To my work colleagues, nursing, medical and administrative, I say “thank you”. To those nursing staff who agreed to participate, your time and your honesty in discussion was greatly appreciated. To the medical staff who allowed me access to certain statistical data, thank you. To Nikki, who guided me through the use of technology I was unfamiliar with, I am in awe of your patience. I would particularly like to thank my medical supervisors, Dr. Lawrie Palmer, Dr. Teena Silakong and Dr. Mil Chan for their ongoing support and education.

To my family and friends who have encouraged me in my study over these past three years I am sincerely grateful. For listening to my concerns, and then offering the support and encouragement that helped me to continue I particularly wish to thank Sue and Jean.

# **Chapter 1. Introduction**

## **Introduction and context**

This thesis is the result of a mixed methods study to investigate the perceptions and views of current community nurses to an extended hour's community nursing service at Northern Adelaide Palliative Service (NAPS). It also seeks to satisfy the thesis requirement for the Master of Nurse Practitioner degree.

A single site study, this project has been conducted at the Modbury Hospital where the current community Clinical Practice Consultants (CPCs) in palliative care are located. The community service provided by NAPS consists of a multi-disciplinary team approach to care involving doctors, nurses, physiotherapist, occupational therapist and social workers to address all patient and carer needs. All members of the team are available to visit patients and carers in their home environment, but this service is currently only provided from Monday to Friday between 8.00 in the morning and 4.30 in the afternoon.

The role of the CPC as the primary care provider is predominantly one of care co-ordination and liaison with external health providers including the patients' general practitioner. On acceptance into NAPS, the CPC is usually responsible for the initial assessment and care planning of the patient. This process may involve referral to other members of the NAPS team depending on the individual need of the patient. The CPC will

also provide advice on symptom management and is the primary contact for the patient or carer if they call the NAPS office during business hours.

This chapter will introduce the study and provide an overview of the following chapters.

## **Background**

The modern palliative care movement is credited to the work undertaken by Dame Cicely Saunders in the United Kingdom during the 1960's, with her ideas to incorporate research and education into the care of the dying patient (Twycross, 2007). More than half a century on, palliative care has continued to evolve and grow across the globe, and is provided in a variety of settings by many different service models.

Within Australia the growth of the palliative care services has extended across the country, but the access to services for all is not equal with limited services available to those in rural areas for example (SA Health, 2007; SA Health 2009). Similarly the service models of care vary widely throughout the nation, with services generally having been developed based on local needs and available resources.

These inequities have been reviewed by governments at both a commonwealth and state level, and have prompted calls for equity of access to palliative care for all. Palliative Care Australia, the peak national organisation representing all whose ideal is to promote and foster quality end of life care, has also raised the issue of inequity of access and service provision. (Palliative Care Australia, 2005).

Following these reviews, there has been the development and distribution of plans for the future development of palliative care services that have included strategies for improving

equity of access to care, increasing community capacity to provide care and some standardisation of services provided(SA Health, 2007; SA Health, 2009; Palliative Care Australia, 2005).

Palliative Care Australia has also developed and promoted a set of standards for the provision of palliative care to assist in addressing some of these issues and provide benchmarks for the care provided by individual service providers (Palliative Care Australia 2003; Palliative Care Australia 2005).

In South Australia, the Health Care Plan 2007 – 2016 outlined the state government’s prediction that there would be increasing numbers of people requiring end of life care, and that this care would involve all areas of the health care system. The SA Health Palliative Care Services Plan 2009 – 2016 expands on this concept and proposes several changes to existing services to achieve this(SA Health 2007; SA Health 2009).

One of these changes outlined a consolidation of Palliative Care services across the Adelaide metropolitan region. This has resulted in three palliative care services across the metropolitan region – central, southern and northern. As per the SA Health Palliative Care Services Plan 2009 – 2016, each of these services is responsible for the provision of end of life care across a variety of settings including dedicated inpatient palliative care beds, in the community and also in a consultancy role. In addition, each metropolitan service has been allocated the responsibility for the provision of support to specific regional and rural areas within the state. The development of multi-disciplinary teams to optimise care and participation in research, education and quality activities were also integral to the implementation of the plan within each service (SA Health, 2009).

Despite calls for the standardisation of metropolitan services to ensure equity of access, there are many differences in the way each service in Adelaide operates. One such example of this is the provision of access to palliative care service after hours. After -hours are defined as weekdays 1630 – 0800, weekends and public holidays.

Prior to the integration of the Modbury and Lyell McEwin Palliative Care Services to form NAPS, after-hours calls for the Modbury service were handled initially by the nursing staff of the in-patient unit, who had access to the community nursing notes of patients within the service. Further referral to the Palliative Care consultant could be undertaken if required. Following the integration of the services and relocation of the NAPS community office, this system ceased.

At the present time in NAPS, the after-hours service is provided by the Palliative Care Registrars on a rotational basis, with a Palliative Care medical consultant available for additional support if required. Advice is provided to patients and/or their carer's by telephone only, with patients referred to the Emergency Department of the hospitals or the Emergency Care Paramedics (ECPs) for additional assessment or treatment if needed.

The purpose of this project is to investigate the perceptions and views of the current NAPS community Clinical Practice Consultants to an extended hour's community service. This information will provide insight into potential benefits and barriers to an extended hour's service from a nursing perspective. It will also help to obtain their views of any current patient need for a change in service delivery, and identify the possible benefits to their patient group of any such change. A 'snap-shot' focus of the current after-hours call system will provide data on the number and nature of after-hours calls received. Analysis of this

data will identify if the current system of requiring a Palliative Care Registrar to be the initial contact after-hours is necessary, or if there is a need for a review of the current model of service at NAPS.

## **Outline of the study**

This chapter has introduced the project, and provided a background to the development of palliative care services. It has outlined the purpose of the project.

In the second chapter, a literature review will be provided. This will discuss current literature in relation to palliative care, service models used, with a particular focus on extended hours services and the Australian experience.

Chapter three will describe the methodology and the reasons for the approach taken in undertaking this study. How this particular methodology is relevant to the study undertaken will also be discussed.

Chapter four will describe the methods used in this study, with information on participants and recruitment process clearly defined. It will also include discussion of ethical considerations and a description of the study setting.

The fifth chapter will detail the findings of the project, with a thematic analysis of the data collected from the participants. This will be reviewed in conjunction with themes identified from the literature review.

Chapter six will provide discussion on any findings of this project in relation to the possible perceived benefits or barriers to an extended hour's community nursing service at NAPS. The significance of this information and its relevance to current practice will be detailed, along with any limitations to this project and recommendations for further investigation.

## **Summary**

Palliative Care and the provision of care to patients has undergone many changes over the past half century. Historically, services developed locally and in response to regional needs, available resources and health professional interest. As public awareness of palliative care has grown, and with the acceptance of palliative care as an integral part of patient care has come a need to ensure that all have equal access to palliative services. The integration of metropolitan palliative services and the associated responsibilities of each service were initiated by the government to address some of the issues of access.

Differences between services and the models of service provided do however still exist. This study aims to look at the after-hours provision of care within palliative care and to investigate the views and perceptions of community nursing staff relating to an extended hours nursing service, and to evaluate the data collected to identify areas for further investigation.

## **Chapter 2. Literature Review**

### **Introduction.**

This chapter will review current research on service models of palliative care, in particular relating to the provision of after-hours care. An overview of palliative care generally and discussion of a variety of models used will first be provided, followed by a review of the literature relating to extended hours service models. Predominantly studies relating to community settings have been included. A discussion of the common themes identified in these papers will also be included, with a separate section on papers from Australia to follow.

The number of papers from Australia were limited, and no research on this area specific to Indigenous or culturally diverse groups was identified within this literature search. As paediatric palliative care is generally considered to be a separate specialty, no studies involving paediatrics have been included.

### **Databases and time span.**

A comprehensive search of electronic databases was undertaken. Databases accessed electronically included Cumulative Index of Nursing and Allied Health (CINAHL), Scopus, PubMed, Informit and Google Scholar.



While the initial search was restricted to the past ten years, due to the frequent citing of some articles and their relevance, these have been included despite being outside of the initial time constraint.

## **Search Terms**

The key search terms used were palliative care, hospice, end-of-life care, community nursing, after-hours care, extended hours of care, service models and models of care. These terms were used both singly and in combination. Only articles written in English were included, and further selection was based on their relevance to the project.

## **Palliative Care**

From the beginnings of the modern hospice movement with Dame Cicely Saunders in 1967 to recent times, palliative care has grown to achieve specialty status in several countries across the globe. It has evolved from caring only for the inpatient with terminal cancer to include caring for people with end-stage progressive disease, and across a variety of settings. Yet despite this growth and development, Twycross (2007, p. 8) believes that palliative care is still in its infancy and describes the following issues:

“The provision of palliative care is still patchy;  
It is not available for most of those who need it;  
It is not fully accepted by the medical profession in most countries;  
It is not a core component of most national health systems”.

These issues of inequity of access to services, and the general availability of palliative care services to those in need, along with issues of recognition of the specialty by both other professionals and funding models are echoed by others.

The National Palliative Care Consensus Statement( Palliative Care Australia, 2011) highlights these issues in identifying the priorities and goals which include all Australians having access to the necessary resources and equitable access to palliative care, calling for government( both state and federal) to support palliative care through funding and legislation and an acknowledgement of the need for education and research to be an integral part of the provision and promotion of palliative care in Australia. In addition to this statement, Palliative Care Australia also developed and promoted a set of Standards for the provision of palliative care to all Australians. These were developed “to support and enhance quality of care for patients with a life limiting illness their families and carers” (Palliative Care Australia, 2005, p. 3).

In the United Kingdom, the National Gold Standards Framework (GSF) Centre is the national training and coordinating centre in the provision of end of life care. The GSF offers a variety of training programmes across a range of settings and health disciplines to optimise the care of people nearing the end of their life. Other strategies employed include the provision of tools, support for staff and active involvement in national policy development involving end of life care. The main aims are to improve care quality through workforce education, co-ordination and communication from one care setting to another and outcomes of care by allowing people to die in their place of choice and reducing inappropriate hospitalization (Thomas & Free, 2006).

In addition to their training programmes, the GSF have the “seven Cs of the GSF” which are:

“C1 – Communication

C2 – Co-ordination

C3 – Control of symptoms

C4 – Continuity of care

C5 – Continued learning

C6 – Carer support

C7 – Care in the dying phase” (Thomas and Free, 2006, p.34)

The issue of communication, both between patient and health professionals as well as between health professionals themselves, co-ordination of care between services and promotion of continuity of care along with education for patients, carers and health professionals are integral to the provision of good palliative care.

Whilst it is acknowledged that there is a need for specialty palliative care services, in the United Kingdom, there is strong encouragement for the care to be provided by the General Practitioner (Thomas and Free, 2006). Bestall et al (2004, p. 381) found that while some referral to specialty services did occur, it was not standardized in terms of referral procedure or criteria, and that additional resources were required to provide training, and to support patients at home. In addition, one of the key points demonstrated was that “...palliative care in the UK is not equitable for all”.

In a study reviewing UK palliative care providers about factors influencing place of death, Thomas (2006) identified 5 major factors which included:

- service infrastructure – related to concerns of budget, funding , policy and availability of 24 hour services, and
- cultures of practice – the patterns of referral and collaborative arrangements between specialty palliative care services and the General Practitioner.

Whilst a study of small numbers and of a single geographical location, the study supports the notion that access to palliative care is not equitable to all, and that policy and budgetary issues along with the level of education and training of health professionals remain concerns.

The need for the development of palliative care services within the realm of primary care is highlighted by Murray et al. (2004). As primary care teams often have long-standing relationships with patients and carers, particularly for those with chronic diseases, these teams are well placed to discuss issues relating to goals of care and to identify emotional distress as it arises. As Murray et al. (2004) concludes;

“General Practitioners and community nurses are trusted by patients and are in a position to provide effective, equitable and accessible palliative care. This will happen only if they have adequate time and resources and work in a system that encourages such care” (Murray et al., 2004, p.1057).

In contrast, a systematic review by Finlay et al (2002) of palliative care across a variety of settings within the United Kingdom found that there did “not appear to be any major difference between city, urban and rural areas”(Finlay et al. , 2002, p.263). This conclusion is offered with a caution due to variations in outcomes measured, varied interventions offered by services, and that many studies reviewed were considered to be of poor quality.

A stated consistent effect of palliative care involvement was the noted increase in levels of satisfaction of care expressed by both carers and patients across a variety of care settings.

End-of-life care in the United States experiences some of the same issues as identified in the United Kingdom. Over the past forty years, there has been rapid growth in the development of palliative care as a specialty, and a variety of hospice and palliative care programmes are in existence across America in many settings (Giovanni, 2012). Weiner and Tilly (2003, p.1) describe the provision of end-of-life care in America as “fragmented and uncoordinated, with little integration of medical and long-term services”. Whilst there is an acknowledgement of the growth of services due to the efforts of the palliative care professionals, it is noted that “this effort must continue to expand in order to reduce access disparities across the nation” (Giovanni, 2012, p.125).

Geographical location influenced numbers of hospitalisations, while the nature of the inpatient facility had an influence on the length of stay, treatments received and transfers to hospice services. Poorly defined standards of quality and reduced numbers of healthcare professionals working in palliative care or hospice care in rural areas particularly created additional problems for patients. The issues of public policy, funding measures and education and support for health professionals are also common with the United States (Giovanni 2012).

There was some discussion that changes in the education of nurses in the United States could be utilised to address some of the problems by educating about system and policy changes along with end-of-life care interventions and communication skills (Giovanni 2012; Reinke et al. 2010; Wittenberg-Lyles et al. 2011).

Weiner and Tilly (2003) believe that a five –part strategy is required to aid in improving quality of care at end-of-life in the United States. These strategies include:

- gathering accurate data on cause and location of death, utilization and cost of services, and the variations by patient. This data would help to inform policy makers on need and access to services;
- public involvement through discussion with health systems to allow for choice of providers and treatment;
- exploration by government officials of alternative funding measures for palliative care;
- examination of opportunities for improvement in care standards for those in nursing homes and community settings; and
- examining the current structure of the Medicare and Medicaid (the two main sources of funding for end-of-life care in the United States) benefits to review areas of eligibility criteria, rates of payment and quality improvement of care.

Once again, issues of policy, funding, education and the culture of practice are all seen within the realm of palliative care.

In an article on a hospital based consult palliative care service, strategies were implemented to develop and optimise a service at a not-for-profit health care system that serviced in excess of half a million patients each year. Over a five year period, the programme was planned, implemented and evaluated with the following five strategies being listed as key to its success:

- Planning;
- Education;
- Communication;
- Accessibility;
- Evaluation.

These strategies were employed on a local level and tailored to meet the needs of the health care system as the service evolved and grew. The success of the programme was measured by growth in services, both staffing numbers and referrals and patient numbers, along with satisfaction surveys of referrers and patient/families. Another measure of success was the cost savings attributed to elimination of unnecessary tests and services after patients were transferred to the care of the palliative care service (Radwany et al., 2009).

In a study from the Netherlands by De Korte-Verhoef et al. (2012), a retrospective chart study was undertaken over a twelve month period. This paper looked at out-of-hours referrals by general practitioners to hospitals for patients at end- of life. Specifically related to palliative care, the patients were all located in the community setting. De Korte-Verhoef et al. found that whilst the general practitioner was traditionally the key person to provide end-of-life care in the community, the past twenty years had seen a change. With the decreasing availability of the general practitioner out-of-hours patients were now more likely to be seen by a locum. This had the impact of interrupting the continuity of care for the patient with a negative effect on issues such as symptom management, patient treatment goals and wishes regarding place of care and death. As a result, many patients were referred to hospital and often admitted, despite their preferred wish to be cared for at home. The lack of communicating this type of information to the locum service was cited as the major

reason for the loss of continuity of care. It was noted that those patients who were receiving professional nursing care or whose general practitioner had communicated the relevant information to the out- of -hours service were significantly less likely to be referred to a hospital (De Korte-Verhoef et al., 2012).

The literature reviewed above has shown that there are some common areas of concern in the provision of palliative care irrespective of what country the care is being provided in. Issues of communication, continuity of care and ongoing education and support for both palliative care specialist professionals and primary carers are all areas that need to be considered. Additionally, the increasing cost of healthcare generally has forced governments and health insurance companies to consider what is the most cost effective method of providing the required care. This includes palliative care. These issues have led to some palliative care services examining the service model that is utilized to provide the optimal care for the patient, and some of these will now be discussed.

### **Description of models of care**

Historically palliative care services evolved regionally and the model of service that was used was dependent upon the availability of qualified health professionals and their preferences. The growth of palliative care as a specialty and the increasing public awareness of palliative care and corresponding demand for services, along with financial considerations have led to some changes in the manner in which care is delivered.

In recent times in the United Kingdom there have been several documents produced discussing palliative care , the expectations of health professionals working in palliative



care and the manner in which palliative care should be delivered. The National Health Service(NHS) Cancer Plan (DoH, 2000) and The National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) make statements about the need for palliative care to be available to patients throughout their illness and across all healthcare settings, while the Draft National Plan and Strategic Framework for Palliative Care: 2000-2005(NCHSPCS 2000) discussed the inequities in accessibility to service, place of care, flexibility of services and the need for the development of partnerships between healthcare professionals and services to optimise individual patient care. A statement produced by the Royal College of Nursing (RCN) in 2003 highlighted the expectation for specialist nurses in palliative care to promote and develop specialist palliative care across all health settings (RCN, 2003). The National Institute for Clinical Excellence (NICE) has highlighted the need for collaboration between specialist and generalist health care providers to optimise patient care and access to services, and promoted education across all levels of staff (NICE, 2004).

Despite the publication of such statements there remains a variety of models providing palliative care within the United Kingdom. Many patients still remain within the acute care setting or the hospice environment, despite the evidence that there is an increasing desire for patients to have their care provided at home (O'Brien and Jack, 2010). Factors that can influence place of care or death include the availability of healthcare resources, inability of the carer to cope, poor symptom management and unmet nursing needs (O'Brien and Jack, 2010). The acute care or hospice inpatient models will not be discussed in this literature review. Rather, a review of some of the community/home-care models will occur.

A paper by Dodd et al. (2011) discussed an integrated case management approach to providing care closer to home. Whilst not specifically for the palliative patient, it focused on adult patients with complex care needs that were experiencing an acute health crisis, and patients requiring end-of-life care were included in this paper. These patients had been identified as “particularly vulnerable to poor standards of care, poor communication between health and social care agencies” (Dodd et al. 2011, p. 96), as well as often experiencing difficulties in transitioning between healthcare services.

The aim of the project was to reduce or prevent hospitalisation for these patients, and if hospitalization was unavoidable, to facilitate discharge. A multidisciplinary complex care team was developed which included nursing, medical, allied health and administrative staff. A case manager was appointed whose role was to oversee the team, manage budgets and coordinate the activities of the team. Close liaison was established with a variety of healthcare workers and facilities including general practitioners, local hospitals, local voluntary/charity organisations, district nurses and local residential care homes to name a few.

The principle behind the team was for the identification of patients at risk or in crisis and to coordinate the appropriate services and resources to prevent hospitalization where possible. In the management of end-of-life care, the team role was to work with the patient and carer to facilitate care at the place of the patient’s choice (Dodd et al. 2011).

While the team was meant to provide a rapid response to acute situations that arose, the small size of the team meant that they were unable to offer a twenty-four hour service or to cover weekends. Despite this, patient and carer satisfaction surveys were positive in their

comments of the interventions of the team and the support that was provided. A key factor in the success of this programme was the development of collaborative working relationships with other healthcare professionals and agencies, and maintaining good communication about patient needs (Dodd et al. 2011).

Alsop (2010) describes another collaborative approach from the United Kingdom involving community nurse specialists in palliative care. Employed by the Hospice, their role was to support the patient and carer at home. In this project, community nurse specialists were involved with the primary health care team. A particular focus for this project was to assist with the management of the patient with a chronic illness, prevention of unnecessary hospitalisation, and end-of-life care coordination (Alsop, 2010).

Integral to the success of this project was the education of primary care health staff provided by the community nurse specialist. The education sessions served as an opportunity to establish networks and share experiences, as well as provide education about palliative care, symptom management and the roles of different health care professionals. In addition to this, palliative care pathways were established that provided clear information for the primary health care team on needs assessment for the patient and carer, and provided some guidance about the need for referral to specialist services. Feedback from primary health care workers indicated that they felt well supported by specialist teams, had increased knowledge of how to plan care for patients and have discussions with other professionals as needed. It also clarified that non-cancer patients were appropriate to refer to specialist palliative care services which has improved equity of access to palliative services in this region (Alsop, 2010).

In addition to the development of pathways for patients at end-of-life, it was identified by Jackson and Dixon (2012) that the development of carer pathways could be implemented to improve service delivery. The purpose of the carer pathway to be used concurrently with a patient pathway was “to achieve integrated care for carers and patients” (Jackson and Dixon 2012, p22).

The carer pathway was determined after discussion with the carer about the timing, the manner and the location of support needed. A carer support worker was appointed to individual carers, allowing for the building of a trusting and supportive relationship that could cross healthcare setting boundaries if needed, and that extended into the bereavement phase as required. This support worker was also able to advocate for the carer with other healthcare professionals as required (Jackson and Dixon, 2012). Communicating and including the carer in planning at end-of-life is congruent with the holistic nature of palliative care.

Another model from the United Kingdom described by Sharp and Oldham in 2004, involved the establishment of a nurse-led palliative outreach service. Two nurse practitioners developed an outreach community service that supported ten community hospitals. The role of the nurse practitioners was to respond to referrals for specialist palliative care, the provision of education to the multidisciplinary team and involvement in clinics for breathlessness and pain management. Education was provided to various levels of health care staff and based upon a needs analysis. Ongoing monthly education sessions were provided and were favorably received. The support role in the hospitals was focused on supporting patients and families, along with collaborative management with the primary care team. A satisfaction questionnaire was sent to all staff who had utilized the service and

the results were positive and utilised in future planning and prioritization, though response rates were low (Sharp and Oldham, 2004).

In a paper on palliative care in the community, Hardy (2011) discusses the need for the appointment of a coordinator of care. Palliative patients (and their families) are often confused due to the variety of services and people they have encountered in their illness trajectory. Different health professionals, different roles, different hours of work and different contact details make a confusing maze to be worked through.

Hardy refers to the 2011 Palliative Care Funding Review and its suggestion that:

“a core element of good palliative care services should be that someone coordinates the care of the patient, a complex and multifaceted role that would work across organizational boundaries” (Hardy 2011, p.574).

It is acknowledged that whilst this role would be beneficial to patients and families, it would only be valuable if it is accepted by all relevant stakeholders in the provision of care.

In the United States, palliative care is described as “a field of medicine aimed at alleviating the suffering of patients” (Labson et al. 2013, p.e-S30), whatever their location, stage of disease or age. Hospice care however “is defined by the provision of palliative care for patients at the end of life” (Labson et al. 2013, p. e-S30).

Funding for end-of-life care , the Hospice benefit, as provided by Medicare is payable only for care that is for comfort( NOT curative), is provided by a Hospice programme, and have a signed statement from a doctor or hospice medical director certifying they have less than 6 months to live. Due to the restrictive nature of this benefit, it was identified that many patients had unmet needs, due to their life expectancy or choice of treatment regimes. Palliative care can be provided from a variety of settings including hospitals, nursing

homes and home health agencies. One such home-health based service described by Labson et al. (2013) is Kaiser Permanente's In-Home Palliative Care Program. Criteria for referral were similar to a hospice programme but included the following differences:

- a prognosis of twelve(12)months or less;
- not necessary to forgo curative treatment.

The five key elements of this programme are:

- A multidisciplinary approach;
- Care coordinated by a palliative care physician;
- Home visits by all team members;
- Assistance with Advance Care Planning ;and
- After-hours home visits, seven (7) days a week if required.

(Labson et al. 2013)

Another home care service model providing palliative care is Advanced Illness Management (AIM) from Sutter Health. This programme offers palliative care to patients with a longer prognosis, and without the need to cease all curative treatment. The programme provided ongoing symptom management, assistance with Advance Care Planning, goal management and coordination of care between health services and providers, including the dissemination of appropriate information. The formation of multidisciplinary teams that include representatives from the home, hospital and other agencies involved in care have provided an integrated approach to patient care(Labson et al. 2013).

Both of these models incorporate an holistic approach to care, involving a variety of health care professionals who work collaboratively, and involve the patient and family in decisions including treatment choices and care location. Success was measured in terms of patient satisfaction with care, home deaths achieved, reduced hospitalisation and presentations to emergency departments and overall reduced costs of care. In all instances, both services had significantly better results than other health care services (Labson et al. 2013).

In a paper on improving outcomes and lowering costs of in-home care, Boling et al. (2013) describes the need to embrace modern technology to expand the care that can be provided within the home environment. The use of telemedicine is cited as an example. Boling et al. (2013) also emphasizes the value of the multidisciplinary team approach and strong collaboration between specialist services and the primary health care team. Supply and fitting of home modifications, and ongoing nursing care, respite services and home rehabilitation are also listed as beneficial to promoting home care. Whilst the article refers to care of the geriatric patient predominantly, in discussion of the palliative care patient, most of the concepts remain valid. In addition, Boling et al. (2013) describe the home setting as more conducive to end-of-life discussions and the building of a trusting relationship.

In Canada a project was undertaken to improve continuity of care for the palliative patient and to reduce the variation in palliative care provided to the cancer patient. This followed the identification of gaps in such areas as symptom management, poor communication and coordination between professionals and services, lack of awareness, underutilisation or inappropriate use of current resources and services. This project, the Palliative Care

Integration Project (PCIP) is the subject of the paper by Dudgeon et al. (2009) and involved more than thirty organisations. This project did not seek to establish a new service model, but rather to optimise the existing services.

The steps for achieving this included the integration of care delivery across a variety of health care settings, the adoption of recognised standardised assessment tools across services and health settings, education across all services and for all levels of health professional to promote a standardised approach and treatment regime, and ongoing communication and collaboration between health services, primary care health workers, patients and families (Dudgeon et al., 2009).

Two other Canadian papers discuss the shared care model of palliative care in the community. Marshall et al. (2008) identified gaps in current practice which included:

- Access issues relating to variable patient access to services, poor integration of services, and lack of accessibility to specialist services for physicians;
- Assessment issues relating to appropriate tools for use in assessment and care management;
- Care issues relating to lack of appropriately skilled staff, lack of respite service, and poor communication between services; and
- Education and decision support issues to allow for best practice skills, knowledge and behaviors in palliative care to be implemented, lack of opportunities for continuing education and mentorship and development of palliative care ‘champions’ within the primary care service.



A program was developed and implemented over a fifteen month period during which these areas were addressed. A multidisciplinary integrated team that included a palliative care medical specialist, a palliative care advanced practice nurse, bereavement counsellor, psycho-spiritual advisor and case manager were developed. Medical and nursing members of the team participated in an on-call roster to be available to the community doctors and nurses twenty-four hours per day, seven days a week. All members of the team assisted in the provision of education to the community doctors and nurses to promote their knowledge of palliative care. A screening system of patients was established and standardised to promote timely referral to the shared care team, and joint consultations were undertaken. Care plans for patients were prepared in collaboration with the specialist team and community staff as well as the patient and family, the family physician however remained the primary health care professional. Documentation detailing assessment and treatments, along with contact details for staff was prepared for the patient to take home (Marshall et al., 2008).

A high priority in this project was the need for continuous and coordinated communication between the specialist team and the family physician. Regular weekly meetings were scheduled to ensure all referred patients were discussed, in addition to communication of changes in health status, care needs and possible treatments as required (Marshall et al., 2008).

Education also was considered important to the success of this project as it allowed the family physician and community health workers to increase their knowledge of palliative care assessment and management. The subsequent growth in skills and confidence to

provide optimal care for the palliative patient was also a positive outcome identified (Marshall et al., 2008).

Evaluation of this project revealed that the family physician believed the most critical aspect of the project was the extended access to specialist palliative care expertise, followed by the education provided by the team.

Overall, they believed that:

“the project improved quality, communication, coordination, continuity and integration of care and allowed them to maintain their role as the primary care providers” (Marshall et al., 2008, p. 1703.e4).

Benefits for patients were listed as an improvement of care through the anticipation of increased needs, reduced anxiety, and the ability to remain at home for place of care.

De Miglio and Williams (2013) also discuss shared care models of palliative care. This paper addresses/highlights the need to maintain sustainability of a service in the face of increasing demand, budgetary constraints and workforce pressures. They describe shared care as existing when the specialist palliative care team (a minimum of a medical specialist, nurse and social worker with expertise) work in collaboration with the primary health care team of family physician and/or community nurses. Once again strategies of communication, education and resources were highlighted as pivotal to maintaining sustainability of a shared care model, and overall sustainability of a service (DeMiglio and Williams, 2013).

This paper also highlighted some areas of concern that impact upon the shared care model of community based palliative care to continue, despite evidence that such programmes

enhance care provided to patients and families. These concerns included the poor integration of health services across Canada, including hospitals, hospices, long-term care facilities and the home environment. Difficulties with funding and government policy around health care can also have a negative impact. Despite this, the writers remain optimistic that shared care models in community palliative care have the opportunity to succeed if primary care givers are encouraged and supported, and there is collaboration between health care providers (DeMiglio and Williams, 2013).

### **Extended hours palliative care community services**

In the literature review, several articles were found that focused on extended hours palliative services. The articles in this section relate to the experience in the United Kingdom, and offer insight into the issues around the development and the satisfaction of patients and health care professionals with such services.

Recent trends in health care in the United Kingdom include the transition from hospital to community – based care, with a particular emphasis on providing end-of-life care at home. To enable this change in care location to occur requires appropriately skilled healthcare professionals to work in the community to support patients and families (Gallagher, 2013). Many palliative care health professionals working hours were on a Monday to Friday basis, but as Rowlands et al. (2012, p. 24) states “Patients’ symptoms and needs do not diminish at weekends or on bank holidays, nor are medical emergencies any less likely”.

Gallagher (2013) supports this and comments that carers of patients may feel the most pressure in the out-of-hours period. A project on extending a community specialist palliative care service to a seven day service was undertaken. Following a survey of other UK specialist palliative care services and a literature search, interviews of the local district nurses were undertaken. As the district nurses already provided a 7 day service, their opinions were sought regarding any concerns they had with the provision of palliative care out-of-hours and their understanding of the role of the specialist palliative care team.

Issues identified during these interviews included lack of communication, continuity of care and confidence in the care provided. The lack of support from specialist palliative care nurses in out-of-hours periods was also highlighted and related predominantly to difficult symptom management in a patient. The experience of the out-of-hours general practitioner was also an influencing factor. The possibility of being able to receive support from a specialist palliative care nurse out-of-hours was welcomed by the district nurses (Gallagher, 2013).

In view of this, a trial of an extension to the existing service was commenced, with one Clinical Nurse Specialist (CNS) to be on duty in the extended times. This person was available to provide advice and support and a home visit could be provided if considered essential. Strict criteria were established for the out-of-hours role to ensure realistic expectations were set, and these detailed the referral and assessment procedures for both known and new patients (Gallagher, 2013).

Evaluated at regular intervals, the extension of the service across seven days proved successful. The increased availability of specialist palliative care staff improved continuity

of care for patients, and communication between health care professionals. Data collected from the use of the out-of-hours service was able to inform on areas of education. In addition, comments from the district nurses and general practitioners indicated that use of the extended service had assisted in reducing hospitalisation for some patients (Gallagher, 2013).

Rowlands et al. (2012) discuss an extended hours service that operates across seven days also. Located within a cancer centre it was initially proposed to cover twenty-four hours per day with a Clinical Nurse Specialist (CNS). This was modified to hours of 9am- 5pm, due to limited numbers of staff, prohibitive salary costs and specialist palliative medical advice already available 24 hours per day.

As only one CNS was rostered for this service, patients were prioritised. Known patients who were unstable, deteriorating or terminal were identified in normal hours and scheduled for review by the out-of –hours CNS. Liaison with senior inpatient staff by the CNS enabled identification of new patients in need of specialist palliative care review (Rowlands et al., 2013).

Evaluation of this service revealed that the service was well received by staff at the centre, with an increasing number of contacts being made. There was also utilisation of the extended hours CNS by the specialist palliative care team to perform weekend review of known patients of concern. Over a two year period collected data has shown that patient contacts on weekends continued to increase with the major reasons being symptom control, pain control( listed separately), and psychological support. Comments from the specialist palliative care team have indicated that the extension of the service has positively

influenced the practice of the team during standard hours. Staff have felt less pressure on Mondays and Fridays, and also some patient interventions requiring specialist review may now start on a Friday rather than the following Monday (Rowlands et al. 2013).

King, Thomas and Bell (2003) in their paper, review the impact of an out-of hours protocol for community palliative care. Whilst not an extended hours service as such, this protocol was designed to improve out-of-hours care for the palliative patient. Participants in evaluating this project included primary healthcare providers, including general practitioners and district nurses.

The protocol that had been introduced focused on the areas of communication, carer support, specialist medical advice and drugs and equipment, and was designed to provide guidance and service advice to the primary care team. Communication was via handover sheet which was completed with details of the patient, diagnosis and treatment. Faxed to the out-of -hours provider with a copy at the patient home this was intended to ensure current information was available at all times. Patients and families were also provided with comprehensive contact details of health professionals for after-hours emergencies (King, Thomas and Bell 2003).

Out-of-hours providers were able to contact the specialist palliative medical doctor twenty-four hours per day, seven days a week for advice on the telephone, and they were encouraged to use palliative care guidelines that were already available. Medical practitioners were also supplied with palliative care bags containing frequently used drugs and equipment that they could use when visiting a palliative patient. Carer support was

encouraged through the protocol, and practitioners were to assist in a coordinating role to arrange additional support as needed (King, Thomas and Bell 2003).

The evaluation of this project referred back to the four focus areas of communication, carer support, specialist medical advice, and drugs and equipment.

Communication was generally agreed to have been improved as a consequence of implementation of the handover form, but it was also felt that they were time-consuming to complete and difficult to maintain with current information due to the rapid changes that can occur in the palliative patient. Many participants also felt that the form prompted them to anticipate possible future care needs of the patient. Carer support was less positively evaluated, with many participants believing this area was neglected as the needs of the patients were considered the focus. Some nurses felt that the availability of emergency contact numbers to carers lessened anxiety and therefore provided additional support (King, Thomas and Bell 2003).

The availability of access to specialist palliative care advice was regarded as a positive by participants. Similarly, the palliative bags as supplied were found to be useful in ensuring appropriate medications and equipment was available when needed. Some district nurses believed the provision of these bags could be extended to their role, but due to the medications involved restrictions on personnel permitted to carry the bags applied (King, Thomas and Bell 2003).

Overall, this paper reports that the protocol had a positive impact on palliative care in the community, particularly in relation to improved communication, promotion of anticipating changing patient needs and improved access to drugs and equipment out-of-hours. The

authors advise that whilst this protocol is reflective of community palliative care in the United Kingdom, “the underlying problems that the protocol seeks to address, such as inter-agency communication, continuity of care, and the anxieties of unsupported carers, are likely to exist in any system” (King, Thomas and Bell 2003, p. 281).

Taubert and Nelson (2010) reviewed the issue of communication between in-hours and out-of-hours services. With changes to the provision of out-of-hours care across the United Kingdom in recent years, patients are now more likely to be serviced out-of-hours by distant emergency clinics or by telephone advice rather than their local general practice. In Wales, this practice exists, despite many recommendations and reports advising that palliative care should be “delivered by the General practitioner or District Nursing staff who have been sufficiently trained in palliative care” ( Taubert and Nelson, 2010).

In their paper, Taubert and Nelson (2010) identify the following areas of concern in relation to the palliative patient, as advised by the medical staff responsible for the out-of-hours system:

- Information exchange between in-hours and out-of-hours providers was described as problematic and insufficient in providing the relevant information to provide optimal care. This included both verbal and written information.
- Out-of-hours workloads were considered to be increased by the lack of planning by in-hours practitioners with regard to palliative care patients, their wishes for treatment and end-of-life choices.



- Continuity of care was cited as difficult due to the short shifts worked in out-of-hours, which caused problems for both patients and families as well as leaving the medical staff feeling less professionally satisfied.
- Obtaining specialist palliative care advice out-of-hours was variable, but it was clear that there was a lack of knowledge by the out-of-hours providers regarding the availability of this service and how to contact them.
- Language barriers were identified between some health professionals.
- Exchange of information within the out-of-hours service between different professionals, and also between doctors and nurses was also raised as an issue by some.
- The lack of accessibility to some specialised equipment and medications was also perceived as problematic.

Some of these issues identified are not dissimilar to those noted by Worth et al. (2006). In this paper, the views of the health professional and also patients and carers about out-of-hours care are discussed.

The decision by patients and/or carers to contact out-of-hours services was perceived as 'reluctantly made'. Their reasons for contacting included symptom management, advice and general support. A variety of factors could impact upon their decision to make contact including previous experience (either positive or negative) with the out-of-hours service, familiarity (or not) with the provider of the service, available contact information and language difficulties. For professionals, a lack of information from in-hours providers and poorly updated information made the provision and continuity of care difficult and more time consuming (Worth et al. 2006).

The varying availability of resources, including district nurse, medications and equipment were also listed as areas of concern that affected the ability of the out-of-hours service to provide good care for the palliative patient. A lack of social support services particularly in rural areas was raised as a concern and highlighted the inequity of service provision across a region. Whilst these issues are identified as barriers to the provision of effective out-of-hours palliative care, the paper also suggests that the potential for improvements exist with an expansion of the resources available to out-of-hours care, including nursing and supportive care (Worth et al. 2006).

Nyatanga (2013) in an article about the impact of out-of-hours service provision on end-of-life care also raises concerns about these services and their ability to provide the care needed for all who access them. Four Government recommendations relating to end-of-life care provision from 2011 are listed by Nyatanga, (2013, p.132) as:

- Access to end of life care by trained staff
- Advance care planning for identified patients
- Working together by professionals through care that is coordinated through multi-disciplinary teams
- Education, training and skills development for staff working in end-of-life settings

This paper asserts that despite these recommendations, the provision of out-of-hours care to palliative patients is sub-optimal. Medical professionals in the out-of-hours system are not confident and do not have sufficient skills to provide end-of-life care, and the lack of continuity caused by the current system, means they are unfamiliar with the patient, carer and treatment choices. This is a cause for additional anxiety amongst patients and carers.

Nyatanga(2013) believes that additional funding and training for out-of-hours staff in palliative care, communication and advance planning, and the ability to have multi-disciplinary teams assist in the provision of care are all measure that could be beneficial to the provision of palliative care out-of-hours (Nyatanga, 2013).

### **Common Themes**

Throughout the papers discussed above, common themes continue to emerge whether in relation to palliative care generally or the variety of service models that are available.

Similarly, these themes are generally consistent globally.

The five main themes identified were:

- Communication- whether this is between healthcare professionals or with patients and other support services, the need for clear effective and current communication was highlighted consistently as a major requirement of the provision of optimal palliative care.
- Co-ordination of care- the need to ensure the co-ordination of services and to ‘untangle’ the confusion of services and staff for patients and families is important to maintain effective and efficient care, and to reduce anxiety and stress for patients and their families.
- Continuity of care – this promotes patient and carer confidence in health care professionals and can be achieved either through the provision of regular, familiar personnel, or by ensuring all required information about patients care and wishes are clearly provided to alternative( or out-of-hours ) staff. This care is required over a 24/7 period.

- Education- ongoing training and development of both specialist and primary health care providers is critical to the provision of palliative care. It ensures best practice in care is maintained, and provides non-specialist staff with the knowledge, skills and confidence to provide palliative care, thereby building capacity in the community.
- Resources- the provision of adequate resources including funding, equipment and personnel are essential to the provision of effective and quality health care, particularly for the palliative patient whose needs can change rapidly and significantly.

Do these themes recur within the Australian palliative care environment? The next section will review literature from Australia, with a particular focus on out-of hours service provision.

### **The Australian Experience.**

Despite the growth and development of palliative care as a recognised specialty in the Australian health care system, palliative care services remain disjointed and the service models of care vary considerably across the country. This is despite several discussion and recommendation papers by governments and other interested bodies in recent years (SA Health 2007; SA Health 2009; Palliative Care Australia 2003; Palliative Care Australia 2005).

As recently as September 2014, a report from the Grattan Institute stated that "...we do not provide enough support for carers, end-of-life services are fragmented, and sufficient

palliative care is often not available” (Swerrisen and Duckett, 2014, p16). This report addresses issues such as the pressure on informal carers to support someone dying at home, a lack of co-ordination between services and a healthcare system that is difficult to navigate, and limited availability of palliative services in some areas of Australia.

Recommendations of measures to improve the provision of palliative care are made and include the increased use of Advance Care Planning through the education of both health professionals and the public, and increasing the availability of community based palliative care services, not necessarily through staffing numbers, but through innovative use of existing community care packages. The report also suggests that Australia review systems that are in place overseas with a view to adopting more successful ideas for community based care (Swerrisen and Duckett, 2014).

Abernethy et al. ( 2008) in their paper on specialist palliative care services and the impact on caregivers, also declare that the specialist services in South Australia are varied in their structure and operate across inpatient, outpatient, hospital consultation and community settings. This paper did not expressly look at models of service delivery, but rather the overall impact of the specialist palliative care service regardless of the model of care. The writers conclude that involvement of a specialist palliative care service at end-of –life care resulted in improved short-term outcomes, which included such things as improved communication about illness trajectories and information about services that could be accessed, increased levels of emotional support for both the patient and caregiver, and increased assistance with nursing and medical support (Abernethy et al., 2008).

With emphasis being placed on the need for collaborative models of care and the promotion of palliative care being accessible to patients whilst continuing with usual ( or potentially

curable) treatments, it has become essential for additional education and training in palliative care to be available. Yates (2007) discusses two such strategies that have been implemented to develop the palliative care workforce in Australia.

The Palliative Care Curriculum for Undergraduates (PCC4U) has as its aim to provide education on palliative care to all undergraduate students in medicine, nursing and allied health. Rolled out in three phases beginning in 2003, this programme has seen the development of learning resources that can be tailored to the various healthcare disciplines, and can be undertaken in a flexible manner. The National Program of Experience in the Palliative Approach (PEPA) provides workshops and workplace training for healthcare professionals from a variety of disciplines. This programme has been very popular as it not only provides training, but also provides the opportunity for networks to be established that provide support after completion of the placement. Both of these initiatives are focused not on developing specialist palliative care providers, but rather educating the primary health care professional (Yates, 2007).

Brumley et al. (2006, p. 27) state “problems exist in the provision of palliative care interventions after dark”. As a consequence, they undertook a project aiming to improve after -hours access to clinical information for a regional community palliative care service. An After Hours Palliative Care Information Sheet (one page) was developed that included patient history, current clinical condition and medications, patients understanding of disease process, prognosis and expectations. In addition, information on patient preferences in relation to treatments, place of care and death were included, along with any anticipated needs if possible. The information was to be updated regularly by the community palliative care nursing staff and forwarded to the patients general practitioner ‘on-call’, as well as

being included in patient notes. Evaluation of the project discovered the limitations of using this form and included the difficulty in predicting if a patient would require after-hours assistance, difficulties in restricting the information supplied to one page and the duplication of nursing notes. On a positive note, nurses involved in this project believed that patient outcomes were improved as the nurses were more confident in their approach to care due to increased knowledge about the history, current condition, treatments and future care plans for the patient (Brumley et al. 2006).

In 2009, Ciechowski et al. reported on a project that explored the provision of an after-hours palliative care service in three regions of Victoria. Of the three regions, one was classified as urban, one as rural, and the third a combination of both. Both health professionals and patients and carers were interviewed about the after-hours service and identified the following as positive indicators:

- Education to patients and families about symptoms and their management;
- Good communication amongst team members; and
- Provision of an after-hours telephone service and triaging of calls.

Additionally, some challenges were identified, and these included:

- A need for uniformity in after-hours care;
- Training, access to and remuneration for General Practitioners; and
- Support for people receiving palliative care and their carers.

(Ciechowski et al., 2009)

The paper concludes that whilst some satisfaction with aspects of the service was expressed, a number of gaps were also identified and indicate the need for further research into this area.

Some reports about the development of after –hours palliative care service provision were located in the literature search. In an evaluation of an after-hours telephone triage from a Hospice in Victoria, key elements were identified and addressed. These included the use of best practice care, client information systems, triage service, nursing and medical support and data collection and quality assurance. The triage position is staffed by senior palliative care nurses and operates from 1630 – 0700 weekdays and all day on weekends and public holidays. Home visits to patients if required are provided by community nurses. This system commenced in 1997 and continues to be a model of after-hours palliative care service provision at the present time (Chiddell, 2013).

A second report on an after-hours palliative care project for rural Victoria was located, and identified the same key elements required for service provision, though it noted that a more local triage point would be more appropriate for smaller rural services. It also identified that ongoing education for triage nurses and palliative care service providers, provision of suitable technology and appropriate staffing levels were necessary to maintain a triage service (Gippsland Region Palliative Care Consortium, 2012).

A discussion of a shared care model of palliative care service provision is provided by Swetenham, Grantham and Glazter (2014). This discusses the alliance between the specialist palliative care services and the South Australian Ambulance Service (SAAS), where the extended care paramedics (ECP) are available to act as a rapid response to after-



hours calls from palliative patients. This service combines “expert phone advice and the face assessment and management carried out by the ECPs” (Swetenham, Grantham and Glaetzer, 2014, p. 215).

A review of this programme identified that this collaborative approach works well, with many after-hours call from patients and families able to be resolved without the need for a visit, but if a visit is required, the ECPs are able to attend. With their additional skills and the support of the specialist palliative care team, many issues are able to be resolved at the patient’s home resulting in hospital avoidance. Patients and families also indicated satisfaction with this service as it allowed for professional assessment and treatment if required within the home. The visit by the ECPs was also found to reduce carer anxiety. It is suggested that this model “has demonstrated success in terms of efficient appropriate response, safe compassionate clinical care and integrated multidisciplinary teamwork” (Swetenham, Grantham and Glaetzer, 2014, p. 216).

Whilst there was limited available Australian literature specifically relating to after-hours palliative care service models, those reviewed along with more general palliative care papers, revealed the same concerns from other countries. Issues of communication, education, a lack of co-ordination of services and the need for continuity of care and sufficient resources are all identified as barriers to the provision of optimal palliative care.

## **Summary**

This literature review has attempted to provide an overview of existing literature on palliative care both generally and in relation to after -hours models of service provision. Papers from overseas and Australia have been reviewed and some common themes identified. These have included both the belief that palliative care should be accessible at all times and also discussion of the barriers that can impact on the provision of such a service. The literature review identified that there is a 'gap' in the service provision of palliative care in the community setting, and that this 'gap' occurs outside of standard business hours. Although a variety of different models have been implemented to address this issue, there is no identified best practice.

The after-hours service at NAPS allows for the provision of telephone advice to community patients and their carers. This advice is currently provided by the palliative care registrar on-call. This research seeks to answer the question as to what are the views and perceptions of the current community nursing staff to an extended hours community nursing at NAPS. This may provide insight into any perceived potential benefits for patients and their carers, or any need for a review of the current service model.

The next chapter will discuss the methodological approach chosen to undertake this project and the reasons for the choice selected.

## **Chapter 3. Methodology.**

### **Introduction**

This chapter will provide a description of the research methodology used in this study and the reasons for this choice. A discussion on the use of qualitative versus quantitative methodology will also be undertaken, along with a description of the theoretical perspective behind the research approach. Some major qualitative approaches are also discussed. A brief outline of the purpose of the study is included to show why this methodology was chosen.

### **Purpose of this study.**

The purpose of this study is to gain an understanding of the views and perceptions of current nursing staff to an extended hours community service in the field of palliative care. There are two main elements to this study. The first is the collection of data from these staff about their views – a personal account of their feelings and thoughts. This data will be analysed for the emergence of any patterns or themes that arise from individual interviews. As this data comes from the individual participants and is a reflection of their thoughts and views, it is subjective.

The second part of this study involves the analysis of retrospective descriptive data relating to after-hours contact to the service. This data is objective, and its analysis will provide

information about the nature and volume of after-hours calls to the service. It may also provide information about the type of health care response that is needed.

The focus of this chapter is related to qualitative methodology, as this is the primary data source to be used for analysis. A description of the quantitative data, its purpose and the methods used will be outlined in the methods chapter that follows.

### **Quantitative versus qualitative?**

Quantitative and qualitative research have very distinct strengths and differences.

Quantitative methods are viewed as objectivist, with a focus on facts, data based upon numbers and with the relationship of the researcher to participant classed as distant. The relationship between theory and concepts is based on processes of deduction and confirmation. In qualitative research, the researcher is viewed as being close to or inside the research process, and the focus is on the meanings obtained from the data which is most often in textual form. The relationships between theory and concepts is derived from an induction process or emergent themes (Gray, 2009).

Historically the trend has been for research to be approached under either a quantitative or qualitative methodological approach, but in more recent times there has been an increasing position that at times the use of a mixed-method approach may be beneficial (Gray 2009, Schneider et al 2013). As this is a relatively new concept in research, there are varied definitions that may refer to the term 'mixed-method' research. For the purpose of this study, the definition described by Tashakori and Creswell (2007, p. 4) was used:

‘research in which the investigator collects and analyses data, integrates the findings and draws inferences using both qualitative and quantitative approaches or methods in a single study or a program of inquiry’

Additionally there are many different ways in which a mixed-method approach may be adopted, but for the purpose of this study, a simultaneous approach has been adopted. As the study is exploratory in nature, there is a qualitative foundation to the research, and the quantitative methods will be used to provide additional and complementary information (Schneider et al., 2013).

### **Qualitative Foundation**

As an exploratory study into the views and perceptions of individuals, a qualitative approach was felt to be the most appropriate in order to answer the research question.

Qualitative research has been defined in a variety of ways.

Strauss and Corbin (1998) describe qualitative research as:

“...research that produces findings not arrived at by statistical procedures or other means of quantification. It can refer to research about persons’ lives, lived experiences, behaviours, emotions, and feelings...” (p. 10 -11)

By allowing understanding through the exploration of the “attitudes, beliefs, meanings, values and experiences of research participants” (Schneider et al 2013, p. 105) the opportunity to gather data that provides the nuances of the narrative is provided.

Strauss and Corbin (1998) also discuss that the preference and personal experience of the researcher, a study of areas of which little is known, and also the nature of the research problem, are factors that indicate suitability to a qualitative approach. This study was exploratory in nature, seeking to investigate personal views of staff in relation to a model of service provision. Prior to this study, the views of the nurses working in this service in relation to extended hour's service were unknown. In addition, their views on what constitutes an extended hour's service and the variations that an extended hour's service model may take were also unknown. This study was seeking to understand each individual's view on extended hour's service provision and these views are the personal subjective feelings and descriptions as provided by the participants.

Addington – Hall et al. (2007) describe qualitative research as being highly useful and frequently used in palliative care, because that research that looks to “explore processes and /or meanings” (p. 141) is suited to qualitative research methods. For these reasons, a qualitative approach for this part of the study was deemed appropriate.

## **Theoretical Perspective**

Prior to discussing the research approach used, it is necessary to determine the theoretical perspective that underpins this study.

According to Crotty (1998) theoretical perspective refers to the underlying philosophical assumption of the human world and the social life within that world as held by the researcher. Gray (2009) whilst discussing several different theoretical perspectives, argues that positivism and interpretivism are among the most influential. Positivism holds that the

social world exists separately to the researcher, with a strict set of laws governing both the natural and social worlds. In contrast to this is the post-positivist stance with a range of different perspectives, including anti-positivist, post-positivist and critical inquiry.

One such example of an anti-positivist stance is that of interpretivism. Gray (2009) discusses the difference between natural reality and social reality and the need for different research approaches and asserts that social sciences are ideographic, often dealing with individual actions. Interpretivism is ideally suited to qualitative research as it is an excellent method for exploring an individual's interpretation of experiences. Some examples of an interpretivist stance include symbolic interactionism, phenomenology, realism, hermeneutics and naturalistic inquiry.

This study is exploratory in nature, seeking to understand the views and perceptions of the community nurses regarding their 'working world'. From a theoretical perspective, an interpretivist stance is most applicable.

## **Research Approach**

As an investigation of the views and perceptions of current nursing staff toward an extended hours service model, this study at its simplest, could be labelled as using a descriptive, exploratory approach. Schneider et al. (2013) assert that this approach is now the most common approach used in nursing and midwifery research, and that such an approach is more generic in its principles than other more 'traditional' qualitative approaches. It has been described as "liberating" in that researchers have been able to express their data and findings in a very free manner, with adoption of some common

aspects of a variety of qualitative approaches, rather than being “governed by longstanding theoretical and philosophical positions” ( Schneider et al., 2013, p.107) that apply to the more traditional methods of qualitative research.

The major traditional qualitative approaches generally considered are phenomenology, grounded theory and ethnography. Whilst these approaches are interpretive in nature, the ways in which experiences and phenomena are explored differ. The choice of a particular approach is governed by what the researcher is hoping to discover, and the nature of the study undertaken. This means that experiences and phenomena may be explored in different ways, and as such can see the production of different research outcomes (Schneider et al., 2013).

This study, whilst it is both descriptive and exploratory in nature, is grounded in the traditional approach of phenomenology. A brief overview of a number of major qualitative approaches will now be given, along with the reason for the choice of phenomenology as the appropriate choice for this study.

## **Phenomenology**

Phenomenological research, according to Gray (2009, p.28):

- Emphasises inductive logic.
- Seeks the opinions and subjective accounts and interpretations of participants.
- Relies on qualitative analysis of data.



- Is not so much concerned with generalisations to larger populations, but with contextual description and analysis.

The focus in phenomenological research is from the perspective of the individual. As DePoy and Gitlin (2005, p. 72) state, phenomenology does not seek to understand “cultural patterns”. Rather, it is concerned with those phenomena that are pivotal to the individual human experience. For this reason, phenomenological research is well suited for investigating individual emotions or experiences such as fear, happiness, and feelings of stress, pain or situational occurrence (Streubert and Carpenter, 2011).

### **Grounded Theory**

Grounded theory differs from phenomenology in that it is explicit in either generating or elaborating on a theory from the data collected (Strauss and Corbin, 1994). Not solely focused on social processes, it “has also evolved to explain human action and interaction in clinically related issues of social, psycho-social or spiritual dimensions of life”( Schneider et al 2013, p. 112).

Data is collected through a variety of ways including interviews, direct observations, document review or a combination of all or any of these. Generally there is no limit on the number of participants, but rather a collection of data until theoretical saturation is reached (Streubert and Carpenter, 2011).

Grounded theory research may be undertaken utilizing a variety of philosophical perspectives, with either objectivism or constructivism being the primary choice.

It is however, generally accepted that a theoretical framework derives from the research, is usually context –dependent, and that often the resulting theory is seeking to provide a solution to a problem (Schneider et al. 2013; Strauss and Corbin 1998; Streubert and Carpenter 2011).

## **Ethnography**

Ethnography has as its central theme the concept of culture and has an objective that seeks to understand the meanings and activities of those within a cultural group. The researcher seeks to determine the impact of the broader social context and relationships on the individuals' experience (Schneider et al., 2013). Other features of ethnography include the studying of 'sites', rather than individuals. This type of research attempts to utilise high numbers of informants/participants, and while some interviewing does occur, a major source of data collection is through observation.

Streubert and Carpenter (2011) describe six characteristics to ethnography. These include the researcher as an instrument, conduction of fieldwork, data collection and analysis which are also common to other qualitative research methods. The final three of a focus on culture, cultural immersion and the role of researcher as researcher versus researcher as a cultural member are considered to be unique to ethnography.

As has been discussed, there are some similarities between the three methodologies discussed. The reason for choice of a particular methodology in preference to another is often due to the differences between them and how that applies to the nature of the research

being undertaken. A brief summary of some of these differences is provided in Table 1 below.

**Table 1. An overview of some differences in three methodologies.**

<b>Phenomenology</b>	<b>Grounded Theory</b>	<b>Ethnography</b>
Study of the meaning, structure and essence of the phenomenon as perceived by the individual or individuals.	Study of a process, action or interaction involving many individuals.	Study of the cultural characteristics of a group of people or cultural group.
Studies individuals and explores the construction of their world.	Used to generate theory based on the analysis of data collected.	Studies sites and discovers relationships between culture and behaviour.
Uses in-depth interviews primarily for data source, and often has smaller numbers of participants ( 5 -15)	A variety of data collection techniques may be used which continue until theoretical saturation is reached (no new concepts from the data emerge, or theory is validated.)	Uses primarily observation, with some interviews with as many informants as possible.
Uses an inductive approach to construct any theories or models that may arise from the data. Not necessarily concerned with generalisations, but with contextual description and analysis	Uses both inductive and deductive processes to discover theory through the analysis of data collected.	The researcher becomes immersed in the culture as an active participant, with analysis of cultural themes being developed.

(Adapted from Schneider et al., 2013, p.25.)

The nature of this project was to explore the individual perspectives of current nursing staff toward an extended hour’s service model. It utilised in-depth individual interviews as a primary data source, and the participant base was small. The results from the data analysis apply to the context of the current working environment of the participants and does not seek to apply generally to palliative care services. As such, a phenomenological foundation to this study was considered most appropriate.

## **Summary**

This chapter has provided the reasons for the choice of the theoretical perspective and research methodology used in this study. A brief overview of a number of qualitative research methods is included and their key similarities and differences has been discussed. The purpose of the study and how this is related to the choice of methodology and theoretical perspective has also been discussed. The following chapter will discuss the methods utilised to undertake the research project.

## **Chapter 4. Methods**

### **Introduction**

This chapter outlines the methods used in this project. Details of the project design and setting are provided along with the recruitment process employed. A discussion of the interview process and the role of the researcher will be addressed. Participant inclusion and exclusion criteria are provided, and the issues of reliability and validity are outlined. An overview of a pilot interview undertaken by the researcher for preparation is also provided.

### **Design**

There are two main elements to this study- a qualitative collection of data from the current nursing staff, and a quantitative analysis of the after-hours calls to the service. The design of both aspects will be discussed.

### **Qualitative data**

This project initially involves the use of a semi-structured interview with current nursing community CPCs to elicit their views on extended hour's service for community. Semi-structured interviews allow for the participants to respond openly and freely. This form of interview also allows the researcher to ask additional questions or alter the order of

questions asked if any new issues or concepts may arise (Gray, 2009). The research topic is defined, but participants are afforded the opportunity to present their ideas in their own time.

The choice of a semi-structured interview to undertake this study was determined by the need to allow participants to freely express their views whilst also allowing the researcher to ask additional probing questions to encourage the participants to elaborate on the information provided (De Poy and Gitlin, 2005).

The use of the interview as a data collection method is also supported in Gray (2009, p. 370) with the statement:

“ If the objective of the research, for example , is largely exploratory, involving, say the examination of feelings or attitudes, then interviews may be the best approach”

Whilst a well-designed questionnaire may also have provided information about the views of the participants in relation to extended hours service, it was determined that the use of the interview would yield richer data by allowing the researcher access to more than just the verbal responses. The interview allowed the observation of body language and also to hear the nuances of the replies given. It also allowed the researcher the opportunity to ask participants to expand on answers or new concepts that arose in the interview (Gray, 2009). A questionnaire, no matter how well constructed is unlikely to provide this opportunity.

It is necessary when gathering data from participants to establish rapport to allow the participant to feel comfortable and able to respond openly. The semi-structured interview, whilst time-consuming allows for the participant to not feel rushed or pressured by having

to answer extensive numbers of questions. It also allows for the use of prompts to ask the participant to expand on a response and to redirect them if necessary.

Recorded interviews were transcribed with participants provided with the opportunity to check the accuracy of their transcript. Following agreement of accuracy, analysis of the data was undertaken. This analysis was undertaken using an inductive approach to identify any patterns that may have emerged in the data. Patton (1980) states that “Inductive analysis means that the patterns, themes and categories of analysis come from the data...rather than being imposed on them”( Patton, 1980, p. 306).

Themes were able to emerge through the researcher becoming familiar with the data collected and the drawing of associations with the questions used at the interview and the review of the literature.

### **Analysis of calls received**

An examination of data relating to the number and nature of calls received after-hours was undertaken to assess the level of practitioner required to respond appropriately. De-identified data was collected for a ‘snap-shot’ period of thirty days only, and excluded calls related to the inpatient unit of the health service. This information was analysed to determine if there were any patterns related to the nature, timing or response required to the calls.

## **Setting**

This project was undertaken in a single site public health service located in the north-eastern region of Adelaide. The focus was on the community service as provided by the Northern Adelaide Palliative Service (NAPS). Prior to 2013, palliative care in the northern/northeastern regions of Adelaide was provided by the Lyell McEwin Hospital and the Modbury Hospital respectively. As part of the SA Health Palliative Care Services Plan 2007- 2016, these services integrated to become NAPS, amalgamating two different service models.

The current service model now provides for the Clinical Practice Consultants (CPC) of the community to provide a service that operates Monday to Friday between the hours of 0800 and 1630. Outside of these hours, weekends and public holidays are considered ‘after-hours’. For after-hours periods, patients and families needing assistance have the following options available to them:

- They are able to seek telephone advice only from the palliative care medical staff rostered on call ;
- They may call their General Practitioner, or more commonly the locum service for a home visit;
- They may call an ambulance for attendance; or
- They may present at the Emergency Department of their nearest or preferred hospital.



## **Study sample**

Purposive sampling was used rather than random sampling due to the qualitative nature of this research. As this study was to explore the views of a particular group of nursing staff relating to a specific issue, this approach was the most appropriate. As Gray (2009, p.180) explains:

“Informants are therefore identified because they are known to enable the exploration of a particular behavior or characteristic relevant to the research.”

## **Inclusion/exclusion criteria**

All current permanent community Clinical Practice Consultants were invited to participate, and provided with written information relating to the purpose of the study and their role as a participant if agreeable. Any relieving staff, or staff of less than two years' experience as a community nursing staff member of NAPS were excluded from the study as it was believed they would have insufficient experience of the current system and patient /caregiver needs.

## **Ethical considerations.**

In Australia human research is governed by law that details the rights of participants and the responsibilities of the researcher or institutions involved in human research. In 1992, The National Health and Medical Research Council Act established the National Health

and Medical Research Council (NHMRC) as a statutory body with functions, powers and obligations relating to human research. In conjunction with the Australian Research Council (ARC) and the Australian Vice-Chancellors' Committee (AVCC), the NHMRC developed a National Statement on Ethical Conduct in Human Research 2007 (updated March 2014). This statement is designed to provide guidelines for researchers, Human Research Ethics Committees and others in relation to ethical considerations, as well as responsibilities for safety and quality of research being conducted. Issues of governance which involve areas such as data collection and storage, conflict of interest and research misconduct are also discussed. It is necessary for a research proposal to satisfy the requirements of the National Statement and be judged as ethically acceptable prior to the commencement of any research (National Health and Medical Research Council, 2014).

This study has taken place within a single site within SA Health. In accordance with SA Health policy, ethical approval was sought from the Human Research Ethics Committee (TQEH/LMH/MH) prior to the commencement of recruitment of participants or data collection. This process involved review of the research proposal from both an ethical and governance viewpoint before the research process began. A copy of the letter of approval may be found at Appendix 1.

Gray (2009, p 68) describes research ethics as concerning “the appropriateness of the researchers behavior in relation to the subjects of the research or those who are affected by it”. The four main areas of ethical principles are:

- Avoid harm to participants;
- Ensure informed consent of participants;

- Respect the privacy of participants; and
- Avoid use of deception (Gray, 2009, p73).

As this study was conducted within the workplace with current staff, harm can be considered to be anything that may cause the participant stress or embarrassment. To avoid harm it was essential to ensure anonymity was maintained with regard to data collection and storage, along with the reporting of findings. For this reason, interviews were held individually in a separate office at the site. Participant data collected was coded to prevent identification, and all data was secured within a locked filing cabinet and office. Data is to be retained securely for five years. Electronic data was stored on a password protected computer.

Prior to interview, each participant was provided with information regarding the study, and if agreeing to participate, they were given a consent form to sign. The information provided detailed the role of the participant and the purpose of the study, along with advising that participation was voluntary and that they may withdraw from the study at any time. The provision of sufficient information to prospective participants is critical to ensure informed consent (Gray 2009; Streubert and Carpenter 2011; Depoy and Gitlin 2005; Schneider et al. 2013).

The privacy of each participant was ensured through the secure storage of data. All data collected was made inaccessible to all but the researcher. Similarly, the information relating to participants codes was kept securely. Privacy was maintained by the researcher ensuring that they do not repeat or indicate responses from one participant to another.

Avoidance of deception was obtained by ensuring that participants were fully informed of the purpose of the study, any potential benefits or risks to themselves, and the level of participation required if they accepted the invitation. This information was reviewed again prior to the commencement of each interview to ensure the participants understood of the process and to verify their willingness to participate.

## **Data Collection.**

### **The interview**

For the purpose of this study, the use of individual semi- structured interviews was used as the primary method of qualitative data collection. These interviews were semi-structured with the use of prompts to encourage expansion of answers or ideas. All interviews were audio-taped to allow for accurate transcription at a later time. It also enabled the researcher to focus on each participant without the distraction of note-taking. This attention helped to allow the participants to feel that their contribution was important and allowed for a free flowing conversation throughout each interview.

Participants were initially asked to describe their experience in palliative care and also in the community care setting. The purpose to this was two-fold in that it enabled discussion about their experience level along with providing a non-threatening start to the interview, hopefully to promote open and honest responses. The interview then proceeded to general questions and/or prompts about models of care for community services with a particular emphasis on palliative care. Participants were asked to describe the models of care they

were aware of, and to provide their ideas of what an extended hour's model of care may involve. Participants were also asked to comment on any potential benefits to their particular client group, along with any perceived barriers to an extended hours community nursing service.

After completion of the interviews, the audiotapes were transcribed. Transferring the data collected from the spoken to the written word was able to assist in analysis. Repeated listening of the audiotape provided greater familiarity with what was said, as well as how it was said. The emphasis used by the participants at certain times during the interview, provided clarity and illustrated the strength of their views on the issue under discussion.

### **Analysis of after-hours calls**

An examination of the number and nature of calls to the after-hours service of the NAPS was also undertaken. This data was collected for only a thirty day period to provide a 'snapshot' of this component of the service. The purpose of this was to determine the number of calls, the time periods the calls and the level of practitioner required to respond appropriately. This determination was made by the researcher, based on the reason for the call and the information required to effectively respond to the patient or carer concern. Provided that the information required or the action needed to effectively respond were within the scope of practice of the CPC, the call was deemed as being able to be responded to by a CPC. This information was used to assist in determining if there was a need for further investigation of this issue. This data was collected using a standard after-hours call log currently used by rostered palliative care medical staff. All identifying data was

removed from the form by NAPS administrative staff prior to it being received by the researcher. This form has been included as Appendix 2.

### **Pilot Interview**

In preparation for the research, a pilot interview was undertaken by the researcher. This involved each step of the process from interview to transcription of interview, and provided the following benefits for the researcher:

- Familiarisation with equipment;
- Practice of interview technique and question;
- Practice of transcription of recorded interview; and
- Receiving feedback to allow for review and modification to questions, and interview technique.

For the purpose of this exercise, a retired colleague with extensive experience in palliative care and knowledge of community care models was recruited to be the ‘participant’. The following describes the findings from this pilot interview.

- The interview was conducted and completed in approximately one hour as anticipated, and the audio equipment was easy to use for both the recording of the interview and the playing back for transcription. The audio quality was clear and without distortion.
- The transcription of the interview was more time intensive than anticipated, requiring in excess of six hours to complete. This was due to the need to continually replay the audio to ensure exact transcription of the spoken word.

- Feedback from the ‘participant’ was that the flow of the interview felt “smooth and logical”, and that the questions/prompts “encouraged open discussion of ideas”. It was also stated that there were times where the researcher should allow” more time for responses to be made”.

This process made the researcher aware of any changes required in either technique or interview structure along with time requirements before undertaking the actual data collection process. As the primary source of data collection for this study is that gathered from the interview process it is essential to be prepared and understand the process (Streubert and Carpenter 2011; Gray 2009).

### **Data Analysis**

All data collected were transcribed and participants were offered the opportunity to check the accuracy of their transcript. Upon agreement of accuracy, an analysis of the data was undertaken. An inductive approach was used to identify any patterns that may have emerged in the data. According to Patton (1980, p.306) “inductive analysis means that the patterns, themes and categories of analysis come from the data”. Identification of any patterns of similarity in data after its collection is referred to as thematic analysis, and allows for the grouping of similar responses from individuals. This can allow for meaning to be interpreted from the data collected (Addington-Hall et al., 2007).

To accomplish this, the transcripts were read and reread to search for any similarities or themes. Any related ideas or concepts that emerged from the participants perspectives were

organised into categories. This information was then reviewed against the themes identified in the literature review for any similarities.

### **Issues of reliability and validity.**

Throughout the research process, it has been important to maintain rigorous data collection and analysis. Quantitative research evaluation ensures this through measures of reliability and validity. Such measures however are not applicable to qualitative research and so another approach must be utilised. According to Lincoln and Guba (1985), the term of “trustworthiness” is used to evaluate qualitative research and encompasses concepts such as credibility, transferability, dependability and confirmability.

Credibility refers to the confidence in the accuracy of the findings, and this may be determined through various methods. One such method utilised in this study was through member checking, which involved the participants checking the transcript of their interviews for accuracy. This was employed by the researcher and along with checking accuracy of the data collected allowed for the researcher to maintain reflexivity through self-correction and self-awareness.

Transferability, or the inability of it, is often a criticism levelled at qualitative research. As the sampling in qualitative research tends to be purposive not random, generalisations across situations or conditions is difficult.



Gray (2009 p. 191) argues that the “the results from individual cases allow us to build working hypotheses that can be tested in subsequent cases”. In an effort to allow for transferability, this study has provided “thick” descriptions of the data collected.

Issues of dependability and confirmability are both able to be determined through the use of an audit trail. An audit is able to reveal the stability of the findings and clearly show the connections between data collected and the interpretation of the researcher (Gray, 2009, p 194).

### **Role of the Researcher**

Streubert and Carpenter (2011) describe the role of the researcher in phenomenology as having specific responsibilities as they gather, record and analyse the data and then document their findings. It is essential for the researcher to be aware of their own beliefs and values in relation to the area under investigation and to ensure that they maintain reflexivity throughout the research process.

Conducting research within one’s own work area has advantages and disadvantages that need to be considered. As a clinician of many years’ experience and currently working within the Northern Adelaide Palliative Service, the participant group were already known to the researcher. This meant that the researcher had an awareness of any jargon that was used during the interview, and also an understanding of the daily routines of practice. As a result time was not lost in clarifying such matters that may have been needed if the researcher was unfamiliar with the setting or participants. As the researcher was known to

the participants, there was no requirement to become part of the group and participants will often speak freely and easily to someone known (Addington-Hall et al, 2007).

But disadvantages to conducting research within one's own workplace can also occur. There can be concerns regarding the expectations of the participants on the researcher and their role within the team. Some participants may feel constrained when asked to speak about their personal views for fear of possible peer pressure. There may also be some concerns regarding the hierarchical relationships between the researcher and the participants (Addington-Hall et al, 2007).

During the recruitment and interview stage the researcher endeavored to ensure that all participants felt comfortable and non-threatened. To alleviate concerns of privacy and confidentiality, a fully informed consent process was undertaken, and participants were advised that they were assigned individual codes for the purpose of both the interview and the typed transcript. To encourage the participant to talk openly, the interview guide (Appendix 3 ) was provided for them to read and access throughout the interview. This enabled them to clearly identify the areas for discussion, while at the same time enabled them to discuss issues in the order they felt most comfortable with.

## **Summary**

This study consisted of two main elements, a qualitative collection of data from participants and a quantitative analysis of after-hours telephone calls to NAPS. Prior to the recruitment of participants and commencement of data collection, ethical approval was obtained.

A semi-structured interview was used to collect the qualitative data, and the researcher sought to ensure that all participants felt comfortable and non-threatened throughout both the recruitment and interview stage. Informed consent was obtained from individual participants, and privacy and confidentiality was maintained at all times. The after-hours telephone data was de-identified prior to analysis to protect client anonymity, as well as the identity of the medical staff completing the form.

A pilot interview was undertaken by the researcher to raise awareness of any changes required in either technique or equipment prior to commencing the data collection process. Credibility of the qualitative data was maintained by having participants check the transcribed interviews for accuracy prior to analysis for any themes. The following chapter will present the results of the data collection, both qualitative and quantitative.

## **Chapter 5. Results**

### **Introduction**

This chapter presents the results of the investigation of nurses' perceptions and views of an extended hour's community nursing service at the Northern Adelaide Palliative Service (NAPS). The main purpose to this investigation was to gain an understanding of the views of the current Clinical Practice Consultants(CPC) working in the community with regard to extended community nursing services in palliative care generally and also within the region serviced by NAPS. It was also intended to enable the researcher to determine if there were any common themes that emerged out of the interview process, and if there was any similarities to the literature review undertaken. It would also allow the researcher to understand the participants' views regarding any potential need for a change in the current service model, what potential benefits there may be for clients, and what potential barriers might exist to any change.

In addition to the interviews performed, a snap-shot of the after-hours calls received by NAPS were reviewed to allow for identification of the times calls were received, the reason for the call and whether the call could have been responded to by a CPC, or whether a medical officer was required. Currently the after-hours service at NAPS is provided by a telephone support that is staffed by the rostered palliative care medical officer on-call. In reviewing the after-hours call, the researcher aimed to establish whether the after-hours

service required a medical officer at all times, or if the CPC would have the knowledge, experience and skills to participate in after-hours service delivery.

The qualitative descriptive data obtained from the interviews has been reported in text, while the quantitative data from the review of the after-hours calls has been described in text as well as through the use of tables. These results will be discussed separately.

### **Participant information and demographics.**

Originally it was intended to invite all nine permanently employed CPCs working within the community nursing service at NAPS to participate. Due to a resignation between the time of commencement of this project and the gaining of ethics approval, this number was reduced to eight. Of the eight invited, one was on annual leave and unavailable. Of the remaining seven, six participants accepted the invitation within the nominated time frame.

The participants involved were all female aged between forty and sixty-five years of age with an average age of fifty three. All had experience within the community palliative care environment, with five of the six also having worked in other community nursing settings. The experience level of the CPCs in palliative community service ranged from six to twenty-five years.

### **The interviews**

The interviews were undertaken individually in a semi-structured manner. Whilst one hour was the anticipated time frame allowed for the interview, the actual time taken varied according to the individual participant and their responses. All participants were identified

by an alphabetical code (A to F) to maintain their anonymity. These codes are used throughout this chapter to reference specific quotes that are used to identify areas reported.

In all, the participants detailed extensive experience in palliative care and across a variety of settings including inpatient (in a hospice or palliative care ward or the acute care environment) and community. Two described their involvement across different palliative care services within Adelaide and their experience within other community services, whilst another was able to talk about their experience from overseas as well as in Australia.

### **Extended Hours of Care – models identified.**

The next area under discussion was for the participants to describe their understanding of the term “extended hours of care”. All participants were able to describe a model of service delivery that provided a twenty-four hour service across a seven day week. Of the six participants interviewed, three had previously been employed in a palliative care service that provided a twenty-four hour service operating across a seven day week. The after-hours component of this service was supplied by the CPCs with medical back-up as required. For two participants, the CPC was rostered on-call for a week at a time, with the expectation that they would also still perform their duties during the Monday to Friday standard hours. Not surprisingly, both the participants described this as being exhausting physically. The following comments made by these participants indicated that they felt this model with the CPC being the first to receive after-hours calls was less than satisfactory:

*“-A lot of patients ended up in hospital either because the Doctor on call was not available or the nurse felt unsafe to leave the patient at home-”;*(Participant E) and;

*“A lot of patients actually verbalise that they want to speak to a Doctor”.*

*( Participant E)*

One participant had experienced calling in to palliative care services after-hours whilst working for another organization. On being connected to a CPC this participant was quite critical and said:

*“I don’t want a nurse, I want a Doctor because I can’t prescribe medications. I can take verbal orders, I can organize pharmacy drop offs, I can do all that stuff but I can’t actually get medications or anything like that without a Doctor, so I need a Doctor on call to assist me to get the medications in the home and administer and change if required.”*(Participant F)<sup>1</sup>

A third participant had been employed overseas in a twenty-four hour service that operated across a seven day week, but the nursing staff were only rostered for one night and one weekend day a month. While the nurse was the first contact point, a medical consultant was available if required. This service worked closely with the local Doctors and the District nurses. Initially this service was for telephone advice only, and the comments made were

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<sup>1</sup> The underlining of words in this statement is used to illustrate the emphasis placed on these words by the participant during interview.

favorable in terms of the system and the benefit to patients, carers and other health professionals involved in the care of the palliative patient.

*“It was different in the UK. You were attached to a group of Doctors and a group of district nurses. You were a part of that team and there was continuity and you would have meetings every week or fortnight to go through your caseload and discuss patients. Generally if you hadn’t seen them they had. Very good continuity and a team approach.”, (Participant D) and*

*“Most of the time you could deal with it over the phone with the district nurse in the house, you could get the GP. You could do a lot of it remotely”.(Participant D)*

There was also expressed a sense of job satisfaction with the comment:

*“You had to know your stuff, but more autonomy”.(Participant D)*

At a later stage, this model was changed to enable the on-call nurse to attend the patient home provided there was a district nurse or doctor able to meet them there. Whilst stating that over a twelve month period, they were only required to do this once, the CPC felt this change to the service model did not add to the service, and made the comment:

*“Most of the time it is a Doctor they need. I could give advice about medications within the remit of what they’ve got otherwise they ring the GP or the locum”.(Participant D)*



This CPC also described that a colleague in New Zealand currently works in a model that provides twenty-four hour service to the home of patients as a lone practitioner and expressed concern about the personal safety of such a model.

Two participants had participated in a short trial of nurses being the initial contact for after-hours calls from community clients for a palliative care service. Both described that this trial indicated that the calls received needed the expertise of the Doctor rather than the nurse.

*“The majority of calls, around 85% could not actually be handled by a nurse as they needed medication alteration or ended up needing admission to hospital”.(Participant B)*

A service model of staggered hours was described by some as another form of extended hours care. In this model, some staff would commence and finish the shift later than the current working hours across a Monday to Friday week. Two participants in particular were enthusiastic about this type of model as they perceived benefits for patients and carers. One such comment illustrating support was:

*“I have had some really good conversations with patients and relatives out of hours when others are not around and you haven’t got someone tapping you on the shoulder. These are really personal phone calls and I think it is really important to allow time for each individual patient”(Participant C);*

One CPC had actually participated in a hospital wide trial of staggered hours which involved some staff working from eleven thirty am until seven thirty at night. These times

were chosen as they did not incur any increased wage costs for the trial. The purpose of the trial was to create a clearer pathway for the patient that presented to the Emergency Department, whether this was for treatment and discharge home or admission within a timely fashion. In this trial, a team of a nurse and Doctor were rostered for the later start time in recognition of the teamwork nature of palliative care. During the trial, the CPC recalled that response times to review patients in the Emergency Department and determine their plan of care were rapid and effective. During this time, the team were also responsible for receiving the after-hours telephone calls from community patients. Despite feeling that the trial had been successful for the palliative care team, a staggered hour's model was not continued at the hospital. The disappointment felt by this CPC was expressed in her comments:

*“We could prevent hospital admission or presentation if we were able to offer more than a nine to five Monday to Friday Palliative Care Service.”, (Participant B) and*

*“We could make a difference to the patient’s journey if they did not have to present to the ED unless absolutely unavoidable.”(Participant B)*

Other models of extended hours care known to the CPCs included such things as a CPC acting as a triage nurse over twenty-four hours whose role was solely to direct any calls to the either the Doctor, nursing staff during the day or the Metropolitan Referral Unit(MRU) to provide out of hours in home nursing support. Those that raised this concept were aware of a similar system operating interstate. The concept of a “split shift” system was raised by

one CPC as a possible way of extending hours of service. This particular CPC had worked under this type of model and found it to be effective, but acknowledged that it was not in a community setting. It was also suggested by three CPCs that extended hours of care could be providing the service over the same hours, but over a seven day week rather than Monday to Friday. This would also include public holidays, which are currently considered out of hours.

### **Extended Hours of Care at NAPS– views, benefits and barriers.**

Of the six CPCs interviewed, most were quite definite in their views about the concept of an extended hour’s community palliative care nursing service at NAPS.

They were unanimous in their view that a nurse providing the on-call telephone service twenty-four hours each day would not value-add to the service. The reasons they provided for this were varied but included such comments as:

*“The reality - most calls needed a doctor.”; (Participant E);*

*“Nursing wise I think it’s covered in the community. From a practical point of view being a nurse out in the field looking after palliative patients, you really need a Doctor” (Participant F), and*

*“As a nurse our powers are very limited. Generally we need a doctor to make any decision about medication – for any medications at all. A lot of the time – a lot of it is about medication and symptoms and perhaps little changes that need to be made and we can’t do that*

*anyway. So I don't see there's a value in putting another layer in the on-call system".(Participant D)*

One CPC who had previously worked within such a system indicated the frustration and resentment that had been experienced with the comment:

*"it was not wholly accepted by the nurses but a condition of our employment".(Participant E)*

The other discussion by the CPCs around extended hours of care focused on a staggered hours approach to the delivery of care within the community. Opinion from the CPCs was divided on this concept with two believing it would be a positive change for patients, carers and staff. These CPCs felt that there would be benefits to patients, families and also themselves if they were able to work in this manner. They expressed concern for the need to be able to speak with patients and carers outside of the normal working day after patients had been to appointments or treatments, or carers had been to work or providing transport and care for patients. This was expressed by one in the comment:

*"Some of our patients are still having active treatment, so the patient's day is full of treatments and doctor's appointment and so on. When I have called a patient after five o'clock at night they have said now is the time I can quietly sit down and talk to you."(Participant C)*

Two other CPCs were less adamant in their stance. One stated that depending upon the flexibility of a staggered hour's service; it may be beneficial at certain times in a patient's illness trajectory to be able to work outside of standard hours. The other stated that while they thought the current service covered the patient need, further investigation into patient

calls out of hours may indicate that there were some “gaps”. This participant also later made the comment that

*“if we had an extended service that provided care up until six or seven o’clock then that might enable some increased family and carer contact”.* (Participant A)

Two CPCs however did not believe there was any need for an extended hour’s service of community palliative care. They believed that the current system that utilised the district nurses and the Extended Care Paramedics (ECPs) with the ability to telephone for specialist palliative care advice provided the patients with the service they needed. One expressed this by saying:

*“They’ve got the district nurses until ten o’clock, and then the ECPs who have taken over the role of this rapid response thing. I am not sure that we would add anything.”* (Participant D)

For those who supported the concept of an extended hours of service in NAPS, the potential benefits of such a service centred around the ability to provide extra support to patients and families and to facilitate contact with families or carers that were normally unavailable during standard working hours. There was also mention of the potential to reduce hospital admissions or presentations to the Emergency Department, and to maintain the patient at the location of their choice. Even for those CPCs who were hesitant or unsure about the need for an extended hour’s service, these benefits were identified. While the first two CPCs believed continuity of care was also a potential benefit, the latter did not as they felt this was only going to occur if the CPC providing the after- hours care was also

responsible for the patient during standard working hours. For the two who did not believe such a need existed, they did not perceive any benefits.

In the discussion of barriers to extended hours of service, all agreed that budget restrictions, closely followed by resources – in this case staff – would be the major barriers to any extension of hours to the service. Some staff who stated they did not believe there was a need for an extended hours community nursing service at NAPS also indicated their reluctance to participate in such a service as represented by the comment:

*“...element of me that doesn't want to do it” (Participant A).*

This again relates to resources, or the potential lack of them.

### **Current client group**

The final question asked of the CPCs involved their opinion of the potential benefit to their current client group. Currently the service at NAPS is divided into four teams of CPCs covering an extensive and diverse area in Adelaide. This question was asked to investigate if the region the CPC currently worked in had any influence on their views about the need for extended hours of service. The socio-economic differences between regions are distinct, with some areas considered to be among the most disadvantaged regions in Adelaide, while others were listed as affluent. (Australian Bureau of Statistics, 2008) In addition some areas are relatively new residential developments with high numbers of young families with mortgages, while others are older established suburbs with many retirees.

The responses indicated that the socio-economic make-up of a region might influence the opinion of the CPC as to whether that client group may benefit from an extended hours service. Those staff working in areas that considered disadvantaged were more enthusiastic about the need for an extended hour's community nursing palliative care service. This was indicated by the comment:

*“I think that to be able to talk to people who are the carers of their loved ones but are still managing to go to work, being able to talk to them out of their work hours which coincide with our work hours would be absolutely beneficial.”(Participant B)*

### **The after-hours telephone calls**

Data collection of the after-hours telephone calls received by NAPS was collected over a thirty day period to investigate the number, nature and timing of calls received by the service. After-hours at NAPS includes weekdays from four-thirty until eight the next morning and twenty four hours on weekends and public holidays. This data was also reviewed to determine if a medical officer was required to respond, or if a nurse could have provided this service.

Over the collection period, a total of fifty six calls were received. Whilst these calls were spread across all days of the week, thirty two (57.1%) occurred over the weekend. The nature of the calls received was examined and revealed that medication issues were the

major reason for contact. The breakdown of reasons for call is shown in Table 2 below.

Calls received that are listed as ‘Other’ include such things as providing advice to either patients, carers or other health professionals generally, liaison with other agencies including the South Australian Ambulance Service and South Australian Police, and the provision of prescriptions to patients. Liaison with services such as the ECPs, District Nurses and staff at Aged Care facilities occurred on twenty occasions throughout this period and included general advice (counted under ‘Other’) as well as specific advice regarding medication dosage and administration.

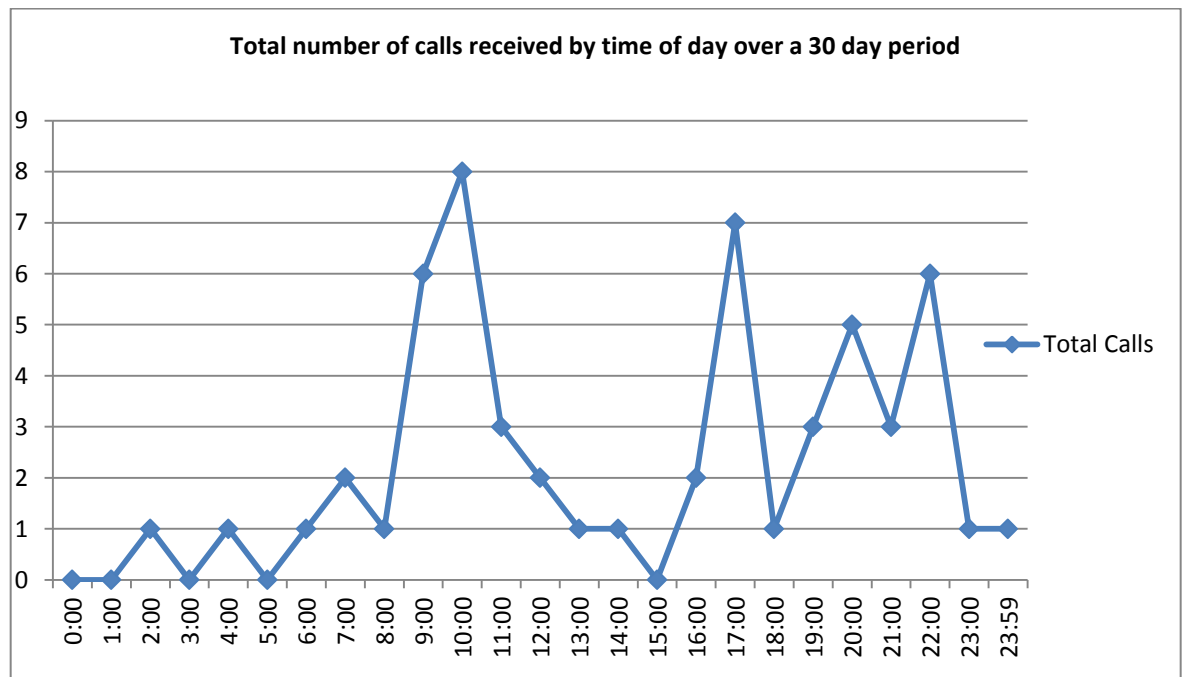
**Table 2. Number of calls received versus reason for call.**

<b>Reason for call</b>	<b>Number of calls</b>
Medication Issue	19
Symptom Issue	16
Other	13
Hospital/Hospice Admission required	4
Patient Deceased	3
Equipment Issues	1
Deterioration	0
Psychosocial Issue	0



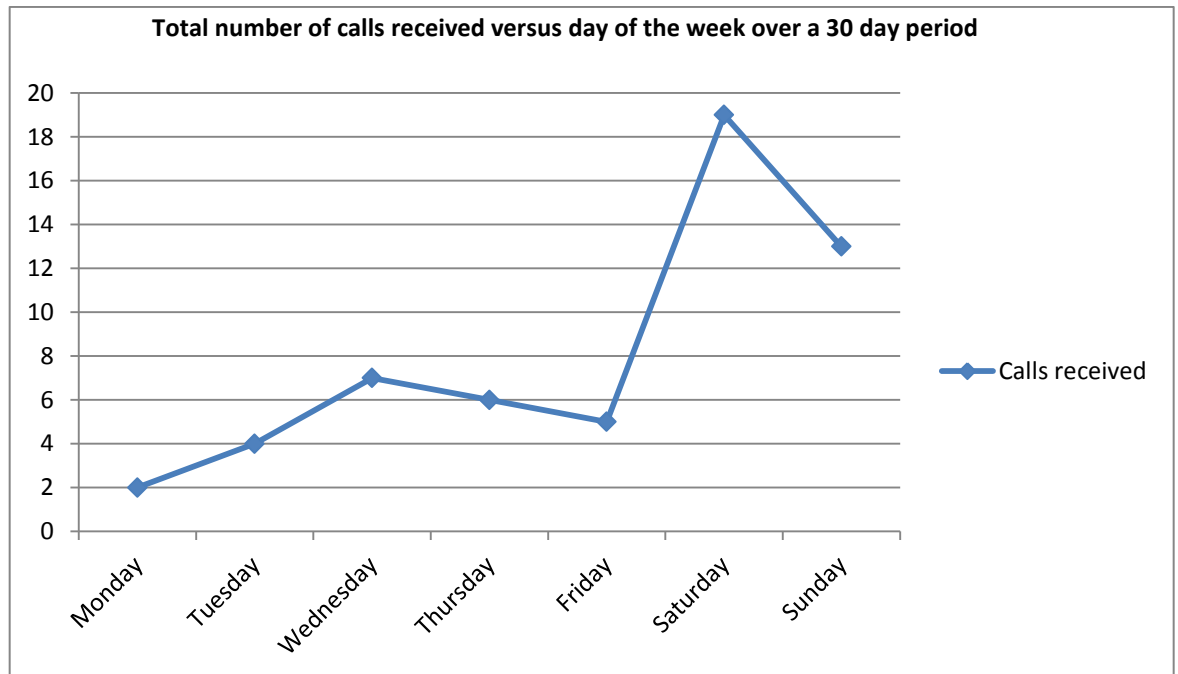
The time that calls were received was also examined. This revealed that calls were received across the twenty-four hour period, but only eight (14%) were received after ten at night and before eight the next morning. The majority of calls were received between five in the afternoon and midnight with twenty-five ( 44.6%) calls, closely followed by calls received from after eight in the morning until five in the afternoon which numbered twenty three( 41%). The spread of the timing of calls is illustrated in Figure 1.

**Figure 1. Total number of calls received by time of day over 30 day period.**



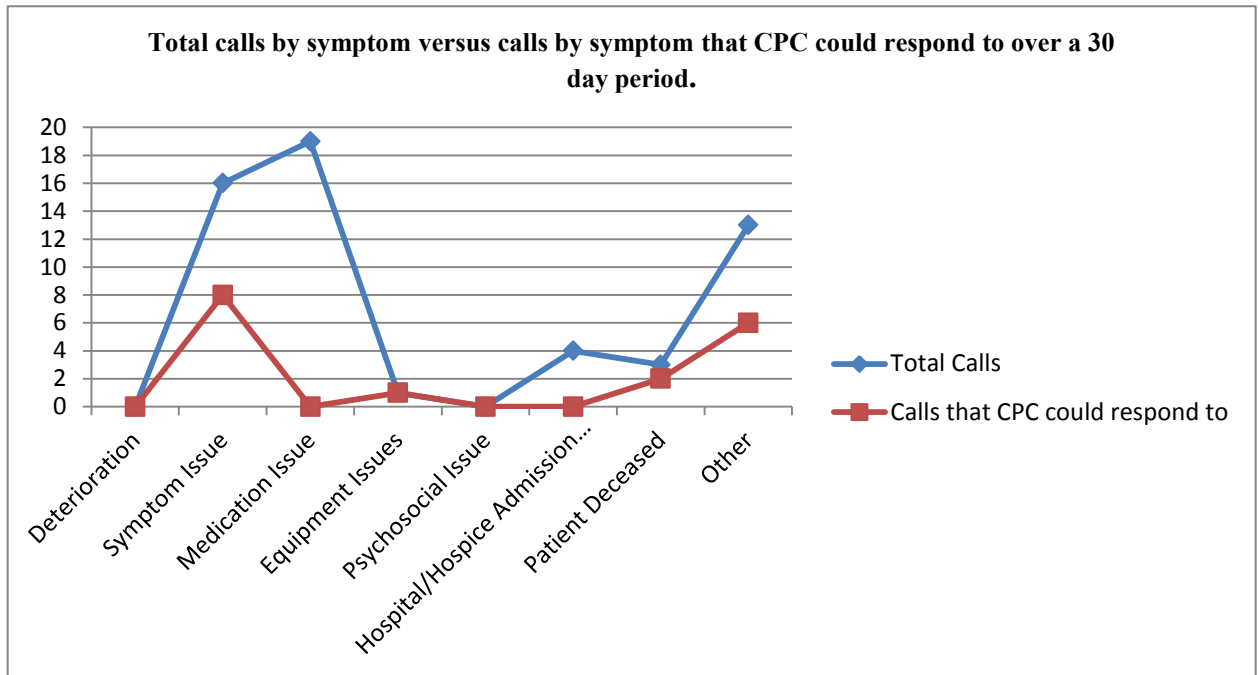
The majority of the calls received occurred during the weekend, with nineteen (33.9%) calls received on a Saturday, and thirteen (23.2%) on a Sunday. This is illustrated in Figure 2. The time of calls received across the weekend was spread across the twenty four hours with the greatest number of calls (93.1%) received between the hours of eight in the morning and ten at night. It should be noted that during the collection period, there were no public holidays.

**Figure 2. Total number of calls received versus day of the week over a 30 day period.**



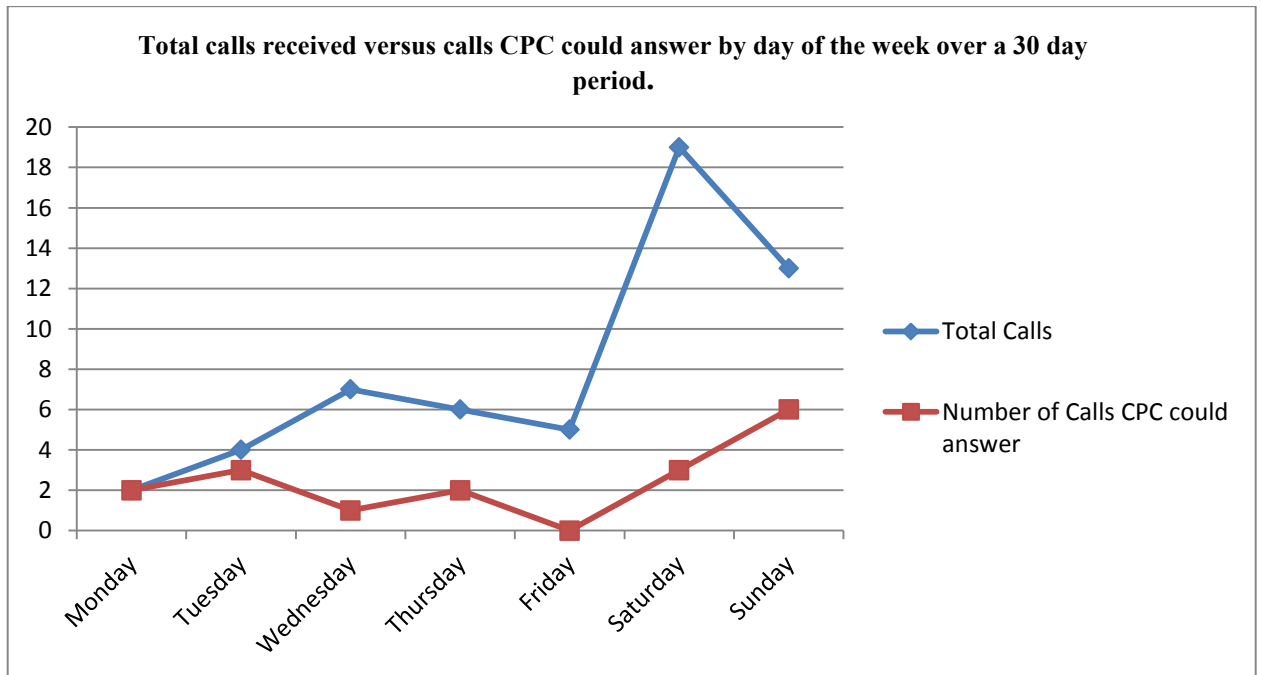
When reviewing the nature of the calls the researcher believes that seventeen calls could have been managed by a CPC effectively. This is 30.3% of the total calls received. These calls involved issues of symptom management, bereavement advice, equipment issues and other calls including liaison with other services. There were five calls that potentially could have been answered by the CPC, but this could not be fully determined by the data provided. These calls are included in the total number of calls received. Figure 3 illustrates the total number of calls received and the nature of the call, versus the nature and number of calls that could have been responded to by the CPCs.

**Figure 3. Total calls by symptom versus calls by symptom that CPC could respond to over a 30 day period.**

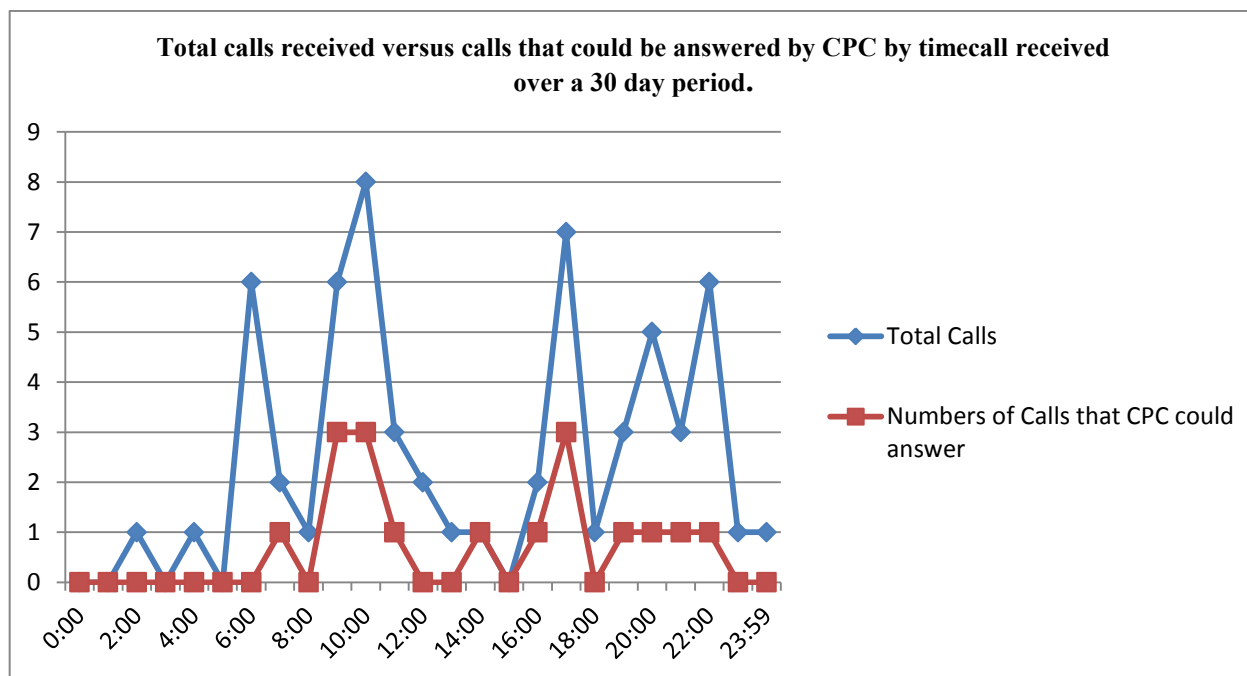


Analysis of calls that were received that the CPC could answer revealed that 52.9% occurred over Saturday and Sunday, with the remaining 47% throughout Monday to Friday. These calls were concentrated between the hours of eight in the morning and ten at night, with sixteen (94.1%) of the seventeen calls occurring within this time frame. This data is presented in Figures 4 and 5.

**Figure 4. Totals calls received versus calls CPC could answer by day of the week over a 30 day period.**



**Figure 5. Total calls received versus calls that could be answered by the CPC by time call received over a 30 day period.**



## Summary

Interviews were conducted with the current CPCs where they were encouraged to express their thoughts about extended hours of care service models both generally and in relation to NAPS and their current client group. The data gathered from these interviews revealed that the CPCs had a good understanding of a variety of models of extended hours care generally and believed that they could provide a potential benefit to patients and carers. In some instances however, there was a discrepancy between the general view of extended hours services versus an extended hours service at NAPS. There was no agreement on the need for an extended hours community palliative care nursing service, nor if there were benefits

to patients of NAPS in the provision of such a service. There was however a consensus on the potential barriers to any extended hours of service model, which included budgetary restraints and resource availability.

The review of the after-hours calls demonstrated that nearly a third of all calls received during this period examined could have been responded to by a nurse. The majority of these calls were received between the hours of eight in the morning until ten at night, with a distribution of approximately half received Monday to Friday and the remainder on the weekend.

Further discussion of these results and their relationship to the literature review will be undertaken in the following chapter.

## **Chapter 6. Discussion**

### **Introduction**

This chapter will discuss the main observations revealed from the study. Beginning with a summary of the purpose of the study and brief description of procedures, it then reflects on the findings of the literature review and the analysis of both the qualitative and quantitative data collected. This will be followed by discussion of study limitations, along with any recommendations for further investigation.

### **Purpose of the study**

This study was an investigation of the views and perceptions of the nurses into an extended hours community nursing service at NAPS. At NAPS, there is a community palliative care service that provides care from Monday to Friday between the hours of eight in the morning until four-thirty in the afternoon, with telephone advice available from a palliative care medical officer outside of these times.

A review of the literature regarding palliative care service provision had identified that there was a need for palliative care to be provided across seven days a week for twenty-four hours each day. This was identified both overseas and within Australia. The literature

identified common themes as critical to the provision of good palliative care, as well as describing some different models of service provision.

Interviews with CPCs within NAPS were conducted to ascertain their views regarding an extended hours nursing service. These participants were also asked to comment on extended hours service models they were aware of, as well as any benefits or barriers with regard to extended hours of service both generally and with a specific client group. This qualitative data was analysed to determine if there were any common themes that emerged, or if it was congruent with the literature previously reviewed.

A quantitative analysis of the calls currently received out-of-hours was also undertaken. This was to determine the number and nature of the calls received and if any of the calls were able to be responded to by a CPC rather than requiring a medical officer.

## **Summary of the findings**

### **The literature review.**

The literature review was undertaken by reviewing literature from overseas initially, and then looking at the Australian experience. Palliative care generally was discussed along with service models that were identified, particularly those relating to the provision of after-hours care. After-hours care was generally accepted to refer to evenings, overnight, weekends and public holidays.

There was general acknowledgement from palliative care professionals that the provision of best practice in palliative care is achieved through the availability of a palliative care



specialist service across seven days a week and twenty four hours a day. This is supported in various countries by guidelines and, in some instances, legislation that has been implemented to promote such services. Although there has been a promotion of extended hours service in palliative care, there has not been a corresponding increase in either health budgets or the provision of additional resources for the development of such services.

As a consequence, a variety of models have emerged as different service groups have sought intermittent funding to institute a trial service, or developed innovative models that utilise existing budgets and personnel. Geographical location, proximity to acute care services, public and private health funding, and the health system of the individual nation have also impacted on what models have developed. These factors were identified both overseas and in Australia. No particular model was identified as ‘the best’, but the consensus was that being able to access specialist palliative care advice for seven days a week and twenty four hours a day provided the best outcome for patients, families and carers as well as other health professionals that work with the palliative patient in the community.

Within this discussion there were common themes that were identified as integral to the provision of palliative care – both generally and in the community setting. The issue of resources, which included funding, personnel and equipment, along with the need for clear, relevant and current communication between health professionals, patients and families were listed as high priorities. In addition, the co-ordination of care, continuity of care and the education of palliative care workers, other health professionals and patients and families were also areas that were addressed. A deficit in any of these areas was perceived as resulting in a service that was less than optimal.

In reviewing the literature pertaining to the Australian experience, these themes were again identified and discussed. Historically service models have arisen out of the individual practices and preferences of palliative care specialist providers, and the resources available to them. Demand for palliative care services has increased with referrals no longer being only for patients with cancer. An ageing population has seen an increase in chronic disease problems, and these patients have an expectation that they should have equitable access to palliative care services. The cost of providing health care services within Australia continues to grow and resources are limited. Despite government reports promoting standardised models of service provision and equitable access to palliative care across the nation, there is limited funding available to implement strategies to achieve this. Similar to overseas, this has seen the development of individual trials and different models of service delivery adopted in some areas to attempt to achieve a specialist palliative care service that is accessible at all times and to all areas.

One such example of the difference in service model provision of palliative care is the after-hours service provided by the palliative care services in Adelaide. While the three Adelaide services all provided a twenty-four hour access to a palliative care specialist service, the model that is used to provide this service differs depending upon the region the service is located in. One service provides after-hours calls with a rotation of nurses as the first contact, another with medical officers as the first point of contact while the third Adelaide service has a combination of both, depending upon the location of the patient.

## **The interviews**

The interviews undertaken were to obtain current CPC views about extended hours service models generally, within palliative care and particularly with regard to NAPS and their current patient group. While all were able to identify a variety of models of extended hours of service, two models were particularly discussed. These included the availability of a twenty-four hour telephone support service for out-of-hours, and a model of staggered hours of working.

With regard to a twenty-four hour telephone support service, all participants were in agreement that the service as it currently operates at NAPS was sufficient. The utilisation of other health professionals to provide 'hands-on' assistance out-of-hours was viewed favourably and having a medical officer for telephone support was perceived as more beneficial than a CPC. Individual expressions about the limits of the CPC compared to the medical officer with particular regard to medication prescription were used to highlight this viewpoint.

A 'staggered hours' service model was also discussed and the views expressed were variable. While viewed as a service model that potentially was a way to benefit patients, families and carers generally, it was not supported by all as a possible method of service delivery at NAPS. Those that were in support of this model, discussed the increased availability of specialist palliative care staff to families and carers outside of standard working hours to provide education and emotional support as important factors in the provision of optimal palliative care. The ability to have a flexible approach to when the staggered hours were undertaken was also perceived as potentially beneficial for patients in

the terminal phase, and the families and carers supporting them. The remaining CPCs viewed such a system as not necessary and not providing any additional benefit to NAPS or any individual patient group.

In principle, all CPCs expressed in various ways support for extended hours generally, however there was no agreement over the need for an extended hours community nursing service at NAPS. Throughout the discussion the issues of resources, communication, education and co-ordination of care were raised by all.

### **The after – hours calls.**

A quantitative analysis of the current after-hours calls received by medical staff at NAPS was undertaken. This data, collected for only a thirty day period was intended to provide an overview of the number and nature of calls received, and allow for investigation of the need for a medical officer to receive these calls or if a CPC could respond appropriately.

The data was grouped by timing of the call including the day of the week, the reason for the call and the type of health professional required to respond in an appropriate manner to the call. The majority of calls were shown to occur over the weekend period when the community service was not operating. The times that calls were received was noted to be highest in the evening, again a period that the community service does not operate. While the second highest number of calls were shown to occur during standard working hours, when these figures were further analysed, the majority of these occurred over the weekend period.

Of all the calls received, approximately one third of calls could have been responded to by a CPC appropriately. The nature of these calls related to symptom management,

bereavement, equipment issues and liaison with families and other community services. With the exception of one call, all of those calls that could have been appropriately responded to by the CPC, were received between the hours of eight in the morning until ten at night. In the review of this data, there were five occasions where a CPC may possibly have been able to respond appropriately but the information provided was inadequate to make this determination.

### **Relationship between the literature review and data collected.**

So how then does this data relate to the literature review? The literature review identified that both globally and within Australia there were gaps in the service provision of palliative care (Twycross 2007; Bestall, et al. 2004; Swerrissen & Duckett 2014). These gaps were particularly identified as occurring in the time considered to be ‘after-hours’. The common themes identified as integral to the provision of palliative care included resources, communication, continuity of care, co-ordination of care and education (King, Thomas and Bell, 2003; Taubert and Nelson 2010; Worth et al., 2006; Nyantanga, 2013).

While the analysis of the qualitative data revealed a consensus that there were gaps in the provision of palliative care generally, this view was not held for the service as provided at NAPS. There was no agreement amongst the participants on the need for an extended hours community nursing service at NAPS or the type of extended hours service that may be beneficial, nor was there overall support for such a service.

Data did confirm that the themes as identified in the literature were mostly supported as important by the participants. Discussion around the issues of resources, in particular staff

and budget were raised as barriers to any extension of hours of service. The importance of ongoing education for self and other health professionals in palliative care generally and for patients and families regarding specific care was highlighted as important to care provision. These views support the findings in the literature review of several authors including Rowlands et al. ( 2012) and Gallagher (2013).

The ability to co-ordinate services for patients in the community was defined as a part of the role as perceived by the individual CPCs, and rated as an important service that they provided. All viewed communication as critical to providing care for patients and families, as well as support for each other and other members of the palliative care multi-disciplinary service. This corresponds with the theme of communication as identified in the literature ( Nyantanga 2013; Worth et al.; 2006, Taubert and Nelson, 2010). It was described that communication between some external services and the CPCs was not always optimal, and that they believed that this had the potential to have a negative impact on the care delivered.

Once again there was disparity between the general view and the specifics of NAPS displayed by the CPCs. This was in relation to the concept of continuity of care within palliative care and the continuity of care at NAPS specifically. All had indicated that continuity of care enhanced the provision of optimal palliative care in the general sense and this reflected information obtained from the literature review by several authors including Taubert and Nelson( 2010) and King, Thomas and Bell(2003). In relation to continuity of care at NAPS however, it was felt that continuity of service was provided by the current service model rather than continuity of care, and some held the view that even with an extended nursing hours this situation would not change. In contrast, two participants'

believed that there would be an improvement in continuity of care if a service model encompassing extended hours at NAPS was implemented.

Analysis of the telephone data supports the literature review findings that there is a strong need for an after-hours service at NAPS. The number of calls received, and the variation of those who sought support after hours - patients and families, other health professionals, aged care facilities and other community services - indicate that the current system is known and used within the NAPS region.

Overall, the combination of the qualitative and quantitative data is not convincing in indicating that there is a desire for an extended hours community nursing service at NAPS. Whilst the concept of an after-hours service is supported generally as represented by the views of the CPCs, there is no consensus for this within NAPS.

### **Implications for practice**

The dissimilarity of responses from the CPC do not present a convincing argument for any implication to practice, apart from the need to potentially undertake a longer and more involved investigation into the issue of an extended hours community nursing service at NAPS. Certainly the data relating to calls to NAPS after-hours suggests that there is a need for an extended hours service, and the literature review supports this stance but the discrepancy of viewpoints of the CPCs means that a single potential model of extended hours service cannot be readily identified, nor is the idea of one fully supported. A

reduction in the number of calls to the medical officer after-hours is not a sufficient reason to change current practice.

In many ways, this study raised more questions than it answers. Why is the concept of an extended hours community nursing service in palliative care viewed as a good idea generally, but not locally at NAPS? What is the underlying message that the current staff are trying to convey? What are the views of the actual users of the system - are they satisfied with the current service; how is current and relevant information made available to those providing the after-hours advice, and how efficient and accurate is the feedback to the community team caring for the patient? Additionally, would changes to the after-hours service reduce hospital admissions or presentations to the Emergency Department, and if so, what would be the potential cost savings; what if any are the benefits to the patient? With calls to increase home deaths and therefore reduce hospitalization costs, this latter could be an important issue to review if undertaking further investigation of this issue.

### **Study Limitations and suggestions for further investigation**

For the quantitative data the collection period was only thirty days, so a 'snap-shot' of calls was all that could be reviewed. As patient cohorts change in number and condition over time, this data set is limited in the information it can provide. Additionally, some data collection sheets were completed with minimal information, thus preventing determination of whether a CPC could respond to the call appropriately or not. As the medical staff completing this data set changed according to a roster system, individual variances in interpretation of required information and level of detail both required and provided



occurred. Informal discussion with medical staff also indicated that there was a possibility that not all calls were recorded as required( Holden & Palmer, 2014, pers. comm., 10 October).

From the perspective of the qualitative data gathered from the individuals, the previous experience that participants had with different service models affected their views and comments. As one participant had indicated and others inferred, their previous experience and their current preferred lifestyle caused them to have a bias against actually participating in an extended hours service which was reflected in their answers. Additionally it should be noted that all participants are senior CPCs of several years' experience, with some approaching retirement. This similarity in age group may also have created a bias in perspective.

Collection of data from patients and families, as well as those health care providers that access NAPS would also have proven beneficial to investigation of this area. As these groups are the 'users' of the service, their views on the accessibility and effectiveness of the after-hours system would have been highly useful data. Unfortunately due to the time constraints of the Masters programme and the obtaining of Ethics approval, this was unable to be undertaken at this time.

As a result of the limitations of this study, any further investigation of this area should involve a more longitudinal analysis of the data collected relating to calls received by the current after-hours service. Additionally, more detailed information about the nature of the call could be collected to enable a more accurate representation of the need for a medical officer or CPC to appropriately respond to the call. The collection of the data by dedicated

staff that were fully conversant of the needs of the study and the information required would also be beneficial.

The collection of data from patients, families and carers, as well as other stakeholders of NAPS (e.g. General Practitioners, RDNS, ECPs) should also be undertaken if further investigation of this area was to occur. Satisfaction levels with the current system could be investigated. Similarly, any negative issues could be identified, and provide guidance for the provision of future improvements within NAPS.

### **Reflections on the Research Process**

The research process has been challenging in many ways and an invaluable learning experience. In particular the process for obtaining ethics approval was lengthy and at times frustrating due to many time delays. On a positive note however, the process of interacting with the participants and the collection and analysing of data has been an interesting and rewarding experience. Being in the privileged position to hear the individual views of the participants discussed in such an open and honest manner was quite a humbling experience.

To complete this research project, the results will be discussed at an education session scheduled to be held in early 2015 at NAPS. All participants will be invited to attend, as will the medical staff at NAPS.

## **Conclusion**

In summary, this study aimed to investigate the views and perceptions of nurses with regard to an extended hours community nursing service at NAPS. With the integration of the Modbury and Lyell McEwin Palliative services to NAPS, there have been considerable changes over the past two years. Not the least has been the increase in patient numbers and the large geographical area that is now served by the community service at NAPS. Additionally changes were made to the management of after-hours specialist palliative care support for patients within the catchment area, with medical officers being made responsible for providing this service. Despite increasing patient numbers, resources remain limited.

Existing research confirms that this situation is not restricted to NAPS, but is a global issue. The management and care of the palliative patient in the after-hours period continues to be an area for investigation and almost 'trial and error' as various models are developed and tested. While the current system employed at NAPS provides a service across twenty-four hours a day, there is no evidence to indicate the level of satisfaction that is experienced by those using this system. This is an area that would warrant further investigation.

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## Appendix 1.



Northern Adelaide Local Health Network  
Research Governance Office  
Level 2, Clinical Trials Unit  
Lyell McEwin Hospital  
Haydown Road  
ELIZABETH VALE SA 5112  
Tel: 08 8182 9346  
Email: nalhnrgo@health.sa.gov.au

21<sup>st</sup> November 2014

Ms Jane Grigson  
University of Adelaide  
North Terrace  
Adelaide SA 5000

Dear Ms Grigson

**HREC reference number:** HREC/14/TQEHLMH/186

**SSA reference number:** SSA/14/TQEHLMH/230

**Project title:** An investigation of the nurses' perceptions and views of an extended hours community nursing service at the Northern Adelaide Palliative Service.

**RE: SSA/14/TQEHLMH/230- Site Specific Assessment Approval**

Thank you for submitting an application for authorisation of the above project. I am pleased to inform you that authorisation has been granted for this study to commence at the following site:

- **Modbury Hospital**

The following conditions apply to the authorisation of this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval to this project:

1. Notification of extensions / annual reviews granted by the lead HREC are to be provided to the NALHN Research Governance Officer (RGO).
2. Confidentiality of the Modbury Hospital research subjects shall be maintained at all times as required by law.
3. Researchers are required to immediately report to the NALHN RGO anything which might warrant review of site approval of the protocol including serious or unexpected adverse effects on participants;
4. Researchers are required to notify the NALHN RGO of any amendments to the protocol (summary of changes) or participant recruitment material (with tracked changes).
5. Adequate record-keeping must be maintained in accordance with GCP, NHMRC, HREC, state and national guidelines.
6. SA Health requires institutions under its jurisdiction to dispose of research materials in accordance with the requirements outlined in the NHMRC Australian Code for the Responsible Conduct of Research.
7. Notification of completion of the study at Modbury Hospital is to be provided to the RGO.
8. A report and a copy of any published material should be forwarded to the NALHN RGO at the completion of the project.

If University personnel are involved in this project, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements

Should you have any queries about the consideration of your Site Specific Assessment form, please contact me on 08 8182 9346 or [nalhnrgo@health.sa.gov.au](mailto:nalhnrgo@health.sa.gov.au)

The SSA reference number should be quoted in any correspondence about this matter.

Yours sincerely

ALISON BARR  
Research Governance Officer  
Northern Adelaide Local Health Network (LMH/MH/PHC).



### **Appendix 3. Interview Guide**

1. Can you briefly describe yourself and your experience in nursing generally, and also your experience in palliative care and community nursing?

This may include things such as years of service in different areas, types of service or field of nursing worked in. An overview of different nursing experiences you have had.

2. What do you understand by the term “extended hours of care”?

Can you tell me what this means to you, and what type of models you may have heard of or can think of?

(Examples may include 24/7, 7 day services, longer shifts)

3. What are your views about an extended hours palliative care community nursing service – generally and at NAPS?

Please elaborate on your answers. What would you see as the benefits or barriers to extended hours services?

4. Based on your understanding of your current client group, do you think that there would be any benefit to an extended hours community nursing service at NAPS and why?

Is there anything else that you would like to add or comment on?

Thank you for your time today.