

**EVERYDAY DISTRICT NURSES' EXPERIENCES REVEALED
THROUGH DISTILLATION:
PALLIATIVE CARE IN THE COMMUNITY – AN ACTION RESEARCH
PROJECT**

by

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**A thesis submitted to the Victoria University of Wellington
in partial fulfilment of the
requirements for the degree of
Master of Arts (Applied)
in Nursing**

Victoria University of Wellington

2006

ABSTRACT

Distillation is used to extract and reveal essential oils and essences. Action research is a methodology that enables distillation of nurses' experiences, to reveal previously unseen elements and essences of nursing care, to identify issues and to extract tangible change or action outcomes. This modified action research inquiry focused on the everyday, palliative care practice experiences of a group of district nurses.

The intent was to develop an understanding of common issues of concern for this group of district nurses when providing palliative home care in a specific community context and to implement practical, achievable strategies in response to these local issues. Five district nurses identified four broad areas for action through four praxis group meetings and comprising one full cycle. These four areas have been named as methods of enhancing support for people and families, possibilities for creatively managing workloads, mechanisms to enrich working partnership with other palliative care providers and possible vehicles for supporting nurses' self care. Implementation of action from this action research project focused on enhancing care and outcomes for people and family served by this group of district nurses in their local community. This study illuminates everyday essences of the district nurse role and the elements articulated by this group in supporting their practice in one New Zealand community. This study also reveals some of the tensions and messiness when employing an action research methodology with nurses in the workplace.

This research focused on a little known area (palliative care delivered by district nurses in New Zealand) in a local community (a culturally vibrant and ethnically diverse yet with poor health and socioeconomic statistics). It has resonance with other nurses, particularly those working in community settings who may experience similar issues and concerns. This research also offers important insights for nurses working in any practice setting, with a desire to unpick and distill local issues they encounter – to take action and make a difference.

DEDICATION

This thesis is dedicated to the loving memory of Jilis Nobel, my partner and soul mate, whose sudden loss from our lives ignited this journey of learning for me. Also to the people and families in this community who I have been fortunate enough to come to know and be with on their journey.

ACKNOWLEDGEMENTS

My first acknowledgement is to my daughter Emma, ‘Ems’, for listening to me “go on and on” (her words) about my research, for your tolerance and patience and on numerous occasions, waiting for me while I “just add one more thing”. I know you are looking forward to having your mum “back”. I thank you so much for your love and support. My love and thanks to Yvonne Lane, you are my dearest friend and my wisest counsel.

I have been incredibly fortunate to have Dr Kathy Nelson as my supervisor. You have showered me with robust dialogue, encouragement and ‘structure’, which has been instrumental for me in completing this work. And so much more, Kathy, thank you. I also acknowledge the support and guidance I received from Dr Cheryle Moss at the commencement and at the completion of this thesis.

My new colleagues at Whitireia Community Polytechnic have humbled me by giving me the greatest gift of all – time. Fran Richardson, Kay Laracy, Nicola Gray, Jo Bond and Cath Tuohy, I cannot thank you enough for your genuine support and ongoing interest. I am also grateful to Whitireia Community Polytechnic for their generosity for research funding. I also acknowledge and thank Kerrin Arcus for your enthusiasm and passion for district nursing along with your critical eye and sharpened pencil.

My greatest thanks go to my colleagues at Community Health Services, past and present and especially to those who joined me in this research project. There are no words to express my thanks to you. I hope this work honours and ‘reveals’ the inspirational contribution you have made and continue to make, to district nursing and to our community.

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CHAPTER 1: Planning for distillation

This thesis reports on research into the richly layered, textured world of district nurse palliative care practice. The nature and scope of district nursing practice is challenging with stark contrasts and multiple shades of grey and is as diverse as the communities the nurses serve.

Life and health circumstances of people and families supported by district nurses are increasingly more complex. Demands on district nursing knowledge, skills and resources continue to grow as the move to community care accelerates. The reasons for this shift will not be explored here, however the growth in this area has implications for community nursing practice, in this instance district nurses. Palliative care is one area of increasing demand in the community. This research provides a view of district nursing in New Zealand and reveals issues common to a group of district nurses who provide quality palliative nursing care at home. In exploring concerns the nurses encounter delivering this service, this group worked collaboratively to construct a plan of action to address these local issues, with the primary focus of enhancing the nursing support and care they provide people and families in this diverse community. This research articulates the essences of the district nurse role and the elements that support this group in their practice in providing quality palliative nursing care at home.

District nurses

District nurses are a 'free to the user' government funded (through national taxes) nursing service. 'District nurse', 'primary health nurse' and 'community nurse' are terms used interchangeably in some nursing literature. In an intentional effort to maintain the focus on district nursing, the term district nurse is consistently used and referred to throughout this thesis. District nurses work in partnerships, carefully negotiated with the person and family, generally providing care in the home. The term 'family' is used throughout this thesis to broadly encompass those people the palliative person deems significant in their life. Essences of the district nurse role, in working with and honouring the uniqueness of the person and family in one New Zealand community, is articulated in this thesis against the backdrop of an ever reforming health system and evolving community health 'care' provision.

For ten years I was based at Kenepuru Hospital, Porirua and was involved in delivering community based palliative care nursing. Initially as a generalist district nurse, then working with a team of district nurses in a practice leadership role, I have reflected over the years on recurrent common issues district nurses have experienced when providing palliative home nursing care with people in this particular community. The relationships the district nurses and I have had with people and families have lasted for some years, from diagnosis and treatment, through to the end of life or for as short a period as a few hours. I was aware a significant proportion of the district nursing work for the team I worked with involved supporting people and their family at home, through the terminal phase of their lives. This research focused specifically on these relationships and experiences.

In considering this research project, my intentions were to articulate the current context of local district nursing palliative care practice and to encourage safe sharing of practitioner knowledge, wisdom and experiences. I hoped concrete outcomes and actions would emerge through using collaborative processes, to directly enhance outcomes for people in this local community. I came to see these research processes as distillation. The aims of the research question were to develop an understanding of issues of concern for these district nurses through articulating common group experiences when providing palliative nursing care. A further aim was to develop and implement practical support and realistic solutions to the issues of priority for the group. These aims were in response to my personal and professional interest.

The district nurse role in New Zealand, is, at best, obscure. There is very little New Zealand literature that articulates district nurses practice and even less that actively locates the district nurses' role in palliative care nursing. District nursing practice is so much more than the technical, practical aspects of nursing care, 'what we do with our hands'. In my experience district nurses are creative problem solvers, deft orchestra conductors (pulling together the 'threads' and resources with people and family, health and social service providers) and have enormous tenacity and perseverance (often required for pushing contractual boundaries). The district nurses I have worked with have been totally committed to people and families.

Palliative care

For the purpose of this thesis, palliative care relates to the total care of people who are dying from active, progressive diseases or other conditions when curative or disease-modifying treatments come to an end (Ministry of Health, 2001). Palliative care has received increased government attention over recent years in New Zealand with the release of the *New Zealand Palliative Care Strategy* (Ministry of Health, 2001). This strategy is an approach to reduce the variability of access to and provision of palliative care services. However, nationally there remains diversity of what constitutes palliative care, when and under what circumstances a person is determined to have entered the palliative phase of their illness and what services are available and subsequently provided to support the person and family.

Thesis overview

This introductory chapter broadly outlines the context of this research enquiry and provides an overview of the thesis. The development of district nursing in New Zealand is diverse. Therefore, the local district nurse context is described in depth in Chapter 2. Although palliative care constitutes only a portion of work undertaken by the group of district nurses involved in this research, palliative care provision is one of a number of health care areas under review on a local and national level. Chapter 2 explores the local impact on district nurses of government driven national changes in palliative care provision.

The specific knowledge, roles and skills evident in district nursing practice are articulated in Chapter 3. The chapter presents international district nursing literature, particularly from Britain, identifying the roles played by district nurses, often in partnership with specialist palliative care providers, in the delivery of home based palliative care. District nurses in Britain have identified terminal care as a significant and defining example of district nursing work. The difference district nurses make in palliative care is reflected in literature exploring palliative care experiences from family's perspectives. District nursing literature revealed the establishment of relationships, the authenticity of these relationships and the pivotal process of coming to know people and families when providing palliative care in the home. British district nursing literature also surfaces issues that challenge district nurses' ability to provide quality palliative care at home. These include resource rationing, challenges

in interdisciplinary relationships, and cumulative grief. These issues are critiqued and explored in Chapter 3.

Action research methodology has been used internationally by a growing number of nursing researchers to focus and address issues in their local context. Reflection, as an essential element of action research is presented. How this methodology has been applied in nursing is critiqued in Chapter 4, with an exploration of the strengths and challenges action research presents. A particular emphasis on ethical considerations when utilised by researchers within their immediate workplace context is also discussed.

The design and planning of this research project are stated. Using an action research methodology, five district nurses shared their experiences, reflecting on their practice of providing palliative home nursing care with people and families over four praxis group meetings. The group worked together to formulate practical and realistic actions they could take to address the issues raised. These localised actions were intended to improve outcomes for people and families in this community. While the focus of the praxis group meetings was palliative home nursing care, the district nurses acknowledged these actions may also improve outcomes for other people and families the district nurses worked with.

Chapter 5 articulates the processes of the action research journey as the research unfolded. Issues that arose and challenged the intended design of the research are explored. This chapter provides the evidence to demonstrate the authenticity and trustworthiness of this action research project.

Chapter 6 presents those issues that resonated within the group throughout the praxis group meetings. The essential elements the district nurses believed enhanced outcomes for people and their families are revealed. The essences of district nursing practice, distilled throughout the praxis group meetings are highlighted. Some comparisons of the New Zealand context are made, as experienced by this group, with those issues and themes illuminated in the international district nursing literature explored in Chapter 3.

Concluding comments and reflection of the research including an update of the action undertaken by the group members is provided in Chapter 7. Implications for nursing practice are presented. Considerations for nurses in practice planning to undertake research, particularly action research, in their workplace are discussed. Ideas and questions to be considered for future nursing research as a result of this action research project are articulated. Limitations of this research project are outlined.

CHAPTER 2: Local and national context

Introduction

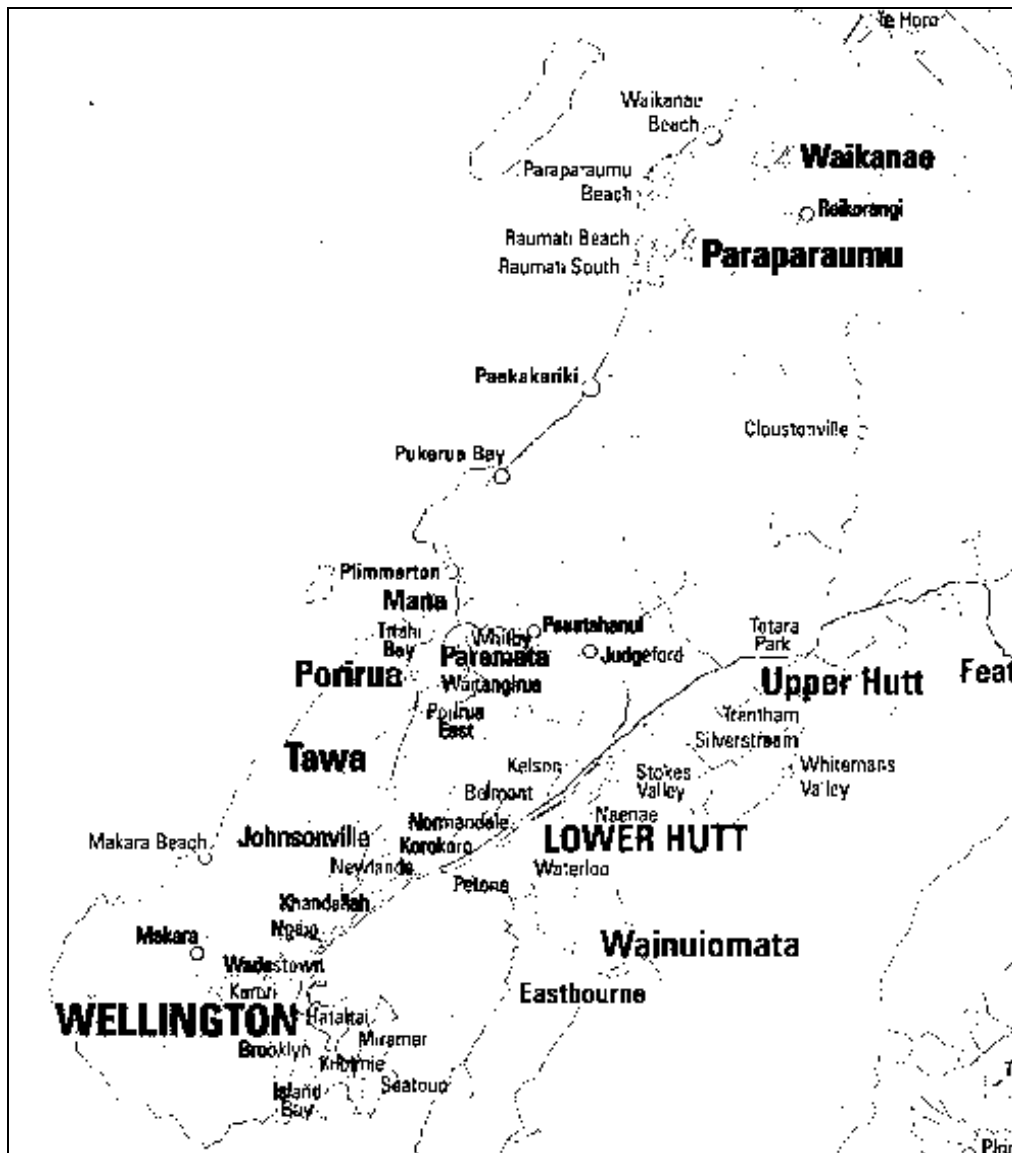
This chapter presents an overview of the community, in which this research is located highlighting the diversity of the local area, including its economic and health disparities. The national context is also outlined. Understanding the local and national context is vital to this research. These contexts ‘shaped’ and directly impacted on the district nurses working environment, their professional relationships with other health providers and their everyday palliative care practice experiences. Emphasis is given to national health reforms, begun in earnest in the 1980s, along with subsequent government initiated changes in health care direction. How these have impacted on district nursing services and palliative care provision locally is explained. As of February 2006, Capital and Coast District Health Board provided palliative care locally, in partnership with a specialist palliative care provider. This development was in direct response to the health reforms and government initiatives presented in this chapter. The chapter concludes with an outline of the current district nursing structure in Wellington and a snapshot of the ‘typical day’ of the district nurse in this community.

District nursing in Wellington, the capital city of New Zealand, is situated as part of Community Health Services (CHS) at Capital and Coast District Health Board (DHB). Capital and Coast DHB catchment area includes Wellington city and all suburbs, extending north up the west coast, including Porirua and surrounding suburbs, through to the Kapiti Coast ending with the boundary of neighbouring ‘MidCentral’ DHB, at Peka Peka, approximately 70 kilometres north of Wellington city centre. Capital and Coast DHB also borders Hutt Valley District Health Board, although the exact boundary continues to attract ongoing dialogue, particularly between the respective Community Health Services.

Capital and Coast CHS has three bases, one being at Wellington hospital, a base 26 kilometres south of the Kenepuru community hospital campus in Porirua, and another, 27 kilometres north from Porirua on the Paraparaumu community hospital campus on the Kapiti coast (see Figure 1). Each base serves a distinctly different community. This research is based in the Porirua Basin. The population served by this group of

district nurses extends past the census designated boundary of Porirua, encompassing other suburbs south to the edge of Wellington city.

Figure 1: Map of Capital and Coast District Health Board



Source: Ministry of Health (2005), reproduced with permission.

Porirua, the local community context

The population of the Porirua Basin is diverse, with 47,370 residents (Statistics New Zealand, 2003, see Table 1). Economic and health disparities are evident within ethnic populations in New Zealand. Porirua has, at 20%, a higher than the national average Maori population; higher than the national average Pacific Nations population (23%) and an increasing population of migrant peoples. In 2001, 18% Maori and

19.9% Pacific Nation peoples living in the Porirua Basin were unemployed, four times the reported rate for Europeans. The 2001 census indicated 5.1% of homes in Porirua did not have telephones, however in some suburbs such as Waitangirua and Porirua East, this rose to 16.3% and 16.8%. More than a third of households in the Porirua suburb of Cannons Creek North did not have a motor vehicle. Although the average household income was higher (\$20,500) than the New Zealand average (\$18,500), there are some suburbs in Porirua that have a higher than the national average number of people with low incomes (less than \$15,000 per annum).

Table 1: Capital and Coast District Health Board notable demographics features

	Total	Maori	Pacific	European	CSC Holder s	Unemployed
Wellington	162,981	12.5%	7.9%	81.6%	20%	7.1%
Porirua	47,370	20.5%	26.7%	63.9%	33%	10.3%
Kapiti	33,666	10.0%	<5.0%	94.6%	25%	7.0%

CSC = Community Service Card Holders [This is an income tested subsidy for GP visits and pharmaceuticals (Cheyne et al., 1999)].

Collated from New Zealand Census 2001, Statistics New Zealand, 2003.

Concerns regarding the poor health status, as a result of socioeconomic factors, for some groups of people living in Porirua culminated in a joint project in 1999 between the Porirua community, the Porirua City Council, the Ministry of Health and Capital and Coast DHB (Porirua Healthlinks, 2000) to address the health needs. People living in Porirua are more likely to be hospitalised for “avoidable and unavoidable conditions” (Porirua Healthlinks, 2000, p.24) than people living in Wellington and Kapiti and these rates are higher than the national average. The project membership acknowledged improving health required a focus on “the wider social, cultural and economic factors that affect health, as well as access to health and disability services” (Porirua Healthlinks, 2001, p. 6). A strategic plan was developed to improve access to and equity of services alongside the promotion of culturally acceptable primary health care and community providers, specifically the development of Maori and Pacific providers. This development reflects current government policy aimed at reducing inequalities for Maori, Pacific people and people on low incomes. New Zealand

health statistics (Ministry of Health, 2002) demonstrate Maori have had and continue to have the poorest health outcomes, along with Pacific people, of all New Zealanders. *Reducing Inequalities in Health* (Ministry of Health, 2002), a joint project led by the Maori Health and Public Health Policy Groups from the Ministry, provides an analysis of these statistics in terms of deprivation. The report indicates “more than half the Maori population lives in very deprived neighbourhoods” (p. 10), and the “average life expectancy for Maori is consistently less than that of non-Maori, even taking into account deprivation” (p. 11). The report comments that for Maori, “historical decisions such as the signing of the Treaty of Waitangi and the subsequent land confiscations have had a significant impact on present health patterns” (Ministry of Health, 2002, p. 17).

In Porirua, reported rates of ‘pick up’, for prescriptions is also below the national average (Porirua Healthlinks, 2000) and anecdotal evidence suggests this is cost related. There are fewer numbers of general practitioners in the Porirua Basin, than in Wellington and the rest of New Zealand (Fleming, 2002; Napp, 2001; Rendle, 2004). Costs to seek medical advice, particularly after hours have also historically been an issue in Porirua (Boland, 2000; Macdonald, 2004a, 2004b).

Dialogue with the community took place, following the development of the new Accident and Medical facilities, based at Kenepuru hospital, which had been scheduled to open in May 2005. However, a final decision regarding part charges for accessing this service took time to be resolved following fierce opposition from the community and the opening of this facility was delayed for three months. Some general practitioners are available overnight for people and their families dying at home. This is an ad hoc arrangement. Otherwise telephone medical support is available from the local Hospice inpatient unit at Wellington, 45 minutes drive away.

Health care provision in New Zealand has undergone numerous structural changes in response to changing government and corresponding ideological stances. This began with fundamental changes in health funding and service provision instigated during the national health reforms in the 1980s and 1990s, directly impacting on district nurses’ roles. These reforms continue to influence the services district nurses now provide. This is also outlined in the following section of this chapter.

National health reform

From 1984 to the late 1990s, commencing with the introduction of Area Health Boards by the fourth Labour government, successive New Zealand governments implemented wide ranging health system reform governed by neoliberalism or a market driven paradigm (Kelsey, 1999). The aim was to achieve greater efficiency and accountability (Gauld, 2001). Neoliberalists believe the market, not the government, is the central institution (Cheyne, O'Brien, & Belgrave, 1999).

These health reforms were instituted alongside far reaching economic and social service restructuring. These particularly impacted on low income people with the introduction of part charges for previously free health services, market rents for government housing and multiple benefit cuts (Cheyne et al., 1999). Various governments during this time instigated a variety of health system reviews, seeking input from individuals aligned to large corporate businesses. Alan Gibbs, a prominent businessman and advocate of the market-orientated approach chaired the Hospital and Related Services Taskforce, just one of a number initiated by the Labour government during this period.

The Gibbs report (as it became known) recommended a funder purchaser provider split (Gibbs, 1988). This recommendation was eventually implemented by the newly elected National government. In 1991, then Health Minister the Honourable Simon Upton referred to the Hospital and Related Services Taskforce's report *Unshackling the Hospitals* (Gibbs, 1988), in deciding to go ahead with the Gibbs report recommendation of separating the purchasing and provision roles which were at that time undertaken by Area Health Boards.

The Health Minister, in his report *Your Health and the Public Health* (Upton, 1991), outlined the establishment of four Regional Health Authorities charged with buying health services. "Their sole task will be to purchase the health services that best meet the needs of their communities" (p. 21) stating that "the Government seeks to increase efficiency, self reliance and fairness, and enhance personal choice" (p. 94). Health delivery became more explicit through contracts negotiated between purchaser and providers. The Health Minister also expected Health Authorities to make a profit. A further myriad of various government reports on health ensued. One such report was

entitled *Providing Better Health Care for New Zealanders 1992*, released by the National Interim Provider Board. This board was appointed by the government and the then Minister for Crown Health Enterprises, Paul East, “to make recommendations within that [*Your Health and the Public Health*] framework to reform the structure of the public hospital system and its associated community services” (p. 5). The National Interim Provider Board asserted “because health care providers will be competing for business they will have a strong incentive to satisfy both the patients in their care and the RHA (Regional Health Authority) which pays most of the bills as the agent of the patient” (p. 68). One of the key principles recommended by the Board for the ‘Businesslike Provider Model’ was that of “an arm’s length relationship between the Government and operational management” (p. 39).

The ‘funder-purchaser-provider’ split was viewed by government, as a way to address perceived monopolies by public providers, with other agencies able to contract for those services they felt they were better placed to provide more efficiently, in this instance community palliative care. In 1993, Area Health Boards were restructured, to form Crown Health Enterprises, or ‘CHEs’. Competition among CHEs, Maori providers, and private and community organisations within a quasi-market would, it was argued, ensure better use of resources and make health care more responsive to consumers (Cheyne et al., 1999).

The effect of this split and the unbundling of services took time, however by 1995 district nurses locally were beginning to experience the impact in their workplace. The 1995 Community Services Review (Capital Coast Health Limited, 1995) stated that “as a consequence of the health reforms”, there was now the need to establish “clearer entrance and exit criteria with both internal and external purchasers” in the new “contestable environment” (p. 2). The review acknowledged Community Health Services were demand driven and with limited resources, was not able to meet all patients’ needs. District nursing services were now contract based, output driven and competing with other health providers to provide nursing services.

Local community palliative care delivery also changed. In October 1997, the then Central Regional Health Authority renegotiated the community palliative care contract. Mary Potter Hospice joined Capital Coast Health Limited (at that stage the

local CHE, now known as Capital and Coast DHB) in the provision of palliative care services. Prior to this provider partnership being established, Capital Coast Health Limited had been the contracted community palliative care provider, and community palliative care services were delivered in partnership with general practice. The Central Regional Health Authority purchased a contract from Mary Potter Hospice for the co-ordination of palliative care in the geographical area covered by Capital Coast Health Limited. This broadened the availability of specialist palliative care services to include care for those people dying from conditions other than cancer. The 'specialist provider', the local hospice, appointed care coordinators to work in the community alongside district nurses and other members of the wider multi-disciplinary team.

In a further significant outcome, a specific contract was signed in 1997, enabling the purchasing of nursing care directly from Community Health Services. The contract focus was those people dying at home, who chose to register with Mary Potter Hospice, met the hospice entry criteria and were accepted onto the hospice programme. Capital Coast Health Limited community oncology nurses who had provided palliative community nursing care were withdrawn. A new role focused on supporting those people having active treatment was created. These specialist nurses were called community cancer nurses.

All registered 'generalist' district nurses from Capital Coast Health Limited continued to provide palliative nursing care in the home. People receiving district nurse services retained the right to choose whether to accept a referral to Mary Potter Hospice for specialist palliative care input. These decisions were generally made in consultation with the family doctor. In the event the person and family chose not to be referred for specialist palliative care or they did not meet hospice access criteria, they would continue to be supported at home by their family doctor and the district nursing service. Elsewhere in some areas of New Zealand, such as Hutt Valley DHB, all palliative care services were already being provided by the specialist palliative care provider, with no input from district nursing services.

A further Labour government late in 1999 heralded yet further restructuring of health services. The four Regional Health Authorities merged into one single Health

Funding Authority. There was now a “desire for service integration and for emphasis on primary care ...[and] would reduce the number of primary health agencies and facilitate improved coordination and interface with other services” (Gauld, 2001, p. 163). Primary Health Organisations (PHOs) were developed. This plan was implemented by the Health Minister, Annette King, in a redrafted document *The Future Shape of Primary Health Care 2000: A discussion document* (King, 2000), and was designed to complement the establishment of the new District Health Boards (DHBs) replacing Hospital and Health Services. While funding for the new DHBs and PHOs would be population-based (paid on ‘affiliated’ or registered patients), the push was now for health services to once again be non-profit organisations. Competition was eliminated and the Health Funding Authority (HFA) abolished. Some purchasing functions of the HFA were handed over to the new DHBs, with the majority of members on these boards elected by the communities they represented (as opposed to Government appointed officials). The newly established Ministry of Health was charged with being the ‘principal agency’ responsible for policy advice, and amongst other things, funding and monitoring the health and disability sectors.

Palliative Care Strategy 2001

The Labour government initiated multiple reviews and published national health strategies, including the *New Zealand Palliative Care Strategy* (Ministry of Health, 2001). The Palliative Care Strategy was developed “in response to an increasing number of problems and issues identified by providers (particularly hospices)” (Ministry of Health, 2001, p. 1). Developing the Strategy involved widespread consultation undertaken throughout New Zealand, with input from stakeholders and sector interest groups. Local public meetings and focus group meetings were held to encourage direct feedback from the public, providers, carers and people already receiving palliative care services. Through feedback from community and provider consultation, along with input from an expert advisory group (in palliative care) appointed by the government, the intent was to “set in place a systematic and informed approach to the provision and funding of palliative care services” (Ministry of Health, 2001, p. 6). The vision was to ensure

All people who are dying and their family/whanau who could benefit from palliative care have timely access to quality palliative care

services that are culturally appropriate and are provided in a co-ordinated way.

(Ministry of Health, 2001, p. vii)

The Strategy reported that for 91% of Hospital and Health Services in 1998-99 (p. 36), “the bulk of hospital service delivery for people who are dying is by district nurses through community health services” (p. 35). Despite this, there were very few individuals or groups who identified themselves as district nurses or representing district nurse groups and appeared to make submissions or attend the publicly held meetings on the palliative care discussion document. Poor co-ordination and integration of services among providers had been identified during the consultation process, with “significant boundary issues impairing the delivery of seamless care (for example, in some places there are poor relationships between hospice staff and district and hospital nurses, and these are not helped by existing contracting mechanisms)” (Ministry of Health, 2001, p. 48).

Also highlighted in the Strategy was the need “for a more responsive system that can support a person’s choice to die at home” adding that in New Zealand, “research shows that 50% to 70% of people would prefer to have the choice of home care; at present, only 31 percent of people with cancer die at home (although for Maori and Pacific peoples the figure is 53% and 42% respectively)” (p. 6). The Strategy is not specific as to how these statistics were collated. In my experience, while people may have indicated earlier in their illness their wish to die at home, when their condition becomes terminal, whether they are able to remain at home is dependent on a number of issues. These include availability of family/whanau support, whether the person’s family/whanau is able to manage the intense, challenging position of caring for a dying loved one, whether the person’s particular symptoms are manageable at home and access to and the cost of the family doctor (GP). Overseas palliative care literature presented in the following chapter provides some insight into these complex issues.

Maori and Pacific peoples were identified in the Strategy as having specific palliative care needs that required addressing, following local ‘hui’ or meetings with community

representatives. While these needs are not explicitly located in the Strategy, the Strategy recommended

In order to address the needs of Maori, it is important that Palliative care services have policies in place that recognise the specific needs of Maori. There are linkages between palliative care providers and Maori development organisations, and that a plan for services for local Maori is developed to assist in meeting the specific needs of Maori. At a local level, where appropriate, each provider should employ one or more care co-ordinators who could meet the special needs of Maori, particularly in those areas with a high Maori population.

(Ministry of Health, 2001, p. 12)

Also identified was the need for palliative care services and other health services to “understand Pacific cultures in terms of care of the dying” (Ministry of Health, 2001, p. 13). The recruiting of Pacific health professionals and volunteers where there is a high Pacific population, such as the Porirua Basin, was encouraged. *Reducing Inequalities in Health* (Ministry of Health, 2002) also highlighted the need for culturally appropriate strategies, drawing on deprivation and health outcome statistics, which for Pacific people are “more skewed” (p. 10), than Maori.

Localised response to the *New Zealand Palliative Care Strategy* saw the immediate palliative care context put under further review. This review was in place at the time of this research. The review involved a DHB wide assessment and evaluation of palliative care services by the planning and funding arm of Capital and Coast DHB. The review, I believe, is a localised attempt to ensure timely access and equity to palliative care services and expertise. It is unclear as yet whether this review will alter the role of local district nurses in palliative care nursing provision. The review could affect local district nursing services. Another Strategy that has impacted on the district nurse role is the *Primary Health Care Strategy* (Ministry of Health, 2001). There is presently a politically driven acceleration to move nursing services back into community (as opposed to hospital focused) organisations. This acceleration is in response to the Labour Government’s *New Zealand Health Strategy* (King, 2000) and

the *New Zealand Primary Health Care Strategy* (King, 2001), and an associated push to move health care provision to Primary Health Organisations (PHOs).

Challenges in creating a national picture of New Zealand district nursing

In New Zealand in 2004, there were 918 registered nurses and 123 enrolled nurses who reported they were employed as district nurses (New Zealand Health Information Service, 2004). Each district nursing service developed independently, in response to changing political, contractual, and institutional and community need. Evidence of this is located in the New Zealand Nurses Organisation (NZNO) District Nursing Section Newsletter, a four times a year publication which updates changes or developments undertaken by district nursing services in the various regions. An example is a pilot programme undertaken in Northland, with some district nurses working within general practices (as is already the case in Britain) in a PHO partnership (New Zealand Nurses Organisation, 2005a). There is also an arrangement in New Plymouth where district nurses subcontract to PHOs to provide some areas of nursing care. No similar developments are apparent in Porirua or Wellington. These developments may signal a philosophical shift in the role of district nurses. In the current climate, it would appear the role of the district nurse has undergone a subtle transformation, to support the reduction in the length of hospital stay, therefore creating virtual wards in the person's home in the community. The role of keeping people out of hospital, more traditionally the role of the district nurses would appear now to have moved towards the responsibility of primary care led services.

There is no nationally accepted level of competence or experience required before a nurse is employed as a district nurse. The level of responsibility and autonomy of district nurses has historically been recognised by district nurses retaining traditional additional salary steps, as opposed to those nurses working in an inpatient setting who do not qualify for these salary steps. In 2005, while this research was being undertaken, a national process to scope district nursing practice (along with other nurses identified as holding senior nursing positions) was completed (New Zealand Nurses Organisation, 2005b). This was in response to the ratification of a national nursing and midwifery collective agreement (New Zealand Nurses Organisation, 2005c). While this exercise was salary related, what may become evident is the national diversity of the district nurse role.

Local district nursing service reviews

Restructuring and redefining of Capital and Coast DHB district nursing services has been in response to local issues or driven by changes in health policy, including service specification contracts outlined earlier in this chapter. Sustained service re-engineering and the potential for role confusion can have a significant impact on those delivering the service, in this instance, generalist and specialist district nurses. Community Health Services (CHS) at Capital and Coast DHB has been reviewed in 1982, 1989, 1990, 1994, 1998 and again in 2004.

Following the 1998 CHS review, some specialist and generalist district nursing services traditionally provided in the home changed. This change continues with district nurse services developing in a variety of community and inpatient settings including clinics, run at each base. This mechanism developed to manage increasing demand, while also responding to the Capital and Coast DHB drive towards ambulatory care. People living at home, their family or neighbours were able to 'self' refer to the district nursing service however this ceased after 1998, with health professionals and social service providers becoming gatekeepers to the service. This created a reliance on these other providers to recognise when a person needed and would benefit from district nurses being involved in their care.

The core business (an essential health management term that has become part of the local district nursing language) for district nurses was redefined in 1998 as 'specialised nursing', with a focus on complex care. This included oncology, respiratory, continence, home intravenous therapy, stomal therapy, wound care and palliative care, along with some of the existing complex 'generalist' district nursing work. Locally, all district nurses at Capital and Coast DHB have an understanding of who is considered to be the core business. District nurses screen new referrals and make decisions (particularly after hours), regarding those people who meet specific criteria to receive district nurse services. Those who do not meet the service criteria are declined access to the service and referred back to the referral source.

As a result of contract boundaries, each person admitted into the district nursing service at Capital and Coast DHB, requiring generalist or specialist district nursing, is aligned to a specific funding stream, called an event. For example, people referred with a palliative diagnosis, or if currently receiving district nursing services and the

person's condition or prognosis changes from active treatment to one of palliation, their funding stream is identified as palliative care. A palliative care event is opened and, if the person was already known to the service, their previous event is closed. Every visit or telephone contact made by the generalist or specialist district nurse is recorded on a weekly running sheet and this is called a 'contact'.

In the latest CHS review (Capital & Coast District Health Board, 2004), community palliative care was identified as one of the main core 'businesses' or components of the district nursing service with a 17% increase in 'events' opened for people receiving palliative care nursing from the year 2001/02 to 2002/03. The total number of contacts made by district nurses in the year 2002/03, were 72,499 (p. 5) with palliative care contacts accounting for 10,919 contacts of these district nurse contacts (p. 33). The data are uneasily unravelled to quantify how much (as a percentage of district nursing resources) palliative care clients receive in hours or time spent compared to other recipients of the district nursing service. One particular area able to be quantified is the on call service provided after hours, as the time spent on a call out or telephone call is documented.

Recommended in the 2004 CHS review was that generalist district nurses (and those specialist district nurses rostered to work after hours) move between the three bases in response to changing demand. In order to meet growing and changing service demands, flexibility is needed, requiring an increase in the number of weekends and evening shifts worked by district nurses. This may impact on the current primary nursing model of care delivery. Also emanating from the 2004 CHS review was a recommendation that new appointments to specialist district nursing roles contribute to the general district nurse roster. Specialist district nursing roles have traditionally been Monday to Friday 8 – 4.30pm roles with some specialist district nurses covering two or all three of the bases. Incorporating specialist nurses into the roster would create more flexibility.

Local district nursing structure

Generalist district nurses employed by Capital and Coast DHB are all registered nurses (this is not the case in other District Health Boards) with full time district nurses working rostered and rotating shifts, covering week ends, public holidays and

evenings, with regular on call (from 10pm until 8am). In 2005, there were 49.8 budgeted generalist district nurse full time equivalent positions (FTEs) at CHS Capital and Coast DHB. These positions included 38.8 FTE general and 11 FTE specialist district nurses. Specialist district nurses are actively involved in patient care either as a primary nurse or in a shared care capacity with generalist district nurses. They are also a specialist nursing resource for the district nursing teams, inpatient units and community providers. In Capital and Coast DHB these positions include five specialist community cancer nurse positions, two stomaltherapy, one respiratory and two continence nurse positions.

District nurses, both generalist and specialist, are spread over the three bases, with Wellington currently having 18.6 FTE, Kenepuru 16.7 FTE and Kapiti 14.5 FTE. The full time positions include a 0.5 clinical component of the Team Leader role and a 0.5 clinical component of the generalist Clinical Nurse Specialist role. Each base has a Team Leader and Clinical Nurse Specialist assigned. All Clinical Nurse Specialist positions were reviewed in a Capital and Coast DHB wide senior nursing review (Capital and Coast District Health Board, 2005). Since 1999, each generalist district nurse is stationed at one specific base, in response to sustained feedback from recipients of district nursing services (via the annual CHS patient satisfaction survey) that they did not like large numbers of different nurses that they didn't know coming into their homes. Criticisms also included nurses having different approaches to care required, contributing to confusion for people and families and potentially slowing momentum in people regaining independence. Palliative care recipients of Capital and Coast DHB CHS are not included in the annual CHS survey. Only people who have been discharged from the generalist district nursing services are canvassed.

General district nurses, and those rostered and rotating specialist generalist district nurses, provide nursing support for people and families admitted into the district nursing service 'after hours' (that is, after 10pm until 8am and weekends and public holidays). The community cancer nurses currently provide rostered after hours on call telephone support, alongside generalist district nurses, for people and families living in the district who are receiving treatment at the Cancer Unit at Wellington hospital. This on call service is currently under review. A collation of call outs attended by district nurses within Coast and Coast DHB indicated the majority of these 'after

hours' responses were to support people dying at home, primarily for symptom management. A number of safety concerns held by district nurses locally in providing an on call and after hours service have been documented (Wilkinson, 2001).

While district nursing support after hours is not widely provided throughout New Zealand, the next chapter will show 24 hour accessibility and availability of district nurses has been identified in international literature as vital by carers providing palliative care. It is instrumental in reducing families' anxieties about their care giving. The need for after hours' nursing support was also identified in feedback received, during the most recent CHS review, from referrers to the service (such as inpatient staff) who requested an increase in after hours' support and responsiveness.

A 'regular' days work for a district nurse in Wellington

District nursing practice in Wellington is supported by the Community Health Service *Nursing Practice Model* (Capital & Coast Health, 1999) and "emerges from a patient centred model of practice" (p. 2). Generalist district nurses working at each base carry a caseload determined primarily by geographical areas, in an attempt to limit time spent travelling and enable as much nursing time as possible to direct care in the home. However, due to fluctuating workloads, these geographical areas may overlap, with two or more nurses at times, visiting in the same geographical area and different families in the same street. While rare, this may be required to ensure consistency for the person and family while matching the complexity of the nursing care the person requires, with the competency and experience of the district nurse providing the care.

The number of people on each district nurses caseload varies. In my experience these variations are primarily due to fluctuating and at times, unpredictable, nursing care required, with the district nurse regularly reprioritising visits, and the numbers of new referrals being received each day. New referrals are generally allocated to the district nurses working in a particular geographical area. The average number of people on a generalist district nurse caseload is between 40 and 50. This includes people who require 'regular' (twice a day or more visits, daily, three times a week, twice weekly visits) district nursing input, and those people who require less frequent district nursing care. Caseloads for specialist district nurses vary greatly and are generally higher in number. Due to the broad scope of district nursing practice, the nature of the

nursing care provided on any one day requires a wide range of competencies by the generalist district nurse to enable them to appropriately respond to the diverse and complex needs of the person.

In my role as a generalist clinical nurse specialist, supporting district nurses in their practice, my clinical caseload was between 50% and 70% of my work. The role required the flexibility to be able to respond to the changing needs of the person and family, the support needs of the district nurses and the ability to respond (at times immediately) in a timely manner. I worked with a number of people and families, as the primary district nurse, due to the complexity of their health and social circumstances. I was also involved in shared care relationships with people, families, and the general district nurses.

While best efforts are made to ensure the planned workload is safe and fair the nature of district nursing practice is unpredictable. This could include urgent telephone calls requesting an unplanned district nursing visit for a person already known to district nurses, new referrals requesting urgent district nursing assessment, or the district nurse visiting a home may find the needs of the person have changed since they were last seen and more nursing care is required. Therefore, more (unplanned for) time is required, demanding further reprioritising of care.

District nurses are challenged on a daily basis to provide person centred care while juggling challenges of contractual obligations, finite resources and time availability. Issues of finite resources and time are explored in greater depth in the following chapter and in my experience of supporting new district nurses, are some of the challenges for nurses working in the community. Along with an ongoing, ever changing politically directed work environment, local district nurses also manage increasing demand for community based nursing services, in this instance palliative care provision. In DHBs around New Zealand, acuity (or complexity) and workload measurement tools have been introduced in an attempt to quantify the work of district nurses and establish safe, efficient workload allocation practices. This has been an ad hoc development with varied outcomes. Capital and Coast DHB has adopted an acuity tool for inpatient settings to ensure safe numbers of staff are allocated. While a separate acuity tool for district nurses has been developed to measure complexity of

care, it has yet to be introduced and is not envisaged to have a direct influence on day-to-day staffing resources. The NZNO, the largest nursing union in New Zealand is currently working on a national strategy to establish safe nursing workloads in inpatient units and have yet to direct their attention to safe community workload management.

Summary

This chapter has outlined the specific community context in which this research was undertaken. This chapter has also focused on the local Capital and Coast DHB response to the directions demanded by government policies. The impact for local generalist and specialist district nurses in providing palliative care as a result of health service restructuring and the associated contractual changes has been discussed. Locally, following national changes in health contracts and funding and service provision, palliative care services are currently provided in partnership between the local hospice (providing specialist palliative care support), Capital and Coast DHB (providing district or home nursing support) and General Practitioners. As highlighted, this was not always the case (and is not always the case nationally). District nurse practice in New Zealand has undergone significant change with their role reconstructed and redefined by others due to national policy and local reviews and this seems likely to continue in the future. The impact on day-to-day district nursing palliative care is unclear.

Chapter 3 reviews international district nursing literature, illuminating distinct district nursing knowledge, in particular the importance of coming to know the person and family in their own context. The recurring themes that challenge district nurses in providing palliative nursing care are presented, along with some recommended solutions from a British context.

CHAPTER 3: Literature review

Introduction

This chapter draws on published international district nurse literature and outlines what is known about district nurse experiences in palliative care. A number of recurring issues and themes have emerged from research, primarily in Britain, with this focus. These issues include the challenges of finite resources, the invisibility of district nursing, managing interdisciplinary relationships and communication and the effects of cumulative grief. What also emerged from the review were valuable insights of district nursing roles and practice knowledge alongside insights into a complex and at times, fraught practice environment. The reviewed research is often limited to district nurses experiences when working with people with a cancer diagnosis, as opposed to the context of this research where the district nurses have a broad ‘palliative care’ approach regardless of diagnosis. Some solutions recommended in the literature to address these issues are also presented. While some resonating issues are accompanied by recommended solutions, reviews of any action implemented to address these issues, are not evident in the literature and are the focus of this research. The national and local context of this research is also markedly different from those contexts explored in the literature.

The specific challenges of delivering culturally appropriate palliative care services are not widely discussed in New Zealand nursing literature. Provision of culturally appropriate palliative care services was identified in the *New Zealand Palliative Care Strategy* (Ministry of Health, 2001) as a priority. There is little published palliative care nursing literature and research located in the experiences of Pacific and new immigrant people receiving or having received palliative care services in the New Zealand context. District nurses working in the Porirua Basin perceived a gap between the needs of Pacific peoples and the teams’ ability to meet those needs. A small research project, using a focus group method, was undertaken by the Community Health Services and the Pacific Health Research Centre to assist district nurses identify these needs and explore options to assist the team to respond more effectively to Pacific people living in the Porirua area (Asiasiga, 1999). While not looking explicitly at palliative care issues, nurses did identify some concerns in

providing culturally appropriate end of life care. The district nurses who participated in this focus group no longer work in the current district nursing team.

District nursing knowledge

District nurses have specific practice knowledge. Difficulty in articulating this knowledge is a recurrent theme in district nursing literature. While nurses often experience challenges when describing knowledge used in their practice (Berragan, 1998), the inability to articulate and claim specific knowledge is of particular concern for district nurses. The highly complex nature of their work is often hidden. In times of service or contractual reorganisation, a functional service approach may be adopted. Specific knowledge and expertise held by generalist and specialist district nurses may be disregarded in order to ‘get the work done’. Connor (2004) describes this approach to the generalist/specialist nurse discourse as nursing-as-a-functional service, “a nurse is a nurse is a nurse” and “any nurse can replace any other nurse” (p. 88). The concept of the generic community nurse is a “myth” (Kelly & Symonds, 2003, p. 120). Difficulties in articulating and claiming specific district nurse practice knowledge leave the true qualities or essences of the district nurse’ role concealed. This makes challenging a functional approach more complex.

Luker and Kenrick (1992) viewed “district nurses [to be] highly skilled practitioners, yet in many circumstances they were unable to articulate the source of their knowledge” (p. 464). Kennedy (2002) provides some rationale for this. She asserts evidence-based decision making in the community setting by district nurses is “an individualised activity influenced by a number of factors including what is acceptable to the patient and family, their social circumstances and the resources available in the area” (p. 712). In exploring the decision making of district nurses while undertaking first assessments, Kennedy identified a number of approaches, with the district nurses first visit taking a much wider view than the referral task. This wider view included building a bigger picture of the person’s situation, pacing the search for information so the visit did not feel like an interrogation and most importantly, making the visit work for the person and their family. The district nurses showed an acute awareness of the impact of first contact, the need to act as a guest and as a professional in the person’s home. They began building relationships with the person and family through reciprocal trust and rapport.

Kennedy (2002) found “the connection between knowledge (knowing that) and skill (knowing how) in the everyday assessment practices of district nurses appeared to lie in the reflexive nature of their actions and context in which visits took place” (p. 718). Reflexivity requires development of practice wisdom. Practice wisdom “is an ever-evolving attribute arising from the ability to hone personal and professional judgement skills [and] emerge from a personal willingness to risk limitations and openness to new learning” (Connor, 2004, p. 77).

The ability of expert practitioners to take a holistic view of situations, with much of their knowledge embedded in their practice, has been termed ‘tacit’ knowledge (Meerabeau, 1991). Tacit knowledge, also referred to as practitioner or personal knowledge in some nursing literature, is an essential feature of district nursing knowledge (McIntosh, 1996). Tacit knowledge is referred to again in the methodology chapter. McIntosh refers to tacit knowledge as professional artistry and relates the difficulty district nurses have in making visible the range and depth of their professional artistry to their practice often being reduced to practical activity. The ability to see the bigger picture is a key essential element in community health nursing practice, alongside working ‘with’ not ‘for’ people, ensuring ownership of health care needs remain with the person, and the ability of the nurse to take a global view of health care systems, services, people and resources (Bramadat, Chalmers, & Andrusyszyn, 1996). The importance of building relationships and coming to know the person is acknowledged in nursing literature. The importance of the relationship with the person and their family within their unique context is central in district nursing.

The importance of knowing the person in nursing

Liaschenko (1997) describes knowing the person, distinct from the ‘patient’, ‘client’ or ‘case’ as acknowledging the person’s “own desires and intentions” and knowing something of “her or his biography” (1997, p. 26). Coming to know the person requires commitment and demands the nurse only initiate action that is meaningful for the person and supports the person’s integrity and control over their lives. Therefore, the actions of the nurse cannot be generalised but are in response to the unique person, in their own context. Coming to know the person takes time and develops over multiple interactions. However, Liaschenko (1997) acknowledges risks in coming to

know the person – the development of the relationship may be unwanted by the person and they may view the nurse as intrusive. Coming to know the person can complicate nursing practice with implications on the nurses' actions. There is also a "powerful possibility for caring to become coercion" (p. 36) with nurses applying pressure on people to 'comply' and agree to a mode of treatment for example and in doing so, damage the person's integrity.

'Knowing' and the development of a trusting relationship can characterise friendship, at times described as "a relationship marked by friendliness and intimacy, in which the professional is perceived as a friend ... the professional 'takes the role' of a friend" (Cain, Hyde & Howkins, p. 32). Hunt (1991, p. 929), in researching language used by symptom control team nurses on home visits, observed this friendliness as being conveyed through "chatting". This form of communication was distinctly different from "formal conversations". When a relationship of trust is formed, "nurses are not only regarded as health professionals, but also become part of the family or a good friend" (Mok & Chiu, 2004, p. 475). Nurses' role is to support the palliative person and family to "gain emotional control, complete unfinished business, work through anticipatory grief, and learn to let go" (Krohn, 1998, p. 278). It may not be possible for nurses to come to know the person and develop a meaningful relationship with the person and family in all settings (Turkel, 1999). However, the importance of the relationship is a defining essence of district nursing practice.

The importance of knowing the person in district nursing

Kennedy (2002, 2004) in attempting to articulate the dimensions of district nursing practice further, identified typology patterns of knowledge – getting to know the person in their own setting, getting to know the family and/or carer, knowing what needs to be done now, knowing what may happen in the future, knowing and recognising knowledge deficits and knowing community resources and services. Underpinning this knowledge is the importance of knowing the person and family as people, through the development of a person and family centred relationship. Connor (2004) describes new possibilities and enhanced outcomes a person and family centred relationship created, when working with a person living with a chronic illness, and three other district nursing colleagues.

While the value placed by the person and family on friendliness is articulated in most of the district nursing literature, the literature also acknowledges some people may prefer a more formal relationship. The onus is on the district nurse to negotiate the basis of the relationship so that it is established from the person's perspective and not from the nurses stand point (Chadwick & Levitt, 1998). District nurses have emphasised the need to get to know the person and family well as an essential ingredient for the provision of good quality palliative care (Luker, Austin, Caress, & Hallett, 2000). Luker et al. assert "community nurses perceive the foundations of high quality care to be grounded in the communication patterns which exist between nurses and patients, nurses and relatives or carers, and between relative and/or carer and the patient" (p. 778). This may reflect the dependence district nurses have on families and carers to support negotiated nursing care, while also acknowledges the challenge in sustaining meaningful relationships with people and families over months and sometimes years.

Development of these relationships opens possibilities for negotiating visiting patterns acceptable to the person and family (avoiding a sense of intrusion) and "negotiating the giving of information about the progress of the illness" between the person and family (McIntosh, 1996). The importance of the relationship between the person, family and the district nurse providing palliative care is a resonating theme (Wright, 2002) with the development of the relationship providing the foundation "to understanding and knowing the clients' and carers' needs and was the medium through which all other care was given" (p. 1183). In Wright's research the importance of developing a trusting relationship from the first visit was viewed as essential by the district nurses and fundamental in shaping the approach to care provided.

There are risks inherently involved in the development of these relationships however, as the professional relationship with family and carers changes from the time of death. Birtwistle, Payne, Smith and Kendrick (2002) warn of potential risks for families, in "fostering dependence on the nurse, and a sense of loneliness and loss when the visits end" (p. 475). While not explicit in how best to address or minimise this risk for families, they acknowledge debriefing and clinical supervision may support district nurses in reducing stress and maintaining professional role boundaries. The issue of

role related stress is explored in greater depth later in this chapter. A further risk identified by de Raeve (1996) is that nurses “can try to plan with the patient’s idea of a good death in mind, but this may simply interfere with being able to respond to the unpredictable needs of the immediate present” (p. 76). Being mindful and tentatively planning ahead for future possibilities within the home context is specific knowledge exhibited by district nurses to reduce unexpected risks or potentially unsafe situations developing as much as possible for the person and family. Good communication, ensuring continuity of care and timely referrals to district nursing services support the development of these relationships, enhancing future planning (Luker et al., 2000).

Unspoken reciprocity – relationships with family

Doane and Varcoe (2005) view family as a “complex relational experience ... where economics, emotion, context, and experience are interwoven and multilayered” (p. 43). The increase in home-based nursing care has altered health service providers expectations of family, with assumptions often made of family providing a degree of the care required for the person. This arrangement is often termed ‘informal care’ (Kirk & Glendinning, 1998). Cost effectiveness of care is a consideration by health care providers, including palliative care (Brumley, Enguidanos, & Cherin, 2003). While acknowledging the importance of developing relationships with the person and family, district nurses have an explicit dependence on the person’s family and informal carers often at a very distressing time when, following a terminal diagnosis, families and carers “find themselves thrust into situations that they were not expecting or even prepared for” (Dunne et al., p. 377). There may be significant impact on family and carers when taking on a care giving role such as lack of control over their everyday life, reduction in self-confidence, changes in employment status, reduction in leisure time and for some, a deterioration in their own health circumstances (Wiley, 1998). However, levels of satisfaction may also be enhanced for people and families actively involved in providing palliative care (Aspinal, Addington-Hall, Hughes, & Higginson, 2003). No published research exploring the experiences and perceptions of palliative people, family and carers in the New Zealand community context was found.

In Britain, the value families place on the role of the district nurse in palliative care is more evident, in providing support visits and practical hands on care. The importance for people and families of psychological support provided by district nurses centered

on time spent offering reassurance and advice, cultivating a friendly relationship (in which the family perceived a sense of interest, care and concern) and highlights the importance of consistency, in having a regular nurse the family could identify as the key person to contact (Wilson, 1999). Families, in commenting on the at times extensive number of health professionals involved in their care, experienced problems in continuity and establishing clarity around inter professional communication processes, with some expressing a sense that the health professionals involved were not communicating with each other (Jarrett et al., 1998). Poor co-ordination of palliative care services has historically been an issue for families (Macdonald, Addington-Hall & Anderson, 1993).

In exploring the views of older people about home as a place of care at the end of life, Gott et al. (2004) found the concerns of those interviewed included the presence of professionals or ‘strangers’. This presence was seen as intrusive with potential to compromise the feeling of ‘home’ especially when equipment was required that may make the home feel like an institution. In addition, there were a number of practical reasons participants identified which impacted on the individuals choice of where to die – lack of family or carer, not wishing to be a burden, concerns about the quality of care and symptom management and worries about physical aspects, such as stairs and positioning of the toilet. However, participants in this study were also clear of their wish that “the patient/professional relationship [be] transgressed to incorporate notions of friendship” (p. 465).

Accessibility, availability and timeliness of district nursing services

“All the patients and carers interviewed spoke warmly and positively about the district nurses involved in their care”, with a general perception the district nursing services were responsive and flexible (Jarrett et al., 1998, p. 479). However, this is not always the case, with literature suggesting a number of factors that challenge family’s ability to access district nursing services for palliative care support. People with long term chronic health circumstances (as opposed to a cancer diagnosis), in entering the

terminal phase of their illness, may not receive any input or support from district nurses and it would appear accessibility to district nursing services is inconsistent. Exley, Field, Jones and Stokes (2005) suggest this may be because district nurses are “seen as only being needed for the practical tasks ...[and] ... they were more likely to be called in only at a ‘crisis point’, rather than providing care throughout” (p. 80), with the professional artistry of the district nurse role reduced to tasks.

District nurses have used palliative care to define and exemplify district nurse practice, particularly when articulation is required to other health providers of the complexity of district nursing practice for contract negotiations (Goodman, Knight, Machen, & Hunt, 1998). Goodman et al. saw associated risks in identifying palliative care as an example of complex district nursing care. People receiving care who were not palliative could be viewed as less ‘valuable’ or complex. This may explain why people with a chronic illness who have an unclear prognosis may not be referred for district nursing support, as opposed to people with a cancer diagnosis where the prognosis may be a little clearer.

There are risks that providers referring to district nurse services may be unsure of the nature of the district nurse role, the support district nurses can provide or unable to clearly identify people and families who would benefit from district nursing input. Lack of understanding of the contribution district nurses make in supporting people and families may lead to people being referred to district nurses ‘late’ in their illness. The issue of timeliness of referrals is a recurrent theme, in the majority of the literature reviewed from both the person and family perspective and the district nursing perspective. The impact of a person being referred to district nurses ‘late’ may include difficulties of building relationships and gaining the confidence of the person and family potentially during a time of crisis, symptom management issues and compromised safety due to lack of appropriate equipment. Lack of clarity of when and under what circumstances a person enters the palliative phase adds further confusion of when to refer to district nurses for palliative support – at the time of diagnosis or at a time of physical deterioration when the person and their family need practical ‘hands on’ support (Hatcliffe et al., 1996). This reductionist approach undermines the support aspects of care, identified as valued by people and their family.

While practical aspects of district nursing care, including symptom relief, are more visible, the provision of emotional support and care of people and family should not be minimised (McIlfatrick & Carran, 2001). Clarity of the district nurse role is further muddled by some perceptions held by the public (Wilson, Pateman, Beaver, & Luker, 2002) that district nurses provided only ‘hands on’ support, with a belief by some recipients of the service that there were other people more in need and they themselves were “undeserving” of district nurses “valuable time” (p. 251). Confusion around the role of the district nurse, experienced by other health providers and the wider public, may be due to the regional variation in district nursing services and contribute to the invisibility of district nurses.

A recurrent area of support and at times, difficulty, identified by families is accessibility of district nursing services after hours. The ability to access 24 hour district nursing support in a timely manner has been identified as a “vital factor” for palliative people, their family and carers, and “instrumental in reducing families’ anxieties about their caregiving responsibilities” (Wilson, 1999). While people and families value the availability of district nurses, they and other health providers have identified issues of access to all services, including pharmacies and equipment, particularly after hours (Dunne et al., 2005; Exley et al., 2005; Fox, 1999; Jarrett et al., 1999; Searle, 1992; Street & Blackford, 2001). Specific problems directly impacting on people and families ability to access district nursing services include unclear communication pathways (who to contact for advice after hours), the unavailability of regular staff to contact for advice (outside normal working hours) and when the person is ‘new’ to the district nursing service and is unknown to the specialist palliative care service (Griffiths, 2001). District nurses, supporting families in providing palliative care at home are often faced with rapidly changing and at times, crisis situations as the palliative phase of a person’s life is unpredictable and a distressing time for family and carers. This distress may be heightened when there is limited access to services overnight and during week ends.

When district nurses are available after hours, often services provided are reduced with fewer staff employed. This can lead to a culture within district nursing services of rationing after hours support and may not be “governed ... by patient need”

(Griffiths & Luker, 1994, p. 1041). The ability of district nurses to meet the needs of people and families while working within resource constraints is an ongoing challenge.

Impact of finite resources on accessibility and availability

Although the profit driven focus of health care in New Zealand no longer exists, the challenge remains in providing quality nursing care while retaining a person and family focus that allows for meaningful responsiveness, within limited resources. Rogers and Niven (1996) acknowledge health resource limitation, with widespread challenges in allocation and rationing, however they assert it is more difficult to avoid in the community setting. The onus and responsibilities on the person and family to provide for everyday living are heightened, by meeting costs of health services required, including prescriptions and GP visits. People and families are shaped by their access to material resources with each family having economic influences, both immediate and historical (Doane & Varcoe, 2005). Additional financial costs for families may also be coupled with reducing or ceasing paid employment to provide palliative care at home. This can be financially crippling and add to levels of distress for people and families.

Due to their services being free of charge Chadwick and Levitt (1998) suggest district nurses in particular have been placed in a position of rationing resources and setting priorities. Rumbold (1993) suggested, it was easier for the nurse working in the community (in determining immediacy of need) than the nurse in the hospital “because for the most part they have only one patient or client in front of them at a time” (p. 182). Although outdated, this perception may still exist amongst other health providers. In my experience rationing of resources has meant working longer hours than employed for and has become a regular way of life for district nurses, to ensure people at home receive the care they require. Goodman et al. (1998) in relaying district nurses accounts of “absorbing the work ... being a sponge ... keep on accepting referrals”, consider this to be a result of the marginality of district nursing (p. 496). Time is an essential ingredient in providing high-quality palliative care in

the community. District nurses, in distinguishing between their 'own time' and their paid working hours reported that with encroachment on personal time, the outcomes were personal stress and distress (Cain, Hyde, & Howkins, 1995; Chadwick & Levitt, 1998; Robinson, Avis, Latimer, & Traynor, 1999; Searle, 1992). Time pressures create additional tensions for district nurses, in being able to authentically support and respond to the needs of the palliative person and their family.

International nursing literature highlight challenges in establishing mechanisms to ensure efficient, safe workloads, particularly for district nurses (Cohen, 1998; Community Practitioners' and Health Visitors' Association, 2003; Rice, 1997; Walsh, 2003; Willis, 1998). Tensions and frustration experienced by district nurses is reflected in statements such as "not able to give the quality of care I think patient needs", "I feel I don't have enough time to give patients the quality of nursing care which they deserve" and "the world of business has definitely taken over, and as well as not giving as much time to the patients as we would like, there is a lack of caring for us as the carers" (Robinson et al., 1999, p. 157). The sense of not being cared for may be related to the relative invisibility of district nursing, confusion amongst other health providers of the role of the district nurse and the difference district nurses can make, in this instance in supporting the palliative person and family.

Invisibility of district nursing

Invisibility of district nursing was evident in research undertaken by Low and Hesketh (2002). "To the users of their services, their patients, carers and relatives – district nurses are highly visible" (p. 18). However in policy formulation, strategic planning or financial strengthening of existing services, Low and Hesketh found district nurses to be the invisible workforce. Issues contributing towards this invisibility included national variation in service provision (as has occurred in New Zealand outlined in the previous chapter), confusion about the district nurse's role and increasing demand for district nursing services to provide increasingly complex community nursing care. Invisibility of district nursing in New Zealand is highlighted by Arcus (2004) who asserts the invisibility of district nurses, may also be due to assumptions grounded in district nursing as a community based, mainly female workforce, along with confusion of the district nurse role.

Invisibility of the district nurse in New Zealand is further evident in the Health Workforce Advisory Committee's 2001 *The New Zealand Health Workforce* report, where district nursing was not mentioned. In 2003, district nurses in Wellington celebrated their centennial (100 years) with accustomed silence. This milestone was not recognised by the district nurses at CHS, or by Capital and Coast DHB.

The role of district nursing in palliative care provision in New Zealand is mentioned briefly in an international palliative care text book (Ferrell & Coyle, 2001) with passing reference to rural nurses and when articulating the roles of specialist palliative community teams in "providing consulting support and education to generalist nursing services who provide most of the direct care to clients and families" (p. 763). Invisibility creates additional challenges in articulating the role and value of district nurses in New Zealand community palliative care provision.

Interdisciplinary relationships and communication

As noted in the previous chapter, the *New Zealand Palliative Care Strategy* (Ministry of Health, 2001) identified role relationship issues amongst some palliative care service providers. Role relationships issues in the New Zealand context between district nurses and hospice care coordinators were also identified by Peach (2001) who noted "tensions have arisen when the local hospice has not provided all of the palliative care but has relied on the district nursing service to undertake some of the functions, undervaluing the expertise of the community nurse" with this arrangement not always fostering consistency or continuity of care for the person and family (p. 290). Chadwick and Levitt (1998) also allude to potential rifts and power dynamics between district nurse and specialist palliative providers resulting in professional carers being unable to work together effectively.

According to Griffiths and Luker (1997), when addressing problems or issues that arose with colleagues, 'etiquette' governed district nurses' intra disciplinary and inter disciplinary relationships. The commitment of district nurses to teamwork, to facilitate smooth social interactions, usually meant patient's care by colleagues would not be challenged. This was particularly evident when the colleague was from another team or organisation, as "in the home, issues must usually be raised out of context and after the event" (p. 127) to avoid challenging in the presence of the person and family.

District nurses may use etiquette to reduce or manage tensions of role confusion or integration of services, in an effort to reflect a unified working relationship to people and family receiving care.

Jarrett et al. (1998) highlights palliative care recipients' impressions of district nurses having less power, autonomy and authority than nurses from specialist palliative care providers. Job titles and role demarcation of the various 'nurses' involved were sources of confusion for some patients and carers. Aranda, in Ferrell and Coyle (2001), highlights relationship difficulties may also occur between nursing and other disciplines "with major issues over role delineation and perceptions that nurses gate keep access to the client and family" (p. 763). Tensions within these relationships can have a direct impact on the flow of communication between the various health professionals involved, creating confusion for people and family (Linkewich et al., 1999). Street and Blackford (2001) recommended strategies to address issues of communication within an interdisciplinary community palliative care team. They concluded that what was required for effective palliative care communication was "a clear understanding of the historical relationship of each service provider with the client ...and ... agreement reached on routine management, standing orders, after hours care and ongoing formal communication and documentation strategies" (p. 649). In order to reach agreement, the establishment of respectful interdisciplinary relationships and understandings were essential.

Where there are a number of services working in partnership to deliver palliative care, with the team approach essential in enhancing care for the person and family, health professionals also need "to understand not only differences in the roles and expectations between disciplines, but also within disciplines" (Blackford & Street, 2001, p. 278). Issues of ownership, and lack of understanding of other team member roles, while attempting to present an appearance of unity and a team approach to care, can be a source of significant stress for nurses (Johns, 1992). However, this stress, while evident in district nursing literature is not as clearly articulated as the stress of cumulative grief associated with palliative care for district nurses.

The impact of cumulative grief for district nurses

Personal and emotional cost associated with palliative care nursing requires a diverse array of personal and institutional supports to manage these costs (Jones, 1998; Marino, 1998; Mazhindu, 1998; Newton & Waters, 2001; White, Wilkes, Cooper, & Barbato, 2004; Witt Sherman, 2004). Stress, burnout and job dissatisfaction, of ongoing reorganisation of services on those responsible for the delivery of health care is also widely acknowledged (Akid, 2002; Crouch, 2002, 2003; Edwards & Burnard, 2003; Injury Management New Zealand, 2001; McDonald, Langford & Boldero, 1997; McVicar, 2003; Schoolfield & Orduna, 1994; Tang, 2003) and will not be examined in detail here. The contributing factors in organisational change are different to that originating from stressors intrinsic in the nature of the work undertaken although the outcome for workers may be the same. Evident in Chapter 2, district nurses locally have undergone significant sustained organisational change which, when coupled with cumulative grief could create additional costs. “Insecurity arising from multiple organisational changes distract and drain energy, making existing workloads feel heavier ... (with) changes in team structure, management and organisational structure, changes in ethos, adjustments to new work areas and new colleagues all mentioned as difficult” (Newton & Waters, 2001, p. 532). Already outlined in this chapter existing sources of stress for district nurses include workloads, time and resource constraints.

Cumulative grief has been described as “the care giver’s emotional response when there is no time or opportunity to completely or adequately grieve for each person who has died ... with the nurse ... attempting to care for others who are critically ill or dying while simultaneously attempting to deal with previous losses” (Marino, 1998, p. 103). Grief experienced by nurses related to unrelieved physical, psychological and spiritual suffering of the dying, is magnified by the depth of relationship between the nurse and the person, time spent together, the nurse’s clinical experience and the personal stress experienced by the nurse at the time (White et al., 2004). District nurses have identified the personal cost of caring associated with providing palliative care as significant, resulting from the palliative nature of care being provided and the authentic nature of the relationships, described earlier in this chapter, being established between the district nurse and the person and family (Dunne et al., 2005; Hatcliffe et al., 1996; Searle, 1992). Open communication and the opportunity to

share and reflect with colleagues have been identified as two possible positive supports to gentle the effect of grief amongst district nurses (Hatcliffe et al., 1996; Searle, 1992). Opportunities to debrief, access to clinical supervision and counseling for district nurses may also reduce stress and grief related to palliative provision (Birtwistle, Payne, Smith & Kendrick, 2002). Clinical supervision can also assist in the revelation of tacit knowledge, particularly for practitioners working in palliative care services (Jones, 1998). There is, however, little research demonstrating the most useful approach to support district nurses to reflect on their practice, particularly as they work in isolation (Griffiths, 1999).

Summary

No New Zealand nursing literature exploring palliative care provision issues within a community setting with district nurses was found. Overseas nursing research does explore district nurses experiences and articulate issues in providing palliative care. However, the very nature of the methodologies utilised in these research instances means there was not explicit collaboration or intent for action, in addressing the issues identified. The research was also conducted in a cultural context quite different from that of the New Zealand experience highlighted in Chapter 2.

I wondered, when reflecting on the international district nursing literature, whether the themes illuminated in the chapter resonated within the New Zealand context, more specifically with the members of the district nursing team I worked alongside. I was enthusiastic to explore this further. The literature posed more questions than it answered. Did local district nurses practice in a similar way? Did they take a wider view than the 'task' at hand? Did local district nurses experience similar issues in their practice? Locally palliative care is delivered in partnership. Were tensions evident in these professional relationships? Is so, how were these managed? Was cumulative grief an issue? Was this compounded by organisational change? Were the individualised solutions proposed in the literature transferable and contextually appropriate? I was aware the context in New Zealand was different and the context within our own local community unique. In exploring these further, alongside presenting a picture of the local district nurse context, I wanted to look at ways of improving care and enhancing outcomes for people and families the district nurses

worked alongside. Action research was the best methodological approach and the following chapter will outline the reasons why.

CHAPTER 4: Action research methodology

Introduction

The research design was qualitative in nature, drawing on localised knowledge and experience of district nurses who delivered palliative nursing care within the particular community context. Sharing of practice experiences or ‘praxis’, hence the praxis group meetings and processes were underpinned by the tenets of action research. The intent was to advance practice knowledge and to formulate and implement a plan of action.

Action research is a form of collective self-reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their own social or educational practices, as well as their understanding of these practices and the situations in which these practices are carried out.

(Kemmis & McTaggart, 1988, p. 5)

Action research enquiry develops new knowledge and understandings and can also facilitate change in a specific context, in a collaborative way. Central tenets of action research are active collaborative relationships between researcher and participants, reflection in action, and practical action applications, responding to the “democratic impulse” as the research unfolds (Bridges, Meyer, Smith, & Carter, 2001, p. 30). This chapter outlines the reasons why I chose action research as a methodology for this project.

This chapter aims to position some of the debates evident in action research in particular ethical tensions, identified by seminal action researchers, between order and messiness in managing research relationships and in addressing research process. Understanding the various positions of these debates was important for this research due to my leadership role within the service. In positioning myself within the research ethical considerations were particularly important. Ethics in action research, an evolving fluid process, are pivotal and cannot “exist as a contained consideration” (Waterman, 1988, p. 103) and sit within this chapter in a separate ethics section. Reflection, an essential element of action research is discussed. Finally, I outline how this methodology was applied in the research design for this project and how

trustworthiness and authenticity of this research project were achieved. Chapter 5 maps the action research journey as the research unfolded. The history and assumptions of action research are well documented (Hart 1996; McKernan, 1991; Wood & Giddens, 2000) and will not be restated.

Although focused on the issues of concern for district nurses delivering palliative care, I chose action research because I wanted to generate actions and outcomes. This local responsiveness I hoped would be transferable to the wider population served by the group of district nurses. Transferability is discussed in greater depth later in this chapter. A further consideration was my own personal experience, in participating in a small research project (Asiasiga, 1999) described briefly in Chapter 3. This highlighted for me that nurses in practice were more likely to commit to participate in a research process that delivered tangible outcomes. I understood the everyday challenges for this group of time constraints and workloads and did not want participation in this research process to be viewed as a burden. I appreciated that the outcomes would be limited to small steps, due to the nature of a small scale/minor thesis and associated time frames, however the group could continue with the work once the research project had been completed.

Given the “primary aim of practitioner research is usually to solve a critical problem or to develop an understanding about the nature of practice, and ultimately to contribute to the body of professional knowledge” (p. 11), Reed and Procter (1996) reinforce that practitioner research, in this instance action research, is about giving voice to and respecting the tacit knowledge of experienced practitioners. Other methodologies utilised in research explored in Chapter 3 highlighted the issues and concerns, but did not always have an action focus. Therefore they were not considered for this project.

Development of difference

Action research is qualitative, emanating from critical enquiry and social sciences (Crotty, 1998). Guba and Lincoln (1994), in comparing qualitative paradigms describe differences and similarities between critical theory and constructivism. It would appear action research could sit in either paradigm. Reason (1994) situates action research as a participatory and co-operative enquiry, as action “research is

always personal, political, and spiritual; knowledge is always from a perspective and for a purpose” (p. 333). Tensions have arisen as action research developed, with numerous approaches and multiple interpretations evolving, such as participatory action research, action science, soft systems methodology and evaluation (Dick, 1992). Reason adds co-operative inquiry to this growing but not exhaustive list of participative approaches. Varying interpretations of terminology lead to participatory action research and action research often being used interchangeably.

Different interpretations have resulted in multiple action research frameworks, often depicting a neat, systematic approach to undertaking an action research process. Kemmis and McTaggart (1988) illustrate action research by a cyclic spiral, with four key stages to each cycle – plan, act, observe and reflect. The action researcher carries out these four stages collaboratively. Kemmis et al. assert “action research involved problem-posing, not just problem-solving” and “is motivated by a quest to improve and understand the world by changing it and learning how to improve it from the effects of the changes made” (p. 21). This tidy, structured approach is further emphasised by Stringer (1996), suggesting an action research interconnecting cyclic spiral of “look, think, act” (p. 17), once again embedded in collaborative processes to address specific issues of concern. Addressing specific issues is achieved by “defining the problem, exploring the context, analysing its component parts, and developing strategies for its resolution” (Stringer, 1996, p. 13). Action research cycles developed generally have the same main characteristics – participatory, practical, cyclical and promote change or action outcomes. However, an orderly, tidy theoretical approach is not always the experience of action researchers in practice, reflecting tensions and degrees of messiness that have arisen due to multiple interpretations. Action research in nursing is no exception.

Action research in nursing

From the early 1980s there was growing interest from health care practitioners in action research, in particular nurse researchers, due to its practical relevance, collaborative nature, the potential for consciousness raising and emancipation. Nurses have worked with action research in many ways. They have undertaken action research to explore issues and bring about change, with other nurses and consumers of services (Blackford & Street, 1999; Hoogwerf, 2001; Kelly, Simpson, & Brown, 2002;

Street & Robinson, 1995; Wallis & Tyson, 2003) and they have used it to explore health and well being issues with community groups (Koch & Kralik, 2001; Koch, Kralik, & Telford, 2001). Nursing researchers have viewed action research as a vehicle to address “the gap between theory, research and practice” (Holter & Swchwartz-Barcott, 1992, p. 298) arguing this is achieved through using an action research approach to look at the current practice context and bringing about change. Hope and Waterman (2003, p. 121) believe “the problem-solving cycle of action research mirrors that of the nursing process”. This stance is extended by Hart (1996) who argues that the cyclic process of action research not only mirrors the stages in the nursing process but also those in the quality cycle. These simplistic views give little respect to the complexities and dynamics underpinning action research or the nursing process.

A further interpretation of action research in nursing is evident by Rolfe’s (1994) assertion that the main aim of nursing research is primarily to advance practice. Nursing researchers’ use of methodologies based in social sciences (where the main aim, Rolfe argues, is to develop knowledge) does little to advance nursing practice. Rolfe believes action research “goes beyond the confines of the scientific paradigm and is able to bring about improvements in practice directly without the mediation of theory ... and results in a model of research which is participative, reflexive and unashamedly subjective, and which generates non-generalizable, personal knowledge directly out of practice” (1996, p. 1315). He emphasises the need to move beyond what he describes as “level 2 research ... primarily concerned with meaning and interpretation” to that of “level 3 research” where the purpose is “not just to describe or explain, but to change” and “that the level 3 research process itself initiates change” (1994, p. 971). The difference between this approach and the action research cycle is, according to Rolfe that research “in the form of reflective practice, becomes part of everyday activity of nurses. They are constantly reflecting on their past and current practice, conceptualizing and generalizing from their reflections and modifying their nursing interventions accordingly” (p. 973). Rolfe (1998) also advocates for research as co-operative enquiry, however he argues “clinical research, if it is to make a difference to practice, must ... be practitioner-based research” (p. 672).

Action research and praxis

Another interpretation of action research apparent in nursing is praxis research. This is described as “when nurses need to not only understand a particular situation – but do something about it” (Street & Walsh, 1995, p. 3). The authors acknowledge praxis research is not “generalisable” but may uncover issues that may be useful (transferable) to others in similar situations. In describing their praxis research model, Street and Walsh acknowledge that “praxis research must be developed reciprocally – the findings need to be disseminated in such a form that the research participants and others in their situation can understand and use them” (Walsh & Street, 1994, p. 27).

Lather (1991) takes praxis to a central statement “that in our action is our knowing” (p. xv). She describes praxis as “uncovering the particularity and contingency of our knowledge and practices [and] is at the core of whatever generative advances we might make regarding our purposes and practices” (p. 14). Issuing a challenge, Lather argues consideration must be given by “those interested in the development of a praxis-orientated research paradigm” to moving toward emancipatory research – “how to maximise self as mediator between people’s self understanding and the need for ideology critique and transformative social action without becoming impositional” (p. 64). This potential challenge for action researchers is explored further later in this chapter. Emancipatory knowledge Lather argues, “increases awareness of the contradictions hidden or distorted by everyday understanding, and in doing so it directs attention to the possibilities for social transformation inherent in the present configuration of social processes” (1986, p. 259).

Incorporating the tenets of action research and the essence of praxis was the approach I wanted to take in this research project. However, in planning the study, I discovered challenges in systematically knowing how to approach the research and how it would unfold. If action research was an unfolding process, the researcher may not necessarily have control. Issues of order and messiness in action research were raised.

An ordered or messy approach

Tensions between order and messiness are explored by Cook (1998) who worked with other educationalist action researchers to look at “how action research developed personal or small group thinking within an organization” (p. 94). Cook describes the

balance between researchers and practitioners “identifying and incorporating their work within a methodology without fixing it as given practice and losing its very essence”. According to Cook (1998)

Lewin’s research spiral and the Kemmis & McTaggart sequence ... begin with [a] ‘PLAN’, but I wanted to know how I could plan before I knew what I was looking at ... if you don’t know what exactly it is causing your problem, that is what the research is all about ... how can you plan what you are doing if your research is to find out what you are doing?

(p. 97)

Whether clarifying the problem constitutes an ‘action’ outcome in action research is less than clear. What the beginning and end points of action research are is also clouded. Le May and Lathlean (2001), two nursing academics, echo this ambiguity in what they describe as the “fuzziness” and “uncertainty” of action research, due to “a lack of clear guidance about the methods of data collection and analysis techniques that typify action research or ... stating precisely how we really do it” (p. 502). Data collection methods (diverse in action research) include observation, reflective diaries, focus groups, semi-structured interviews and questionnaires. This is not an exhaustive list. McAllister and Stockhausen (2001), in carrying out a curriculum evaluation within a school of nursing using an action research approach found no “clear boundary between data collection and analysis” (p. 18). While not providing concrete answers, their study was successful in “exposing previously hidden tensions” (p. 21) centred on issues of collaboration when attempting to reach group consensus. Processes in action research are often untidy, contrasting ordered approaches of other methodologies. However Cook (1998) suggests any untidiness and mess may be missed out in the writing up of action research “for professional clarity and tidiness” (p. 104). Authenticity of the research may be diluted. Other messiness arises because the direction of the research is unknown. Ethical dilemmas may arise as a result of this unknown and these too may be ‘tidied’ away.

Lax and Glavin (2002) in their community action research project with multiple stakeholders, experienced messiness in their research cycle due to relationship tensions. These included varying agendas of those participating, raising questions regarding the genuine commitment of the organisation involved in the project and

challenged maintaining the momentum of the research. Meaningful collaboration contributed to a degree of ‘messiness’. Central tenets such as collaboration have been reinterpreted and redefined with diverse applications by nurse action researchers.

Collaboration

Multiple, varied interpretations abound of what actually constitutes authentic collaboration in nursing action research. This relates to the intent and positioning of relationships between participant and researcher and the variability of participant’s role in action research projects. Holter and Schwartz-Barcott (1992) define three collaborative approaches – technical, mutual and enhancement. They suggest a technical collaborative approach is utilised when the goal of the researcher is to “test a particular intervention based on a pre-specified theoretical framework” (p. 301). The relationship with participants is of assisting with the implementation, rather than working with the researcher to define issues, plan interventions required and evaluate outcomes.

Mutual collaborative approaches demand researcher and participant work together to define potential issues, plan possible interventions and initiate change. These changes, dependent on the ongoing presence of individuals directly involved, may be short lived. The enhancement approach incorporates the mutual collaborative approach actions then moves to assisting “practitioners in identifying and making explicit fundamental problems by first raising their collective consciousness ... bringing to light the difference between stated practices, underlying assumptions and unwritten laws which really govern that practice” (Holter & Schwartz-Barcott, 1992, p. 302). In practitioner based (in this instance, nursing) action research, the positioning and relationships between participants and researcher are critical in demonstrating incorporation of collaboration, a fundamental tenet of the methodology.

Obtaining a “participative worldview is at the heart of inquiry methodologies that emphasize participation as a core strategy” (Lincoln, p. 333) which action research does, in viewing all those involved in co-operative enquiry as co-researchers and co-subjects, although they may not contribute to the enquiry in the same way. Through reciprocity, those participating in an action research enquiry are equally valued. It would appear that despite attempts to tidily define what constitutes collaboration,

messiness can appear in action research due to some of the challenges in relationships between participants and the researcher, the ethics associated with the action research process and who takes ownership of the research. Issues for participants freedom of choice to participate, safety and confidentiality (both during and after the action research project has been completed), informed consent, authentic collaboration and ownership of the research are resonating issues identified in action research projects. These issues may be present to a greater or lesser degree and are explicitly reliant on the ethics of the researcher. The naming of the position taken by those participating in action research I believe demonstrates the power dynamics in the participant/ researcher relationship and has a direct impact in addressing ethical issues within the research. Just as there are varied interpretations of what constitutes collaboration, there are also a number of titles or ‘namings’ to describe those participating in action research, depending on the stance and interpretation of the action researcher.

Participant, collaborator, co-researcher or stakeholder

Subtle use of language emphasises the varied approaches to collaboration in action research. The emphasis of co-researcher provided by Reason (1994) mentioned earlier in this chapter was one of a number of voices. Participant suggests a passive involvement, collaborator evokes a sense of working alongside, co-researcher emphasises a direct positioning within the whole research process, while stakeholder intimates an involvement of those wider than the research project but who may be impacted in some way. Street argues “participatory health research requires a congruence between the values that inform the research approach and the structuring of the research relationships” (1998, p. 119). Words, undertakings and actions of action researchers must show congruence with the central tenets defined at the beginning of this chapter.

The language used to describe relationships in action research immediately reflects the situating of power relationship between the participant/collaborator/co-researcher or stakeholder, and the researcher. Street (1998) echoes Lathers (1991) commitment to emancipatory participation. Street notes “In this frame, research relationships would be characterized by negotiation rather than consensus; an acceptance of the partiality of account; opportunities to challenge regimes of truth; and an acknowledgement of

the multiple, shifting subjectivity of the stakeholders involved” (p. 123). It is my contention that regardless of the name or title within the research to describe those participating, the participants/collaborators/co-researchers/stakeholders potentially face a greater exposure to risk especially when collaborating in action research in their own workplace, than the researcher.

This is because despite the best efforts for collaboration, the researcher remains the researcher – the leader of the research project and this too is reflected in the action research nursing literature. It is for this reason the potential risks for those participating are discussed first.

Ethical issues and other considerations for participants

Williamson and Prosser (2002) argue close collaborative relationships in action research can be “a source of political and ethical problems faced by researchers and participants” as action research for the participants does not “offer the same ethical guarantees concerning confidentiality and anonymity, informed consent, and protection from harm as other research methodologies” (p. 587). There is a balance to be negotiated in action research between researcher and participants in how they work together and who controls the research.

Power

Participants may be extremely vulnerable if they are engaging in an action research process that includes truthful disclosure of their nursing practice, within their employment setting. Williamson and Prosser (2002) believe action research introduces “a greater element of ‘exposure’” (p. 588), particularly if there is an existing, close, collegial relationship between the participants and researcher, as neither “know where the journey will take them in advance, and cannot fully know to what they are consenting” (p. 589). The equality of relationships demonstrated through collaboration, supposedly inherent in action research can be difficult to achieve within the workplace environment due to dynamics within existing relationships. Meyer (1993) and Titchen and Binnie (1993) highlight these power issues. With my established collegial relationships I was very aware power issues could arise due to my role and chose to take the approach adopted by Meyer (1993) where colleagues would decide if they wished to participate.

Titchen and Binnie (1993) undertook a four year action research study in the workplace, where Binnie was a senior nurse in the unit and had the role as lead researcher. I viewed Binnie's positioning as similar to that of mine in that she was a recognised clinical leader within the unit and had established authority and relationships with staff. This posed challenges for nurse colleagues and co-participants being willing to share the truth of their practice due to the existing power imbalance with Binnie being in a leadership position. I believed this could impact on the authenticity of the action research project I was proposing. Individuals may be concerned their professional position could be affected if they chose not to participate, or if through their participation, an issue from their practice was viewed negatively. Participants may also choose not to participate because they have not been included from the inception, there is no developed relationship with the researcher or there are issues such as collegial mistrust which could compromise confidentiality within the group participating in the proposed action research (Bridges et al., 2001). Existing collegial power imbalances for those considering participating in action research are not extinguished and a sense of expectation or coercion, to participate may remain, despite best intentions of collaboration on the part of the researcher.

Cooper and Hewison (2002), in implementing an audit in a palliative care setting using an action research approach, recognised that previous unsuccessful strategies to implement the proposed audit changes had been a "top down" management initiative rather than a "bottom up" practitioner approach (p. 366). However, in collaborating and involving staff (who eventually became self-directing in the process), with outcomes based on group consensus, those participating began to take ownership of the change and responsibility for implementing the audit with positive outcomes in practice. Meyer's (1993) work began as a 'bottom up approach' but later turned into a 'top down' approach due to a high turnover of staff. Staff changes created constant challenges to maintaining collaboration and a sense of ownership by the participants, which in turn made sustaining the momentum of the action research difficult.

Ownership

Williamson and Prosser (2002) recognise "the extent to which the collaboration and negotiation that takes place in action research means that participants 'own' the findings as much as the researcher" (p. 590) and may be a way in which the researcher

can avoid harm to the participants. Le May and Lathlean (2001), Meyer (1993) and Titchen and Binnie (1993) also raise issues of ownership in that ownership must be congruent with action research central tenets. Authentic ownership of action research is an essential essence of action research and is more likely to occur when the research begins as a 'bottom up' approach (as opposed to a 'top down' management approach) or when those participating are actively involved in directing the research from project inception with an equal sharing of power.

Participants directing the research must also, according to Greenwood (1994), dictate the speed and level of action required. This raises a further question of practitioner driven action research whether bringing about or facilitating change in clinical practice, is reliant on ownership of the change process. Issues of meaningful, authentic collaboration and ownership in an action research project are intertwined especially if there is an expectation for an action outcome, which is explicit when undertaking action research. Karim (2001) warns of the risk of those participating being led by the researcher in a particular direction (as they may not be as experienced in participating in research so look to the researcher for guidance) under the guise of collaboration, ownership and equal sharing of power. I would also add consensus.

Coping with and sustaining change is more demanding, according to Wallin, Bostrom, Wikblad and Ewald (2003), than "merely expanding knowledge [as] many professionals have experienced change projects failing because team members become drained and unable to continue their work" (p. 516). Those participating in action research may become disillusioned, the momentum of the project lost with no tangible outcomes, if authentic collaboration is not evident and ownership not shared. A genuine sense of ownership is essential for maintaining the momentum of an action research project. Authentic ownership informs and dictates the direction of issues of informed consent that arise which are, like power and collaboration, unknown and unfolding throughout the action research process.

Informed consent

Issues of informed consent in action research do not stop at the commencement of the research project, in consenting to participate for example. Meyer (1993) reinforced, along with confidentiality, the notion of participants being truly able to give informed

consent in an action research project where the outcomes are not known until the end of an action spiral or until the end of the project. Turnock and Gibson (2001) undertook an action research approach to develop protocols for maintaining patient dignity in an intensive care unit, utilising observation to collect initial data. As there was concern the research being undertaken may influence staff behaviour, the staff on the unit were not advised about the “exact purpose of the study” nor “the true nature of the observations” (p. 472) until after the data had been collected. This approach raises concerns about the integration of collaboration and choice to participate, the integrity of the informed consent process for participants and the intention of working with and alongside practitioners in a respectful manner.

However, if the action researcher took the approach demanded by Kemmis and McTaggart (1998), it could be argued that with the responsibility of the research journey and processes being shared, the group through consensus manages ongoing issues of consent as the research evolves. How informed consent issues are managed throughout the research contributes to the authenticity of the project.

Le May et al. (2001) also acknowledges that ethically, it is “important to point out initially to participants that their contributions may be recognisable on discussion and/or publication of findings because of the nature of the qualitative data generated during the process but that, despite this, their anonymity will be maintained” (p. 506). Meyer (1993) points out however anonymity is potentially compromised by the research having been carried out in a particular area. Other staff working in the area may be aware the research is being undertaken and able to identify those taking part, along with any organisational management who gave approval for the research to go ahead. Anonymity for participants is unlikely. I was well aware the team would know who was participating in the research by the participants’ absence. I was also very aware all management knew of the intended project and the proposed site. In order to gain Ethics approval I required management permission. I also undertook to provide a summary report of the research once this thesis was completed.

Williamson and Prosser (2002) encourage participants in an action research project to consider personal confidentiality in publications or conference presentations. However, Meyer (1993) asserts “whilst the researcher can assure participants that no

one will be named in the thesis, the researcher cannot control what participants say to each other in the field and, as such, vulnerability of individuals may become an issue” (p. 1071). Confidentiality for participants cannot be guaranteed and is dependent on other participants and the researcher.

Challenging issues for nurse action researchers

Issues that challenge action researchers are variable, depending on the researchers’ position in the context the project is being undertaken in. An insider researcher is “a practitioner undertaking research into their own and their colleagues practice” (Reed & Procter, 1995, p. 10). They suggest researchers may move from ‘insider’ to ‘outsider’ or ‘hybrid’ depending on the research being undertaken, with an outsiders position being that of a “guest”, a “temporary” role, where “taken-for-granted assumptions” are not shared and there is “no concern for the everyday use of the research” (p. 30). A hybrid researcher has tacit knowing and established relationships within the practice setting but is undertaking research concentrated on the practice of others. In planning this action research project, I was a member of the district nursing team and an employee of the organisation I was intending on carrying out the research in. My aim was to explore the experiences of the district nurses I worked with. I wanted to avoid my own practice experiences overrunning the project.

Nurse researchers undertaking action research in their own clinical setting come to the research with tacit knowing, an understanding of the workplace culture, “the everyday jargon ... the legitimate and taboo phenomena ... they know what occupies colleagues’ minds” (Coghlan & Casey, 2001, p. 676). Drawing on their own experience can result in richer data being obtained, as they are aware of the nuances. Coghlan and Casey (2001) also consider the disadvantages of insider knowledge, with the researcher assuming too much, flooding the research with their own experiences and thinking they know the answers so refrain from asking more probing questions. Clarity of the research aims may be clouded as the project evolves and developing practical strategies to manage issues arising pose further challenges for action researchers. However, it “may be impossible to envisage all possible scenarios” (Turnock & Gibson, 2001, p. 476). Clarity in addressing this messiness and creating order may be easier for action researchers working within their immediate workplace, due to their insider knowledge.

Titchen and Binnie (1993) believed the ‘insider’ researcher, who they named “actor/change agent”, does not “ignore their part in the situation, but take into account ... the effect of their roles, relationships, values, prior interpretations of the phenomena they are studying” (p. 859). Insider researchers position themselves within the research, recognising and integrating their relationships and insider knowledge. Titchen and Binnie viewed their role as facilitating “the creation of collaborating groups of reflective practitioners, change agents and researcher, rather than groups of co-action researchers” (p. 863). This was the climate I hoped to facilitate in this action research project.

Role conflicts, challenges in organisational relationships and friendships, are magnified when researchers are carrying out action research within their own workplace to gain academic qualifications (Coghlan & Casey, 2001). Researchers may be challenged to meet participants’ unrealistic expectations or disadvantaged by hierarchical or power inequities. Organisational politics can also be challenging for the researcher, if the action research project is viewed as subversive by organisational management. Action researchers need to balance the political environment to avoid compromising the research or their own employment. The politically savvy action researcher, to maintain their own credibility, must assess and manage the “power and interests” of all interested parties (Coghlan & Casey, 2001, p. 677). More importantly, action researchers have a responsibility to work in ways that do not compromise the professional careers of the participants. Action research, when undertaken by those in leadership positions within an organisation, highlights an existing power imbalance and as discussed earlier, may further magnify the vulnerability of the participants. Action researchers must also take responsibility for any backlash following the research, particularly responses of their interpretation of participants’ accounts in written reports (Williamson & Prosser, 2002). How this is enacted while not compromising authenticity is unclear. Being aware of these tensions and considering how they were to be managed in this research project was vital for me in my leadership role. Navigating the political landscape safely and carefully was an important consideration for me, on the participants’ behalf.

Dissemination and commitment issues are more complicated for nurses carrying out action research in their own workplace. The researcher must also navigate their own

expectations and commitments to their profession, colleagues taking part, and if the research is part of higher education, the academic faculty. Achieving balance between these can be challenging (Reed & Procter, 1996). Data analysis or publication findings can be excessively influenced by relationships with colleagues and by organisational politics, potentially impacting on the authenticity of the action research. The researcher may try to meet the expectations of all parties. This is difficult to achieve because action research is collaborative group processes and the journey unknown. Researchers must be very clear from the outset, I believe, in naming their priorities. For me, participant safety was paramount, because of my leadership role.

Action research nursing literature consistently reflects challenges experienced by researchers from outside the immediate workplace, entering cultures and practice areas in which they are not familiar with the specific subtleties and nuances and without established relationships with the practitioners in that practice setting (Bridges et al., 2001; Turnock & Gibson, 2001; Webb, 1989). Establishing a sense of ownership, authentic collaboration and trusting relationships can be difficult for researchers undertaking action research within their own workplace context and these challenges are magnified when the research is undertaken by those from 'outside'.

Nolan and Grant (1992) offer a framework for nurse action researchers to support a sense of group ownership. This includes "a shared and explicit set of values acting as a guide for practice; a recognition that a problem area exists; a common understanding of the problem; a perceived need for change; the situation is seen as amenable to change; a focus on involvement and team building" (p. 307). The ease in which this framework can be applied in action research is I believe dependent on the positioning of the researcher. The action researchers' role, in demonstrating collaboration, in leading not controlling, in addressing issues of power and ethics is pivotal to establishing authenticity and trustworthiness. Proof of congruence in how these issues are approached, considered, managed and articulated by the action researcher contributes to the authenticity and trustworthiness of the research.

Challenges to authenticity and trustworthiness in action research

As a qualitative enquiry, Guba and Lincoln (1994) argue, rather than considering rigour as the only criteria for critiquing action research, that "authenticity criteria of

fairness, ontological authenticity, educative authenticity, catalytic authenticity and tactical authenticity” should also be used to establish the quality of action research (p. 144). This is because of the specific contextual situatedness of the research, the multiple voices, and differing perspectives and experiences of those engaged in the process. Action researchers’ ability to demonstrate authenticity and trustworthiness is challenging because of the many interpretations, diverse voices, evolving processes and the degree of messiness outlined throughout this chapter.

Hope and Waterman (2003) defend action researchers against charges of “sloppy research”, highlighting ethical and action-orientated principles underpinning action research. They view the task of action researchers as creating “an interpretive community within which data/ideas/arguments resonate” (Hope & Waterman, 2003, p. 124). Resonance with other similar communities supports authenticity and trustworthiness, despite the projects being undertaken in specific contexts. Further complications arise because “in any context, there may be multiple cultures, with each of these having their own distinct set of values, beliefs and assumptions” argue McCormack et al. (2002, p.97). Acknowledging, discussing and debating differing perspectives can develop the research further (Hambridge, 2000). Without authentic understanding of the practice context culture, meaningful action and lasting change may not be achievable. Action research is contextual and localised resulting in localised authenticity but an inability to be transferred externally. Interpretations and dialogue could however, resonate with other groups outside the local setting.

Authenticity is demonstrated through truthful articulation of the at times messy processes outlining how the action research was undertaken ‘with’ rather than ‘on’ people. Authenticity is further reflected by collaboration and ownership within the project – how the relationships between participants and researcher are constructed, articulated and demonstrated in the action research process. As described previously, issues of power, ownerships and informed consent are not clearly evident from the outset and must be considered throughout the project, including any summary reports.

Cyclical processes allow for reflection and reflexivity, creating opportunities for ongoing dialogue to “deal with emergent issues and for the refinement of ideas” (Waterman, 1998, p. 102) enhancing authenticity of action research. Cook (1998) also

agrees that the spiral process adds to the robustness of action research, in which reflection on action is an integral component. Reflection is an essential part of action research. Street contends “critical reflective processes are demanding as they require an examination of the realities of practice as experienced” (1991, p. 23). Reflexivity is also evidenced by truthful written documentation of the researcher in their analysis of the action research processes. This provides a paper trail able to be scrutinised. Action researchers must resist temptations to ‘tidy away’ moments of messiness in their writing up of research processes. There is further messiness and debate of the usefulness and what constitutes, reflection. Understanding these debates is critical as they add to the sources of action research messiness outlined earlier.

The messiness of reflection

There are varying interpretations of what constitutes reflection and how reflection should be undertaken with a variety of frameworks suggested as mechanisms to support successful reflection in nursing (Atkins & Murphy, 1992; Johns, 1996; Platzer, Blake & Ashford, 2000; Todd & Freshwater, 1999). There is debate however of how useful reflection is, in changing behaviour or practice (Andrews, Gidman, & Humphreys, 1998; Cotton, 2001). Freire (1970) considered action and reflection to “occur simultaneously [and] a critical analysis of reality may ... reveal that a particular form of action is impossible or inappropriate at the present time” (p. 109). He believed critical reflection was action (praxis) and in undertaking critical reflection, new knowledge of reality emerges. Schon (1983) claims reflection to be a method of linking theory and practice, while distinguishing between reflection-on-action and reflection-in-action. The latter incorporates tacit knowing, of which there is growing acceptance of in nursing (Benner, 1994; Rose & Parker, 1994; Warelow, 1997). Kemmis (1985) also supports the ideal that thinking and reflecting in the moment can change future action. I question the implicit assumption that reflection will change future action. In fact, it may not. One criticism has been the use of reflection only when exploring critical incidents to reveal problems in practice (Heath, 1997; Todd & Freshwater, 1999), rather than using reflection to enhance everyday practice or to celebrate practice.

In reinforcing that reflection makes ‘visible’, ‘invisible’ nursing practice knowledge, Cooney contends nurses in practice “face complex situations everyday, such as caring

for the dying patient and his/her relatives, which defy solution by tradition ... if nurses explore what works, try to understand their actions in the practice situation, examine the context of those actions and learn from the unique situation they encounter, they can widen their knowledge base” (1999, p. 32). Reflection may enable the practitioner, through analysing their actions alongside contextual factors, to develop a deeper understanding of what occurred, thus changing their perception for the future (Lowe & Kerr, 1998). As the context is unique, the ‘happening’ will never occur in exactly the same way again, although there may be similarities in which case the practitioner or researcher can integrate their learning.

Despite multiple interpretations, messiness surrounding process and ambiguity of the ‘right way’ to carry out action research, Rasmussen (1997), suggests the “attributes of action research include mutuality, participation, and systemic inquiry; immediacy, relevance, and usefulness; and action, skill development and learning” (p. 254). These strengths make action research an “authentic methodology for the study of nursing” (p. 264). In summary, action research is a research methodology that relies on collaborative group processes to reach common understandings and bring about responsive local change. It makes sense to me that action research as a methodological approach has been enthusiastically received by nursing researchers. The next section of this chapter outlines how I proposed to manage the ambiguity and messiness of action research in planning this research.

Research design

Groundwork for this project was laid over 12 months before gaining final Central Region Ethics committee approval. Before commencing the action research journey, I ascertained interest in pursuing the proposed topic from the group of district nurses I was working with at that time, through informal discussions about my ongoing study. Feedback was encouraging with team members regularly asking when I was going to make a start. At the beginning of 2004, I entered informal discussions with the then acting Service Leader of Community Health Services, to establish initial management interest and support. I saw there was a risk to the action research outcomes if the project was not supported by the organisation. Once again, the feedback was positive. Planning then began in earnest.

Further issues considered in the preparation phase

In planning the proposed research, the most important aspect was balancing facilitating the research while being in my role as Clinical Nurse Specialist in my workplace. As I held a senior role, a power imbalance similar to that described by Titchen and Binnie (1993), potentially existed with the team I was hoping to collaborate with. I hoped to work alongside team members through three or four praxis groups utilising an action research process. The possibility of unsafe practice being raised created potential conflict of interest, as I, in my leadership role, was involved in yearly appraisal processes with the district nurses. Due to this input, colleagues may have felt unable to freely share their truth of their practice. The intent of the research was to find workable solutions, with no direct searching for unsafe practices. If poor or unsafe practices were revealed, these would be discussed with the group member and my supervisor.

The proposed focus for exploration was potentially sensitive due to the intent for district nurses to share their palliative care practice experiences. Potential distress could occur for group members sharing experiences that raised memories of stress, sadness or distress. Reflections from practice may include reference to third party involvement, potentially interactions with people and families receiving palliative nursing care, other health professionals involved in care partnership and any other significant parties. Managing these issues in a safe way was a key concern throughout the research process.

To reduce risks for potential participants, the consent form articulated their ability to withdraw from the project without having to give reasons and without penalty of any sort. To avoid identification, no names would be used or opinions attributed to individuals in published results. In addition, the information provided would only be used for this research and that any further use would require written consent. There was also an undertaking that those who consented to participate would be provided with transcriptions of meetings throughout the research project and provided with a summary of the research results at its conclusion.

Explicit articulation of how the intended research meets Treaty of Waitangi obligations is required in New Zealand when carrying out research that requires

regional ethics approval. Action research methodology and praxis group processes are consistent with two key principles of the Treaty of Waitangi – partnership and participation. The third key principle of the Treaty of Waitangi, protection, could not be guaranteed because in action research the outcome is unknown. Accordingly, I liaised with the Maori Health Unit at Capital and Coast DHB. I discussed the proposed research with the Community Liaison for Maori for Community Health and Assessment, Treatment and Rehabilitation Services and received a letter of support. Participation in the research was based on occupation rather than ethnicity.

Gaining permission for the research

As an employee at Capital and Coast DHB, I required agreement from the Service Leader for Community Health Services, the Business Manager for Clinical Support Services and the General Manager for Hospital and Support Services of the District Health Board. These endorsements were required prior to seeking ethics approval from the Wellington Ethics Committee, and the Victoria University of Wellington Human Ethics Committee. The Wellington Ethics Committee first considered my application at their June 2004 meeting and the study was approved subject to a number of issues being addressed (Appendix 1).

Following rapid staff changes at Kenepuru Community Health Services and completion of the Community Health Service review, by June 2004 I decided to suspend my study. In January 2005, I resigned from Community Health Services. In March 2005, I forwarded a letter to the Service Leader for Community Health Services and the Business Manager of Clinical Support Services at Capital and Coast DHB, indicating my intent to proceed with the research project and undertook to forward a copy of the letter of approval to proceed once this was gained from the Wellington Ethics Committee. Approval from the renamed Central Region Ethics committee was received on April 16th 2005 (Appendix 2). The change in employment impacted on my role in the research and created some unanticipated issues. These are explored in Chapter 5.

Recruitment of participants

The focus of the research was district nurses experiences in providing palliative care. Inclusion criteria were all district nurses employed at Capital and Coast DHB Kenepuru campus, including part time and casual or short term contract staff who

volunteered and consented to participate. Inclusion of casual and short term staff acknowledged Community Health Services approach in retaining experienced district nurses. These district nurses' particular employment status was a personal choice, providing employment flexibility. The service did not utilise casual or agency staff without specific, demonstrated district nursing experience and competence. I believed part time or casual district nurses could bring another perspective to the group discussion. As the research focus was nurses' experiences, managers and other Community Health employees were exclusionary criteria for participation. The first six district nurses who volunteered and consented to participate were eligible to be included in the praxis group meetings to support manageable group numbers and processes. If sufficient interest had not been gained at the Kenepuru site, other Community Health sites within the District Health Board would have been approached. Sufficient interest was gained at the Kenepuru site so no approach was made to the other bases.

Recruitment occurred in two phases. General information about the research was provided at a staff meeting with the researcher introducing the project, stating intent and asking for interest. Invitations to participate (Appendix 3) were left with contact details for those potentially interested to contact the researcher independently. This was to ensure the recruitment process avoided any sense of coercion and was as safe and transparent as possible. The team requested I return the following week to the next staff meeting for further discussion. A number of requests for consent forms were made at the initial meeting. These were not provided, as I wanted those potentially interested to have time to consider their involvement.

At the second meeting, information sheets (Appendix 4) were presented, providing a more detailed account of the proposed research project and proposed processes involved. The information sheet identified a group contract would be made to maintain confidentiality and minimise the use of names of patients, families and other health professionals. These were incorporated into the group ground rules. Group decisions regarding future sharing of findings were also mentioned in the information sheet, along with contact details of the researcher's supervisor. Consent forms (Appendix 5) for the research were left at the base. I was asked to return the following day by interested potential group members and on that visit was met by volunteers,

with consent forms signed. The group expressed a desire to ‘get started’ as soon as possible. They decided the best time for the first meeting was the following Monday. There were five volunteers who consented to participate.

Method

Three or four praxis group meetings were proposed, with one full cycle of action research being completed within the specified time frame. The cyclical process was to rely on a collaboratively agreed approach. Following consent being gained, I had planned an initial meeting of those interested would be held, to restate research intent, to discuss group ground rules to ensure a safe beginning place for self-disclosure and to confirm time frames and dates of future praxis group meetings. However, this planned meeting was not held. Research intent and beginning processes were briefly discussed the day I collected the consent forms and due to the immediate start of the praxis group meetings, the other items were discussed at the first meeting.

The plan for the first praxis group meeting was to set the ground rules for the project and to explore issues experienced by the group members that they have found challenging, through the sharing of stories from practice. Sharing experiences or stories from practice have become an accepted part of qualitative nursing research. According to Koch (1998, p. 1189) the aim of telling stories ... is to gain another or a different understanding”. Aranda and Street (2001), in utilising participatory research processes, moved from individual stories to reconstructing these as group narratives, bringing about new understandings and creating a “multivoiced, narrative” (p. 796). Critical incident technique is a method of data collection that encourages focusing of an interview or group process on specific instances from stories or narratives from practice (Redfern & Norman, 1999a, 1999b). Through sharing experiences from practice, group narratives could be co-constructed in this research project, by illuminating common group issues. I prepared a narrow lead in requesting group members recall an episode of palliative care that they had experienced as a primary nurse within the previous six months. This approach was considered in the hope it would elicit different practice experiences being shared with an established relationship between the district nurse and the person and family with contextual knowing embedded in the relationship. I developed a number of prompts if material did not unfold. However, these were not required.

The plan for the second praxis group meeting was to share reflections on issues raised in the first meeting with consensus reached on those deemed by the group as most important. The plan for the third praxis group meeting was to explore possible strategies that could be practically integrated into district nursing practice or by Community Health Service to address issues raised in previous group meetings, deemed important by the group. The plan also included the option of a fourth praxis group meeting.

My role, as the researcher was to facilitate the group meetings. There are varying roles and functions of facilitation (Harvey et al., 2002). For this project, the role of the facilitator was concerned with guiding group processes and encouraging critical thinking while working in a co-operative way. I provided afternoon tea for each group meeting, as was the culture when any meetings were held, and booked the meeting room used. The praxis group meetings were proposed to last no longer than two hours and were to be held at mutually agreeable times at the Kenepuru Health Service site.

Agreement was reached with Community Health Service management prior to the research commencing, for the praxis group meetings to take place in work time and on a work place site on the understanding that the praxis group meetings would not be scheduled when there were clinics, team meetings or any meetings with outside agencies booked. This was an issue on two occasions, creating moments of messiness, and is explored further in the following chapter.

Working with the raw data

Each group meeting was audiotaped with two tape recordings (to ensure a backup in case of technical difficulties). One tape recording went to the transcription typist, the other held by the researcher. The transcriber enlisted for the research project signed a consent form (Appendix 6). Having transcribed for other nurse-led research projects the transcriber had an awareness of some of the considerations involved, particularly related to confidentiality. I contacted the transcriber after the transcribing of each praxis group meeting to ensure the transcriber was able to debrief and discuss any issues she found distressing from the material she had been working with. I made a decision not to have individual speakers separated out in the transcribing, in an effort

to further avoid speaker identification. I also made a decision not to collect any demographic data in terms of age, ethnicity or gender as group members involved could be identified from this information. I did however collect data of nurses' practice experience and level of interest in palliative care in the second praxis group meeting. This served to position 'who' the nurses voices were, being presented. The researcher's supervisor had access to the transcripts, along with the group members. All data held by the researcher was stored in a locked cabinet and tapes were wiped once the final thesis had been submitted. Transcripts and research data will be kept by the researcher for 10 years and then shredded (as required by the university and the Central Region Ethics Committee).

I approached data analysis in two ways utilising multiple data sources. These are discussed in the following chapter. Qualitative analysis focuses on the action researcher process and the project outcomes so the first adopted approach was as the researcher analysing group processes as they evolved in the four meetings. These are outlined in Chapter 5. The second approach was thematic, as the researcher interpreting the common issues, essences and elements distilled by the group, which I believe informed and directed the group action taken. These are presented in Chapter 6.

Summary

In this chapter I reiterated the research question. An overview of the positioning of action research methodology was presented, following by discussion of some of the tensions, interpretations, strengths and specific ethical challenges of this approach when action research has been used in nursing. I have also outlined how this methodology was applied in the planning and preparation phase of this action research project. Important issues and mechanisms were embedded in the study design to address specific ethical considerations and to support trustworthiness and authenticity. Chapter 5 faithfully outlines the action research process as it unfolded to demonstrate the trustworthiness and authenticity of this research project. Challenges unforeseen in the planning stage and moments of messiness are recounted.

CHAPTER 5: Articulating processes of the research journey

Introduction

In this chapter, I outline how I worked with the action research processes proposed in the methodology chapter. Articulating research processes as they actually occurred is an important element of any research because while the researcher proposes undertaking a research project in a specific way (as described in the planning section of the previous chapter), challenges previously unforeseen in the planning stages may emerge. Being open to and managing change resulting from unforeseen challenges is particularly pertinent in an action research project where issues of participant safety and informed consent are complex and not guaranteed, due to the unchartered, evolving nature of the methodology. Challenges as they occurred in this research project I call moments of messiness. This chapter describes these moments, identifies the catalysts for messiness and describes how they were subsequently managed.

The research project comprised four praxis group meetings held over a three-month period. Although the research was messy at time, the chapter takes a structured, ordered approach with reviews of each individual meeting. The meeting transcripts, agendas constructed to provide a degree of order, correspondence to praxis group members, and the reflexive journal I maintained throughout the research project, comprise the documented evidence of the research processes outlined in this chapter. Processes developed during the praxis group meetings are outlined to support the authenticity and trustworthiness of the research findings. The research findings are presented in Chapter 6 where resonating group issues are illuminated, aligned with the letter of action (Appendix 7) resulting from the research, alongside essences distilled. Further action undertaken by the group following this letter is shared in the final chapter.

Five generalist district nurse participants volunteered and consented to participate in the research and contribute to the praxis group meetings. Research participants are referred to as 'the group' or 'group members'. All had been employed either part time or full time as a district nurse for more than four years, all had diverse nursing experience prior to their district nursing employment and four of the five had

commenced or completed either nationally recognised post graduate palliative care modules or papers in Community Health at Masters level. Each group member gave written consent for data generated in the action research meetings to be included in this thesis. To authentically give informed consent, I believed the group needed to be aware of the context in which their words were being used. I elected to send members a draft of this and the following chapter so they would be aware of the contextual positioning of their statements (Appendix 8). I undertook not to include additional quotes once consent had been given. Only quotations approved following this reading have been included.

Research data has been extracted from the transcripts of the praxis group meetings, in the form of quotes and are highlighted in *Italics*. Specific meetings are numbered (M) followed by the page number of the transcripts for that particular meeting (P) and are identified in brackets following quotes used. Sequential multiple quotes are at times used to emphasise multiple voices and reinforce resonance of group issues. I have not indented quotes as per American Psychological Association guidelines as I believed this would detract from the resonance I wished to emphasise. Some statements made by members in the praxis meetings may have strengthened understanding of the articulated practice ‘essences’ outlined in Chapter 6. I believed these statements could have directly identified the speaker and I have not included them to maintain confidentiality.

Clarification of language

There are changes in language that highlight changes in my positioning during the praxis group meetings, reflecting my hybrid positioning within the research – as a nurse, a colleague and as a researcher. As a nurse and colleague, with established relationships with group members, I often refer to ‘we’ or ‘us’ in the meetings. The group members also referred to ‘we’ and ‘us’. Despite my resignation from Capital and Coast DHB, I still felt very much a part of the team and a member of the group. As the researcher and intentionally not discussing my own practice experiences, I also referred to the group and group members as ‘you’. The interchangeable use of language may be distracting. It is in response to some of the ethical and power issues explored in the methodology chapter while retaining congruence with practice-based

action research principles. This highlights a potential source of messiness associated with a practice based action research project.

The first praxis group meeting – reconnaissance

There was a one hour time frame for this meeting due to an inservice session the group had been unaware of until that morning. When the inservice session was announced, the group elected to proceed with the research despite the shortened time frame. The group meeting began with me, as the researcher, ‘setting the scene’. Proposed ground rules (Figure 2) were introduced, which I described as “*understandings we have as a group*” (M.1, P.1). I believed concise, to the point ground rules were essential to supporting safe group processes while maintaining focus and momentum of each praxis group meeting. The group agreed to work with the proposed ground rules for this first meeting and to take a copy of these away to consider and give feedback, with desired changes, at the next meeting. Group members were also given a copy of their signed consent form.

Figure 2: Praxis Group Meeting Ground Rules

What is said/shared by members in the group meetings remains confidential.
 Only one person to speak at a time.
 What is said/shared by members in the group meetings is respected by the other members of the group.
 If sharing a situation from practice, members of the group are encouraged not to name patients, family or other health professionals.
 All group members have access to the Employer Assistance Scheme should the sharing of experiences raise any distress.
 Cell phones and pages are placed on vibrate or silent during the group meetings.
 Praxis group meetings will start and finish at the agreed times.
 Members of the group will receive transcripts of meetings one week prior to the next scheduled meeting, to enable validation on content and provide a basis of reflection.

The meeting

Following the completion of procedural issues I invited members to share a recent palliative care experience they found challenging or different in any way. This could be viewed as engaging a negative, rather than a positive approach and may have impacted on members’ decisions of which practice experiences to share in this initial meeting. This was also a variation on my planned introduction that focused on primary district nurse experiences. What emerged were very detailed descriptions of

episodes of care, a number of which occurred some years ago but because of their impact on the story teller, had stayed with and been carried by the members. The recollections of events, the labours and, at times, the distress of these memories was evident by the language used in the telling. The experiences generally centred on the acute deterioration of a person the group member had visited and had no prior knowledge or involvement. I did not elicit if these experiences had been disclosed in the past or if they were being told for the first time.

The events usually occurred at a time of day when the primary district nurse involved in the person's care was not on duty. Two of the group members questioned whether the outcomes would have differed, if the primary district nurse been available to respond to the crisis. The people and families were central to these experiences and reflected the ethnic diversity of this community. As they relayed their practice, members spoke frankly and openly about their experiences and immediately resonating issues began to emerge.

The importance of knowing the person and having an established relationship with them and their family was a recurrent theme in the practice examples articulated by the group. The inclusion and importance of family, with reliance on family to provide information and nursing care, along with some of the tensions experienced when the person's wishes were not congruent with their family's, was highlighted in the discussions. A group member relayed a passage of care that had occurred the previous weekend working with a person and family the nurse had not met before. The person wished to remain at home, however their family were clearly expressing they felt they were unable to continue managing. *"It was difficult when you've not met someone before ... and you haven't had the chance to build up a relationship with the person"* (M.1, P.1). The tension for the nurse was how to honour the person's wishes yet respond to and honour the family's perspectives, wishes and resources.

Tensions in responding to unpredictable, rapidly changing health circumstances in a meaningful way for palliative people and families while juggling other workload requirements also resonated within the group. *"I think that's the thing with palliative care – it's unpredictable, and it's only a part of our role and so you know we do have these other things, we can't just be in one place"* (M.1, P.19). *"Because you're*

thinking of those other 13 patients you've got" (M.1, P.19). One group member described the usual weekend workloads and was supported in their description by the rest of the group. Managing workloads creatively during weekends and in the evenings, with minimal numbers of district nurses rostered on, created additional tensions, as did unclear processes and pathways to secure support after hours for people and families.

A practice issue related to the drawing up of subcutaneous medication for family members to administer was raised during this first meeting that required further clarification. The group meetings intent was not to identify unsafe practices however there appeared some confusion between the members as to whether this practice was acceptable, following a recent review of the syringe driver policy by Community Health Services.

The personal impact of palliative care nursing in the community was raised. Members spoke of replaying to themselves episodes of care they had delivered and in the replaying, they questioned the decisions they had made. The meeting closed with my inviting the group to reflect on the discussion, their experiences. Members were encouraged to raise any further issues or questions at the next praxis group meeting.

Reflection on my role as facilitator and of the group process

I noted in my journal following the praxis group meeting my anxiety in beginning the research. This resulted in the digression from my planned introduction. However, I believed the group led the conversation, evidenced by the sharing of experiences that had occurred some years ago. Making a conscious effort to be unobtrusive, my role was simply to open and not lead the discussion. The transcripts reflect there was little input from me, once I as the researcher, had 'set the scene'. I spoke generally using only one sentence to reflect back, clarify or draw out further statements made by the members. I had wanted to establish a feeling within the group that this was a conversation, albeit with a specific focus. The group members' demonstrated respect for each other and as one finished speaking, another picked up the conversation. I was aware at certain moments, there were questions I wanted to ask but didn't. I had wanted to avoid appearing disrespectful or challenging of members when they were describing their practice. In my hybrid researcher role, I had insider knowledge with

established relationships and my intent was not to discuss my own practice, but to support the group to articulate theirs. My role was to facilitate the group and I didn't want to risk tainting the conversation with my own bias, standards, experiences or perspectives. The climate I wanted to create focused on building group confidence alongside the need for me to establish new relationships, as a researcher, with the members who had been my colleagues. I was also acutely aware of the reduced time frame for this meeting and felt a tension to ensure everyone had the opportunity to share equally. I was committed to this initial meeting being a positive experience for those involved.

Preparing for the next meeting

In preparation for the second praxis group meeting, I included a covering letter with the transcripts outlining a tentative agenda to support the start of the meeting (Figure 3).

Figure 3: Transcript from first praxis group meeting

9th May 2005

Transcript from Praxis Group 2/5/2005

Greetings

Thank you so much for participating in the first praxis group.

Please find enclosed a copy of the transcription. I have changed the name of one staff member who was identified in the transcription. I hope this is okay.

I'm really looking forward to meeting with you again next Monday (16th May) at 2pm at the same venue.

Could you read through the transcript, think about the conversation that we had and the issues that were discussed. I will ask you to validate the content at the beginning of our next meeting.

Are there any issues or themes that were repeated in the session/conversation?

Are there any issues or themes that didn't, that you would like to talk about the next time we meet?

To continue our conversation at our next meeting, I would like us to pick up on anything that was left unsaid due to the time constraints.

I also need to collect baseline data that was requested by the Regional Ethics committee in terms of a general outline of your district nursing experience and any postgraduate study you have completed. This will not be documented individually but a general statement will be made in terms of the group makeup. If you are not comfortable providing this information, just let me know. Look forward to seeing you on Monday.

Kind regards

Donna Voice

The second praxis group meeting – the beginning of distillation

As the group reconvened, members provided the baseline data of their nursing experience necessary to describe who they were as nurses. This conversation was not recorded. The ground rules or ‘understandings’ proposed were reiterated and confirmed by the group without changes. The meeting began with the members reflecting on and responding to the transcripts of the first meeting. *“When I read through ... some of it seemed quite negative. It seemed that we were talking a lot about things that hadn’t gone well, whereas I think a lot of what we do goes really well and I think we need to think about that as well as ... saying ... how we had encountered problems, but a lot of what we do ... is fantastic and we do it really well”* (M.2, P.1). Other members supported the sentiment. I acknowledged this concern. I restated the positioning of the research in focusing on the group issues in providing quality palliative care. I encouraged group members to feel confident in sharing positive experiences during the meetings as these could provide useful tools for other members in their practice. One group member responded *“I guess the positive ... is that it can give different ways of looking at it and managing it to get the better responses and the better nursing care”* (M.2, P.3).

The meeting

A moment of messiness arose with group member names included in the transcripts. I had asked for the transcriptions to be transcribed verbatim and I had not ‘cleaned’ them sufficiently to remove all of the names before I delivered them to the group members. Some names I noted, replacing these with pseudonyms. I had not discussed with the group how they wished to manage any inclusion of their own names whether they were to be removed or pseudonyms used. While members had avoided naming of other colleagues as agreed to in the ground rules, we had not clarified how to manage the members referring to each other during the meetings. I suggested *“Shall we just take the names out altogether”* (M.2, P.1) and the group agreed to this. This process was implemented for managing all names in subsequent transcripts of the meetings.

Group members raised an issue with working with the transcripts verbatim and the inclusion of ‘ums’. *“I didn’t realise there were so many ums!”* and *“Ums and you know”* (M.2, P.1). I responded to this with support and reassurance *“But when you say ‘you know’ everyone goes yeah!”* (M.2, P.1). Some of the members felt they were

not as articulate in the transcripts as they envisaged themselves to be. *"I thought I spoke quite clearly and articulated myself well ... but I didn't ... I can understand the point I was trying to make, I'm not sure if the reader will"* (M.2, P. 8). This echoed with other group members. *"Like you, I don't think that I sounded particularly articulate either"* and *"It's amazing. Is that how we talk all the time?"* (M.2, P.9). The group had read the transcripts and had a clear understanding the transcripts would provide the data for the research. They reflected on their use of language and how they in their everyday practice get their message across. These comments reflected to me a degree of discomfort or surprise for the group members following their reviewing of the transcripts.

One member raised how to amend in the transcript a comment they had made. This moment of messiness required clarification and group consensus to ensure it was done safely. *"So how do we do that if we were to change a bit of what was being written or what I said ... there's just one little bit, that's all. There's one little bit"* (M.2, P.2). I responded by undertaking to make any adjustments as the group agreed. The group agreed to the transcripts being adjusted and to putting the old transcripts into the destruction bin (as opposed to the regular rubbish) to ensure they were disposed of safely, when they received the revised copies. Consensus was reached that this process would be undertaken following each praxis group meeting. This was the only occasion throughout the research where transcripts were amended.

A further transcription issue a group member sought clarification of was in not separating out individual speakers. *"It looks like the response has come from one person, as you're reading it ... you're not seeing that there are five different people here. And it does make a difference to how, well I think it may make a difference to how that's interpreted once you've ... re-written the whole thing"* (M.2, P.2).

I responded by saying my thinking as a researcher had been *"it didn't matter who the speaker was, the experience of all the speakers as a whole forms the picture"* (M.2, P.3). I explained my intention had been not to distinguish between individual speakers as I felt this could make individuals identifiable. This was a particular consideration in my planning of the research due to my previous role within the service and the team. I reiterated what I sought to uncover were themes and issues for

the collective group. The group member responded positively. *“That’s good to know ... because I was only thinking about how you might collate information later. I just thought it might make a difference to how you present that ... but if it doesn’t [matter] that’s fine, then that’s great too”* (M.2, P.3).

Once transcription process issues had been resolved, the issue of articulation (which I had noted in my journal after the first meeting) I picked up on, relating this to a practice experience relayed in the first meeting – *“I was left ... with a sense that often we’re not listened to or we’re not heard ... is it because we’re not specific enough in describing what we’re seeing? That’s just a question”* (M.2, P.9). This opened up a focused discussion with all group members offering an interpretation. A number of issues raised in the first group meeting were raised again in the second, reinforcing the importance of these concerns for the group. One member was already identifying the emergence of themes from the first group meeting. *“I think there are themes that are coming through weren’t there”* (M.2, P.9). This signalled the beginning of the group coming together, refining the wider issues identified in the first meeting, drawing on their practice experiences to provide further examples of tensions illuminated in the first praxis group meeting. This was undertaken alongside articulating some of the methods group members engaged, to manage some of these challenges in their practice when supporting people and families.

Group dialogue initially focused on forward planning and the potential impact of ongoing changes in the provision of medical services, specifically in securing medical support in the home after hours. The need to work within a multidisciplinary team, establish, and maintain close working relationships with other health providers was highlighted by the group as essential in providing quality palliative care. Relationships mentioned included relationships with General Practitioners (GPs), the local hospice staff including inpatient staff, the care coordinators and palliative care consultants and the agency nurses who provide night support for people and families.

Ongoing learning embedded in district nursing practice was raised by one member, *“We’ve all got a lot of learning to do”*. This resonated within the group, *“Life would be boring if we didn’t”* and *“The challenges keep us going”* (M.2, P.21). I followed on from this comment about learning, changing the focus slightly, asking the group

directly whether palliative care in-service sessions provided within the service were *“enough to prepare or is it more on the job ... situation by situation?”* (M.2, P.27). The group was in agreement, *“It’s more situation by situation”* and focused the discussion on their individual formal learning in palliative care. A member then engaged the group to further explore the issue of learning that had been raised. The group members were by now directing the ‘conversation’. The conversation moved to the differences in delivering palliative care in the community as opposed to in the hospital. *“In the hospital environment ... where you have all those resources at hand, and in the home environment ... you’ve got the family looking on and wanting the right things done and ... you want to be doing the right things for the dying person as well. And you don’t have those resources readily at hand”* (M.2, P.22).

The dialogue that ensued highlighted the group members’ individual focus of palliative care *“of making sure that person’s comfortable”* and included, if the person was in hospital, *“giving the patient [and] giving the family the option to taking the relative home, to die. And having that support in the community”* as *“Suddenly they get them home”* (M.2, P.24). At that moment, I drew on my own tacit knowledge *“that Friday night special”*. This prompted the group to reflect on their own experiences of people coming home from the intensive care unit at short notice and the role of the district nurses to support people and family in this process.

Further exploration by the group members followed, of safety issues overnight and the on call arrangements with references made to the recently completed Community Health Service review highlighted in Chapter 3. The group believed a great deal of work had already been done to unpick these particular issues in the review but there was some uncertainty of the implementation of the review recommendations. Once again, the meeting closed after one hour following consensus being reached on a beginning direction that the third group meeting could take – clarifying the issues and possible strategies in getting the issues heard and addressed.

The group did not disperse immediately and conversation related to the research continued. Another messy moment. The informal discussion was such, I sought permission to turn the tape back on, and have a statement one group member had made restated and the conversation began again. I restated my question *“do you think there*

are differences in providing palliative care ... when you were working casual, as opposed to now that you are working full time?" (M.2, P.28). The response was *"Yes I do, I think it's very different, I think it's very rewarding"*, due to being a *"consistent presence"*. What resonated with the group members was the importance of consistency. *"It is essential", "Definitely. For the patient and for us"* (M.2, P.29). One group member recalled how they felt when in explaining to a person they were seeing for the first time, the person turned and said *"oh, that's okay because you're the fourth different person I've seen!"* All the group members agreed *"that's awful when that happens"* and *"definitely to be avoided"* (M.2, P.30). While consistency was valued by the group, the members also believed the consistency of the nurse was valued by people and family being visited. After 10 minutes of further dialogue the meeting finished and the group dispersed.

Reflections on my role in the second praxis group meeting

My role as facilitator, evident in the transcription of this meeting, was to clarify and draw out issues raised by group members. For example, *"Was there anything that we didn't get to?"* (M.2, P.4), *"Is that something that needs to be explored?"* (M.2, P.5), *"Would that be your experience?"* (M.2, P.23). I recall feeling some concern the conversation flow was not at the pace or with the focus of the first meeting but this is not evident in the transcripts. In reflecting back I believe the flow may have been interrupted due to the initial 'intrusion' of sorting through the messiness of the transcription processes at the beginning of the meeting, along with possibly a degree of discomfort or loss of confidence by the group members following their review of the transcripts from the first meeting. From my reading of those transcripts, I came to the second meeting with questions and issues I wanted to explore further. In attempting to elicit what had *"jumped out"* (M.2, P.8) of the transcripts (deliberately attempting to search for evidence of critical reflection in my researcher role), the group members had responded regarding their own articulation. This probing did not appear to be viewed by the group as threatening, more an opportunity to further clarify and articulate their message. I was surprised by the direction taken and on reflection I should not have followed on from their discomfort with my own question regarding articulation. I believe this part of the meeting was not well facilitated. There was a delicate balance of seeking to clarify without dominating the discussion and these interjections may have disrupted the flow of the group conversation. The tentative

agenda I had set to support a sense of order may also have been a source of distraction, breaking the flow. However, I was aware of waiting for a pause in the conversation or a sense that the topic being discussed had been brought to a close by the group, before returning to the agenda.

An informal discussion – clarification of the research

The following day I was back at the base on another matter and was approached by a group member who asked me to clarify again the purpose of the research and what the intended outcome of the research was at the beginning of the next group meeting. S/he commented that s/he did not consider the conversation flowed as well in the second meeting and used the term ‘triggering’ to describe the conversation flow in the initial group meeting. S/he felt this hadn’t happened to the same extent in the second meeting and suggested this may have been because the purpose of the research had been lost a little. The member finished by commenting that participating had made her/him think about their practice. I asked her/him to consider sharing these insights at the next meeting and thanked them for the candid feedback. I deliberated whether to include this informal discussion in the body of this thesis, as it had not been part of the formal research process. This messiness presented a dilemma – was I betraying the confidence and trust of the member by including our informal conversation? It was a moment for me to stop and reconsider the clarity of the project not only for the group but for me also and served as a beginning point for the next praxis group meeting, for me to refocus and restate the intent of the research project. I sought and received written consent from the group member concerned to include this account of the conversation in this thesis.

Working without the transcripts

An issue arose for the transcriber following the second praxis group meeting that led to a four-week delay in the meeting transcripts being processed. This was a further moment of messiness. The third group meeting was subsequently postponed for two weeks, following negotiation with the group. Despite the postponement the transcripts were further delayed. I delivered the revised transcripts from the first meeting to the base with a covering letter outlining the continued delay with a possible agenda for the third planned meeting if the group wished to proceed (Figure 4).

Figure 4: Transcript from the second praxis group meeting

8th June 2005

Greetings. I apologise for the delay in getting the transcripts of our last meeting to you and the postponement of our last scheduled meeting. I am looking forward to meeting with you again on Monday 13th June at 2pm for the purpose of confirming the action needed to move the issues on that we have discussed. I have listed below the issues we have identified but will seek confirmation of these issues with you at the beginning of our next meeting.

Balancing workload and acuity or need – process of triaging

Provisional action plan from the beginning, from acknowledgement of palliative status, to manage untoward events, including a provisional plan for pain relief

A method of supporting families to care for the dying person – would a pamphlet or similar be useful to support families to manage issues such as food, warmth, rest etc.

Debriefing – how, when, who? A team debrief following each death for all of those involved? Clinical supervision? After hours supervisor available? Would it be useful to meet the after hours supervisors?

Working with families – inservice around strategies in working alongside families experiencing distress in a vulnerable time?

Clarify night nurse support – would providing inservices for those agency nurses interested in providing night support increase the pool of night nurses available?

Care planning between agencies and the family – would this ensure a firm understanding of what will be in place on discharge? This would incorporate general situations as opposed to individual or selective situations.

Accessing medical support after hours – raising this issue with all agencies, including Primary Health Organisations, Community Health Services, Mary Potter Hospice and the new Accident and Medical centre at Kenepuru hospital. After a nursing assessment has been made after hours, where to next if a medical assessment is required?

While I have listed a number of issues, I acknowledge there may only be time to focus on a few and I hope we can prioritise these issues to work with.

How do we present the issues that have been prioritised and who do we present the issues to, to take them forward? Do you wish me to remain involved to support the action?

I would also be keen to discuss the possibility of us meeting for a fourth time, to confirm an action plan from our next meeting, to bring the research process to a close and as an opportunity to share a positive story from practice.

Looking forward to seeing you on Monday. Kind regards

Donna Voice

Ensuring an opportunity for group members to read, reflect on and validate transcripts from previous meetings had been considered an essential element in the data collection process. However, the group chose to go ahead with the third meeting without them. To me this demonstrated an establishment of trust in the group

processes, a commitment and focus to the project by the members that contributed to maintaining the momentum of the research. A number of the issues I included in the agenda were not identified by the group in the third praxis group meeting as being a priority for them. An urgent union meeting had been called to nationally scope district nurse practice. Rather than cancel or postpone the group members rescheduled the timing of the third praxis group meeting and let me know the arrangements. They created the order in this messy moment. The group requested this discussion not be taped as the group wished to discuss debates from the meeting they saw as fundamental to district nurse' roles.

The third praxis group meeting – issues and essences extracted

In opening the conversation, I apologised to the group for the continued delay in the transcripts from the second group meeting. I offered my own reflections from the second group meeting and without indicating the informal discussion I had had with the group member, suggested the meeting had *“re-iterated the issues that had come up in the first meeting but in a different way ...[and] validated ...[the content of the] conversations that we'd had in the first meeting”* (M.3, P.1). I asked the group if there were any other issues that had not been identified. Each member reinforced the issues of importance for them. No new issues were identified. The group then engaged in examining more closely the detail and possible contributing factors of an episode of palliative care involving one group member the weekend prior to this meeting which encapsulated all of the issues highlighted by each group member. I raised the practice issue related to syringe drivers from the first group meeting for further discussion, and sought permission from the group to take the issue to a practice leader who had been involved in the syringe driver policy review. Permission by the group was given. I subsequently meet with the practice leader, clarified the processes involved and forwarded a copy of the written documentation associated with this practice to the members.

I suggested the group consider *“where do we go from here and what are the issues that we see as needing to be taken forward”* (M.3, P.4). The members were clear in their agreement that *“the debriefing issue”, “the access after-hours”, “having some education for agency staff [who provide night nursing support] about palliative care”* (M.3, P.4) were issues they wanted taken forward. One member, when discussing the

scarcity of registered nurses able to provide night care (funded through the Cancer Society) posed “*whether other community health bases are ... having the same trouble*” (M.3, P.6). The group members were now taking a wider service view, beyond their own base and immediate workplace context. Issues for group members in triaging after hours, particularly in the evenings and weekends were highlighted in this meeting.

The group moved the discussion further, with members outlining a multitude of contributing factors and possible future solutions to the issues they experienced in their practice. From the examples given, it suggested to me that group members had, during the four-week gap, independently approached a variety of their own established sources to elicit multiple approaches used in other practice and geographical areas to address or reduce the impact of specific issues that had been discussed in the first two praxis group meetings. Members shared openly a variety of ideas, knowledge of processes utilised in other regions, drew on past experiences in working with people and family that had provided useful tools for their practice, along with other avenues they had explored. “*There’s some reading that I’ve done around it, but part of the debriefing thing is ... that you can move forward ... so you have this time to talk, but you have a way that you can move forward*” (M.3, P.15).

The regional palliative care review, discussed earlier in Chapter 2, was raised during the third meeting. Members asked for the discussion not to be recorded on tape. I had been aware the draft review document was due for release by Capital and Coast DHB and had deliberated whether it was my role as researcher and facilitator, to raise this issue at the third meeting. I had decided against it to avoid leading the discussion. Members raised the review, debating potential contractual changes that may occur. They questioned if there was any point continuing this research project, if district nurses were unsuccessful in securing the palliative care nursing contract.

The group cautiously agreed the outcome of the contract tendering process was not a foregone conclusion. However, there was some tension for the group around this issue. There had yet to be any wider discussion within the service and there was some uncertainty around this. I advised members the document was publicly available on the Capital and Coast DHB website. Once again, I reflected on this messy moment

and whether to include the discussion in this thesis, whether it would be disloyal to the group and the research process. This conversation demonstrated an acute awareness and political savvy about the work place landscape and a trust within the group to discuss an issue that had not yet been raised in a wider forum. Specific written consent was given by the group to include this account of the dialogue in this thesis.

I asked the group to consider which of *“these issues ... are specific to this community?”* (M.3, P.26). One member suggested *“some of them will be”* while another suggested *“maybe a survey”* to elicit a fuller understanding, posing *“so would you do some kind of mini-survey to each of the bases just to get the general view of whether these are issues that are across the board for a start?”* (M.3, P.26). This discussion then moved to ascertaining where to take the issues. I proposed *“the need to frame something up to present”* (M.3, P.27). A group member stated *“I think if we present them as an issue for here, we’re taking ownership of what’s happening here”* (M.3, P.27). I then raised the issue of remaining non identifiable. *“We’ve talked about anonymity, and so if we were going to take something forward, then would it be in the form of a letter, kind of outlining the issues that we’ve talked about, and outlining some of the strategies that we’ve talked about in terms of addressing those issues, and then I would be happy to sign the letter as ... convenor of the group ... or on behalf of you who had participated ... if you wanted to maintain anonymity”* (M.3, P.27).

Some members voiced that they wouldn’t mind being known *“if it’s going to benefit the service”* (M.3, P.27). I agreed to construct a letter for the group to consider as a beginning point and the members agreed to consider the issue of identifiability. I asked the group if they wished me to remain involved in the process of supporting their action. They affirmed my continued involvement. The meeting concluded, with agreement on meeting for a fourth time to *“confirm what we’re going to do”*, to reach consensus of whether to remain non identifiable and the final meeting would conclude with a story from members palliative care practice where *“things have worked”* in terms of positive processes for the person and family (M.3, P.27).

Reflections on my role in the third praxis group meeting

In the third group meeting, my role changed from that in the previous two. In the first two meetings, I made a conscious decision not to talk about my own practice experiences or offer my perspective, to avoid dominating or leading the discussion. However, in the third praxis group meeting, I found myself drawing on and sharing my own institutional and historical knowledge developed in my district nursing practice and my leadership role. I was acutely aware of what was service knowledge and believe I did not compromise information I had been privy to in my leadership role.

For example, when discussing triaging, staffing and workload management, I reminded the group of work undertaken during the recent service review in this area. The group agreed they were still collating on call information but were uncertain of the outcomes. When discussing different ways of supporting people who prefer written information I reminded the group of a specific piece of documentation “*upstairs*” (M.3, P 17) at the base. In discussing ways to nurture and support registered nurses interested in providing night support for people and family’s, I raised with the group a previous in-service session presented in partnership by Community Health Service and the hospice provider. This session was attended by nursing agency representatives and registered nurses from these agencies.

My researcher role was particularly emphasised in the last half of the meeting in supporting the group to consider options available to take the action they determined appropriate. I indicated this action would not include me unless the group wished me to remain involved. In raising group members remaining non identifiable, what was apparent in my reflections was my own uncertainty of the differences between anonymity and identifiability, as evidenced by my use of anonymity when discussing future action during the meeting. Clarity in distinguishing between the two became absolutely clear for me during the writing up of this research.

The week before the final praxis group meeting, I delivered the ‘cleaned’ transcripts from the second meeting, a covering letter and draft agenda (Figure 5), and the letter I had constructed for group consideration, to the members. However transcripts from the third praxis group meeting had not yet been completed. The fourth and final

praxis group meeting was therefore also held without the transcripts of the previous meeting.

Figure 5: Preparing for the fourth and final praxis group meeting

20th June 2005

Greetings,

I am looking forward to meeting with you next Monday, 27th June 2005, to complete our praxis group meetings. I wondered if we could meet at 3pm for our final session.

Please find attached an outline of a letter to <name>, Service Leader, articulating some of the issues and some of the strategies the group have identified to address these issues. Could you make any alterations or additions to this letter and bring these to the meeting on Monday? I am hoping the group will be able to reach an agreement on the content of the letter at this meeting.

I am also hoping the group will have an opportunity to share a palliative care episode in which the processes were positive for the person and their family.

Looking forward to seeing you next Monday.

Kind regards

Donna Voice

The fourth praxis group meeting – research closure

In commencing the fourth group meeting, I did not reiterate the group understandings or ground rules and this could have contributed to members over talking. This was not a feature of other group meetings. There was a real energy and enthusiasm amongst the group and it appeared momentum built throughout the research process then culminated in the final meeting. Multiple speakers talking at once meant despite numerous attempts, I was unable to (in cleaning the transcripts) decipher a number of comments from this meeting and was a messy moment for me as the researcher.

I opened the conversation, as the researcher, by acknowledging the commitment and effort by the group in their participation. *“It demonstrates the level of interest and commitment to palliative care”* (M.4, P.1). All the members who initially volunteered attended all four praxis group meeting. The group acknowledged their prior knowing of me had been helpful. *“I’m sure its been made easier by the fact that we know you. I think if it had been someone that we didn’t know, it might not have been quite as easy to share stuff”*. *“Because you know the context in which we work ... which I think ... is huge. “I do too”. “We don’t have to explain ourselves to you all the time.” “And that you understand what we were describing, because you’ve had the*

opportunity to see that first hand as well” (M.4, P.1). The group processes developed reflected a degree of safety, evidenced by a brief exchange between members regarding potential outcomes of the palliative care contract as a result of the palliative care review, with opposing views aired. The group was open to listening to, entering into debate and exploring other perspectives. A member redirected this discussion in offering *“I like the fact that we do some of palliative care, but it’s not our whole focus, because ... it’s quite intense and it would be quite hard to do it all the time”* (M.4, P.2). Members clarified processes in working with the transcripts for the third and fourth meetings, as the group would not be meeting again. Consensus was reached no changes were required to the second praxis group meeting transcriptions. I undertook to get the transcriptions from the third and fourth group meetings back to the group as soon as possible and in the event alterations were needed, members elected to contact me directly. The meeting then focused on the letter I had drafted for the group to consider and centred on reaching group consensus of action to take.

In establishing the intent of the proposed letter, members’ sought clarification *“So in this letter we’re actually just identifying the things that we’ve raised rather than actually necessarily finding absolute solutions?”*, *“Or suggestions for how it might work better”* (M.4, P.7). I encouraged the group to consider including their suggestions and solutions in the letter.

Members emphasised the issues they saw as being important. *“That’s the key thing, because it ... doesn’t only affect our work with the palliative patients, but also any other patients”* (M.4, P.11). The group actively engaged in working through logical processes to address the focused issues seeking clarification from each other whether the suggested solutions would work in practice. *“It is an acknowledgement of some of the ideas and of events so far around these issues, and they’re very practical. They can be real; they’re not airy-fairy, because we know what we’re talking about because we deal with these things”*. *“And at least that will show that we are working, we’re thinking about some of the difficulties that we’re having”*. *“And we’ve come up with some solutions”* (M.4, P.17).

The group was clear in maintaining the focus on the person and family. *“The difficulty is that we can’t box people’s needs”, “That difficulty is something we have to work with because we then have work outside of that and quite often we do. Which means we’re doing things sometimes that are well outside the scope of expected practice”* (M.4, P.14). The expectation was for the research outcomes to make a difference. This was a priority. *“If it makes a difference to the service and how we deliver it ... to the benefit of the patients”* (M.4, P.17). Following agreement being reached on the letter content and where to send it, discussion then moved to sharing practice experiences where outcomes and processes for people and family were seen by the members as positive.

Sharing practice to bring the praxis group meetings to a close

As the first praxis group meeting began with sharing of practice, it was appropriate to bring the final praxis group meeting to a close with sharing of practice experiences. Praising each other rather than individuals acknowledging that they themselves had made a difference initially followed the sharing. The members gave very positive feedback with examples of the differences each other had been observed and perceived to have made for people and their family. *“You put your heart and soul into that. And I think to the benefit of the patient who was able to stay at home ... which was important to him and his family and I thought that you did a great job”* (M.4, P.19). *“The thing that we do though, is that we commit ourselves”* (M.4, P.20). Members emphasised the essential essences *“We can’t do it without the support of the family”, “Its that whole getting to know the family beforehand”, “The best ones, well for me, the ones that go really well are the ones that I’ve had early involvement with”* and *“I’ve built up that rapport with the family as well as with the patient”* (M.4, P.20 - P.21).

Evident in this group sharing was the role of the team, which included family, and team commitment to ‘go the extra mile’ to ensure the person and family were supported, their choices supported. *“Remember there were six of us there ... because we had to move [the person] from one bed to another, so six of us descended ... it was like all hands on deck”* (M.4, P.22). Members discussed their conscious efforts to keep their workload stress and their personal distress to themselves. *“We keep things under wraps while we’re there, around the patient, because we know it’s not*

conducive for them” and *“They don’t need to know that stuff”* (M.4, P.23). The group also acknowledged when returning to the base, the need to share with each other. *“We don’t give ourselves enough pats on the back”* (M.4, P.24). The final praxis group meeting closed with an acknowledgement by members regarding their participation in the research *“It’s really good, thank you”* and *“thank you for the opportunity to talk about our practice”* (M.4, P.29).

Reflections on my role in this final meeting

My role during this final meeting was focused on order - clarifying issues and processes related to the research with the intention of bringing the research to a close with tangible outcomes able to be implemented in practice. Examples from this meeting included *“Is there anything more that people want to add to that one section?”* (M4, P.4), *“Are there any statements there that you would like taken out, or altered, or anything added?”* (M.4, P.5), *“What about a clear process?”* (M.4, P.8), and *“Is that a process that we want?”* (M.4, P.9). I also offered encouragement *“That’s a really good example of action!”* and *“That’s a really good idea”* (M.4, P.15). This encouragement reflected my genuine belief and practical knowing that the action members proposed could be realistically implemented within the service and would elicit tangible outcomes for people and families the group were supporting.

While the praxis groups had finished, the action research process continued. The transcripts from meeting three and four were cleaned and delivered to the group members, with a copy of the revised letter of action and a covering letter (Figure 6).

Evidence of group members’ commitment

Commitment to the project was demonstrated by 100 percent attendance at all the meetings. Members also generally demonstrated commitment to the ground rules, in listening to and respecting each other’s judgements and opinions and to the best of my knowledge, keeping what was shared confidential and within the group. These actions supported positive group processes. Commitment and honouring of each other was evident by the support, encouragement and reassurance given group members when sharing their practice with one another. This sharing validated individuals practice experiences and acknowledged the contextual complexity. There was limited probing by members of others’ practice experiences and I wondered if this was a quiet, respectful acknowledgement of the individual’s experience or if this reflected district

nursing 'etiquette' described in Chapter 3. Resonance of issues reinforced that these were not isolated issues, nor a reflection of individual practitioners 'poor decision making' or 'poor district nursing practice'. They were re-occurring complex issues experienced on numerous occasions by all members of the group.

Figure 6: Transcripts from third and fourth praxis group meetings

21st July 2005

Greetings. Enclosed are the transcriptions from the end of the second praxis group meeting and the third and fourth praxis group meetings. Could you look over the transcripts and advise me of any alterations you would like made.

If I have not heard from you by 28th July, I will assume there are no changes to be made. Should changes be required however, I will have these completed and back to you by the 1st August, at which point I would ask you to discard the old copy or copies in the destruction bin.

I would be keen to collect from you as soon as possible any alterations or additions to the letter we have constructed to Community Health management, outlining the issues of concern the group have identified as part of this research process. I would be happy to visit the base in the afternoon on Monday 25th July to collect these from you.

I also understand two of the group members have resigned since we last met. I appreciate that this is a huge loss to the team. It also raises the issue for the remaining group members as to whether they wish to continue with disclosing their identity or in fact, remain anonymous. I would be interested in receiving feedback around this. I would also be interested in discussing if those members who are leaving the service would be interested in remaining involved (if this is a possibility with their new positions) and participating in perhaps the initial meeting with management.

Once again, thank you so much for agreeing to participate in this process and I hope there will be some positive outcomes from it. I look forward to catching up with you on Monday.

Kind regards
Donna Voice

Commitment by the group was further demonstrated by the discarding of lunch breaks to attend meetings; members eating their lunch while at them. This was despite scheduling the meetings later in the afternoon in the hope the members would be back at the base. The group collaboratively rescheduled the first and third praxis group meetings, moving the proposed starting times to manage unforeseen changes in circumstances at the base, rather than postponing or cancelling the meetings. Members read transcriptions in their own time and came prepared to each meeting

open and focused to move issues previously discussed forward. The group accepted and trusted in the research process and continued with the third and fourth group meetings with out the opportunity to reflect on and validate the transcripts from previously held meetings. Once again, the messiness of the research was managed.

Evidence of collaboration

Group processes reflected collaboration and partnership between the members and the researcher. Core issues were raised time and again, resonating with all group members, and echoed throughout the four meetings. As the praxis group meetings progressed, a process of distillation occurred, as these issues were untangled and ‘unpicked’ through focused and critical exploration by the group. This exploration revealed practical workable solutions to these issues and the essences and elements of district nurses practice.

Decisions regarding action relied on reaching group consensus, which occurred during the final praxis group meeting. Group ownership of research outcomes is evident by the group actions taken to maintain the momentum and the actions that have occurred since the completion of the praxis group meetings. These are discussed in Chapter 7.

As the researcher, I retained a degree of control, particularly in focusing the praxis group meetings. This is evidenced, in an effort to create structure and order, by the setting of tentative meeting agendas and my closing statements made at the end of each group meeting to set up a proposed ‘beginning place’ for the next meeting. I was very mindful that I was an inexperienced researcher and no longer worked in the environment, which had some disadvantages and advantages. These are discussed in Chapter 7. I did not want to set this group up to fail. There were numerous examples of members seeking ongoing clarification, particularly around group and research processes. There was an openness to share practice with other colleagues and myself.

Reciprocity throughout the meetings is evidenced by members’ responses to my questions. For example, I asked “*Is there anything else that you want to touch on today?*” members responded by asking “*Have we covered what you wanted to touch?*” (M.2, P.24). Following my acknowledgement of the group’s commitment to the research, one group member replied “*It’s been good to be able to help you*” (M.4,

P.1). Despite my no longer being a member of the team, my established credibility and relationships with the group contributed to the completion of the research.

Summary

Four praxis group meetings were held. The fourth was an ‘option only’ in the planning stage that the group collaboratively agreed to holding. Meetings were planned two weeks apart, however the third group meeting was held four weeks after the second group meeting, due to transcribing issues that arose. Transcribing issues continued to provide unforeseen challenges and moments of messiness for the third and fourth meetings. How order and moments of messiness was managed has been discussed in this chapter. The planned timeframe for the meetings was two hours. The meetings took one hour. While this reflects unforeseen moments of mess in fitting meetings around work commitments, also reflected was the groups focused approach. Shortened time frames may have impacted on the content exposed during the meetings and could be considered a limitation of the research. However the transcripts reveal very rich, textured, ‘everyday’ practice and shortened time frames may have heightened group focus.

This chapter has highlighted the processes (planned and unplanned, anticipated and unanticipated) as they unfolded during this action research project. Tensions in constructing an ordered approach to the research while addressing moments of messiness have been outlined. My stance as a hybrid researcher and facilitator has been discussed. Inclusion of correspondence undertaken throughout the research by the researcher provides documented evidence of research processes, supporting authenticity and trustworthiness. There was consensus reached by the group on those issues identified as requiring action to be taken. These were supporting people and families, managing workloads, partnerships with other providers and self care and was the framework for the letter of action (appendix 7), forwarded to Community Health Services management. This framework highlights the issues and elements revealed in this research project. Not articulated in the letter were the common essences and qualities of district nursing practice also distilled in the research. These themes are covered in the following chapter.

CHAPTER 6: Issues, essences and elements revealed

Introduction

In this chapter, issues, essences and elements revealed in the praxis group meetings are presented. There are multiple frameworks to analyse qualitative data. In keeping with action research central tenets, group members who participated in the research exposed “themes of concern” (Kemmis et al., 1988, p. 51). Heavy data reliance, extracted from praxis group meeting transcripts, provides evidence of issues, essences and elements presented in this chapter. Written consent has been given to include praxis group members ‘voices’ (Appendix 8). Contrasting the ordered approach of Chapter 5, with each meeting presented as a separate entity, in this chapter data is drawn from all four meetings to distillation of the common group experiences when providing palliative care at home. At times, multiple quotes from multiple speakers are used to highlight resonance of these common experiences.

Consensus or what Stringer (1996) describes as “converging perspectives” (p. 84) of issues is evidenced by the letter of action constructed and agreed to by the group, and forwarded by the researcher to Community Health Services management on the groups’ behalf (Appendix 7). The letter recommended a number of practical solutions and actions that could be taken to address issues the group identified. Not explicit in the letter were group development of common understandings including articulating district nurses roles and collaborative relationships. The group identified specific essences and elements as essential for quality palliative care at home and these are shared first, followed by the issues and solutions.

Complexities and multiple truths of everyday district nursing practice were evident throughout group discussions. To respond to the diversity of peoples’ lives and individual contexts the group could not and did not adopt a cookbook, recipe type approach to their decision making and nursing actions in their everyday practice. Authentically coming to know the person and family in their unique context was achieved through consistency of the district nurse involved in their care. Challenges in entering a crisis situation with no prior knowledge of the person in their unique context were, from the beginning of the research, identified by the group. Members balanced this tension by articulating the differences they were able to make when

working with people and family they knew. The importance of establishing what mattered to the person and family enhanced care and responsiveness to support their choices. This presented other tensions and these are also discussed in this chapter.

The essence of honouring and coming to know the person

Coming to know the person and family occurred over time and multiple interactions. Establishing what was meaningful to the people they were working with formed the basis of decision-making and nursing care undertaken by the group. The group identified establishing a relationship of trust between the person, family and the district nurse as an essential essence of care. *“Building up rapport” “and that trust”* [at a] *“very vulnerable time”* (M.2, P.16) and *“It’s getting to know the person and knowing what they want”* (M.2, P.19). Members directed their efforts to support choices made by the person and family towards a positive outcome, despite the predetermined nature or ‘end point’ of palliative care, based on this knowing. *“The ones that go really well are the ones that I’ve had early involvement with”, “It’s ... getting to know the family beforehand”* (M.4, P.20). The group identified timeliness of referrals to enable development of these relationships as an important element.

Members were clear that consistency of the nurse in developing these relationships was *“essential”, “for the patient and for us”, “because you’ve got a history with them ... you see people on good days and people on bad days”, “and they have that trust in you that ... when something does go wrong, they’re going to tell you about it, because they trust that you will follow through and do what you need to do about it”* (M.2, P.29). One group member described how, through consistency, *“You see little changes in people that you know ... like one guy, he [goes] yachting ... and then one day ... he was very tearful and it wasn’t like him and I just knew something was wrong [the nurse gave advice which the man took] ... the next time I saw him ... he said ‘oh thank you for doing that, because he said, I didn’t know what was wrong’ ... it’s just picking up little things”* (M.2, P.29). Decision-making and providing care and support became more complex when the district nurse was unfamiliar with the person and their presentation. The group believed these assessments were more meaningful with enhanced outcomes and some visits potentially avoided, if the district nurse *“was somebody that knew them well”* (M.2, P.13). Through consistency and having

established a relationship, the primary district nurse was aware of the everyday presentation of the person being assessed and able to quickly recognise any changes.

Group members described the delicate nature of negotiations that took place between the person and family and the district nurses. These negotiations included establishing what the person and family wanted and trusting in this (while remaining open should this change), the terms and conditions of district nurse visits, and possible pathways to accessing additional support. These reflect considerations highlighted in Chapter 3 of the district nurse entering the person's home as a guest and the need to negotiate support that honours the integrity of the person and family in their individual context. Members described carefully negotiating care, judging when the timing was right (in sharing information and accessing additional support), for the person, family and carers. Carefully negotiated boundaries could and did change when the person's physical health needs changed. In describing a current situation from practice, one group member spoke of negotiating additional support for a son (who had chronic health issues), who had given up work to care for his elderly parents, in the form of personal care. *"He felt that was his role and that he was neglecting them in some way if he allowed us to do it ... some sense of guilt maybe"* and after some weeks of gentle negotiation, personal care was accepted and the member believed *"it has been quite beneficial"* (M.1, P.17). Specific positive outcomes of this additional support were articulated, for both the elderly couple and their son.

Sometimes, this meant waiting until the person was ready. A group member recalled a visit with one man who had a complex health history aside from his palliative diagnosis, and was experiencing chest pain. *"He heeded my advice and called an ambulance when he'd had enough ... he spent 5 days in CCU"* (M.2, P.14). While the district nurse had assessed the man and advised him to see his doctor or call an ambulance, the man was only ready to take the course of action advised two days later. In discussing different approaches people take to advice given, the group also acknowledged the wide variation people take when seeking information. One group member described that for one man, *"he reads ... that's what he wanted ... a thing [to read] that says what happens when you die"* (M.3, P.17). Like those district nurses referred to by Kennedy (1994) and Luker et al. (2000), members took a much wider view than the 'task' at hand. There was evidence of tacit knowing with members

prepared to take calculated risks in problem solving, trying new ways, to respond to what mattered for the person and family. The group approach focused on meeting the needs of the person and family in their situation at that moment.

The essence of honouring and being with family

‘Family’ were identified as an integral part of the team supporting the palliative person, with members articulating key roles undertaken by family – care giving, including physical care provision, actively supporting the choices made by their loved one, and being a vital information source. Commitment to family and a desire by the group, to be an authentic presence for them was discussed. Members viewed their role as not only caring for the person but believed they had clear responsibilities to care for family and were guided by family in the most appropriate way to provide this support. *“You don’t want to offend ... the family by doing something that maybe isn’t the way that they would normally do it”* (M.2, P.19). The importance of knowing the person and family was contrasted where there was not this foundation. *“I think the worst part is when you’re dealing with family that you’ve not met before”. “I mean it’s all written, but actually it’s hard for the family too and they haven’t met you before”* (M.3, P.14). The group acknowledged and considered these situations were difficult for the person and family, as well as for the nurse.

One member discussed an episode of care that had occurred for a person and family in the past weekend. The rapid deterioration of the person was such their family *“didn’t feel safe ... [the person] was dying ... [the family] weren’t really ready for that ... so they were needing lots of input from us”* (M.3, P.2). The degree of district nurse input required to support the choices of the person and family to remain at home, was unplanned for in workload allocation. Some forward planning had been actioned on the Friday and additional analgesia prescribed if required. However, by Saturday a syringe driver was required to manage the person’s symptoms. The district nurse needed time to access prescriptions through the hospice doctor, and medication for the driver. The member, in describing the family’s knowledge of what was happening, explained *“they had kind of had talks around the possible changes the night before, they were aware that things were changing, but not that quickly ... [and] when I sort of mentioned to the family that you know, I think she’s deteriorating a lot faster and this could actually be a 24 hour spell if that, they sort of looked at me totally aghast, then I*

had to backtrack myself ... because I thought they'd already had that discussion ... but they hadn't ... the only support I could offer was that any changes, we would be here" (M.3, P.12). There was no GP available.

"The notes stated that any problems over the weekend, it would need to go through after hours. But this was a family who couldn't really afford to be calling after hours doctors all the time either" (M.3, P.13). The member knew the person and family and, although he/she was not the primary district nurse regularly involved in their care, was aware of some of the contextual and situational circumstances for them.

The group took into account economic resources available to family. Members spoke of considering financial implications, particularly when negotiating with family whether to enlist GP support at home, which incurred substantial costs. The hospice medical community consultant who visited free of charge, was only employed for home visits during regular working hours. One member gave an example of tensions for a family when the elderly parents needed full time home care. Their daughter who lived with them worked full time to financially support the household. Members all acknowledged implications of financial and wider resource availability, and their potential impact on meaningful choices, for the palliative person and family at home. The group was aware of a wide range of community resources available and indicated they were proactive in accessing these resources on behalf of families.

Changing roles for family

Members discussed issues and tensions for some family in becoming a caregiver with changes in roles for family members, often (but certainly not always) falling on women in the family to take on the role full time carer. In their acknowledging not all family members were able to take responsibility for aspects of care giving, the group did not view this as a reflection of the relationships between family members. They were aware of potential stress assumptions, by health professionals, of an identified member of a family taking carer responsibility could create for the person and within the family.

"If it's their mother or their father ... that's difficult to suddenly become the carer and be dressing them or washing or doing those sorts of things ... that is pretty hard for

some people to cope with” (M.1, P.17). While avoiding making assumptions of what roles family members may or may not undertake, members acknowledged there were times few choices or alternatives were available for families. For one man *“the only way that he was able to stay at home was by [the nurse] drawing up the medication ... it was labelled and she [the man’s wife] knew what to give and how to give it ... she knew what to do, when to do it, she was quick on the phone [if problems arose]”* (M.3, P.7). The district nurse trusted the couple in their decision making, trusted the man’s wife to undertake this aspect of care and also trusted the couple would contact the district nurse immediately if they had concerns.

Members spoke of family *“making themselves a part of what you’re doing ... and the elder son just saying ‘we’ll take over, we’ll manage’ ... very quiet subtle ways of the family’s wishes this time, not the patient ...[to] play a more active role in ... care”* (M.1, P.16). While acknowledging initially feeling some degree of anxiety in withdrawing from this practical aspect of care with the palliative man, the member saw this was in fact, an extension of family members continuing what they were doing before district nurses became involved, despite the physical deterioration the man had experienced with more intensive practical support needed. The district nurse trusted the family would carry through with the care they had undertaken to provide.

Drawing on, trusting in, and celebrating family strengths and family abilities were acknowledged as essential elements of district nursing practice in supporting people at home. *“I was at a house today and a family member has written a really good care plan ... I thought ... what a good idea”* (M.3, P.17) and *“It’s a very practical idea because there’s not only going to be one or two main carers, that may change, as we do”* (M.3, P.19). While consistency was acknowledged by the group as important, members were realistic this was not always possible for them nor for carers within families. The group believed developing a pamphlet (which could be translated) could be a useful tool to support family members in attending to physical aspects of care for the person, whether the situation was palliative or not. The group envisaged the pamphlet would include space for individualised care support, key points to bring to the attention of the district nurse visiting and specific guidance encouraging family when and how to contact the most appropriate health professional.

Members discussed families who saw *“the nurse’s time as precious”* with some family members genuinely believing *“they’d be wasting it letting the nurse do something they could be doing”* (M.1, P.17). The group also believed *“cultural practices, cultural norms”* (M.2, P.18) held by particular ethnic communities reflected a desire to attend to all aspects of care for their dying loved one and *“maintain their quality right up to the time that they close their eyes and go ... quality of life is everything”* (M.2, P.18).

The essence of presence

In crisis situations, when there was little practical help able to be given (in the event of uncontrolled symptoms where medical assessment was required, for example), the group saw value in being with and staying with the person and their family to support them until back up services arrived. Members saw presence as meaningful support for the person and family experiencing distress. This presence also created an opportunity for the district nurses to share their knowledge and assessment of the immediate situation with these services. Time commitment to ensure resolution of the crisis and the person and the family were in *“in good hands”* (M.1, P.8) created an additional tension on existing workload pressures.

Telephone availability was a recurrent method of support provided by the group for family members to work through issues. One member relayed feedback they had received from a family during a bereavement visit. The family member had shared that, for them, *“It was knowing that if I needed something, or I wasn’t sure about something, I just needed to make a phone call ... there was always someone at the end of the phone”* (M.2, P.15). Another member recalled a recent interaction with a family member s/he had developed a relationship with. When the district nurse visited, the person appeared to be managing *“incredibly”* well, in supporting her dying husband, her daughter who had stopped eating and her mother in law who had a chronic mental health issue and was also staying at the house. *“One day she rung up and she ... just broke down, she never broke down on the phone, she broke down and said, look, I just can’t cope with it”* (M.1, P.10). The member recounted how s/he supported the woman over the telephone, to explore possible options and strategies to meaningfully assist the woman to work through the ‘acute’ sense of not being able to ‘cope’ with what the member acknowledged was an *“intense”* (M.1, P.10) situation.

Balancing the wishes and choices of the person and their family

A tension highlighted by the group when providing palliative care for people and family occurred when the wishes of the person were incongruent with wishes, beliefs or needs of family or vice versa. *“It’s quite difficult when you’ve developed a relationship with both people over a period of time ... difficult to actually honour the dying person’s wishes to stay at home when you can see ... the family aren’t coping”* (M.1, P.15). Uncontrolled pain and other symptoms were very distressing for families and the group acknowledged a sense of helplessness, particularly after hours, in securing reliable strategies to get these issues addressed at home.

One experience shared by a group member highlighted some of the contributing tensions *“His wife was at the end of her tether and in tears ... it was difficult when you’ve not met someone before ... and you haven’t had the chance to build up a relationship with the person. He was in a lot of pain, and giving his wife a really hard time. She just said, I don’t think I can cope another night like this. He ... was very reluctant to go to the hospice, but really did need to be in there ... he was in so much pain. I, in the end managed to persuade him to go to the hospice ... not forever, but hopefully, [to] sort out the symptoms that I felt I couldn’t sort out for him. Perhaps he wouldn’t have had to go the hospice if [the primary nurse] had been on duty”* (M.1, P.1).

There was no GP available to come to the house and assess the man’s symptoms. The group member left the man and his wife to consider their options and then revisited the couple later that day and on *“that occasion he agreed to go to the hospice”* (M.1, P.2). There appeared to be few other options and medical home assessment was not available to support his choice to remain at home. The district nurse rang the hospice prior to the second visit and spoke to a nurse at the unit who *“knew him”* and *“was really supportive, and she too felt he should go into the hospice”* (M.1, P.2). Consistency when working with other members of the wider palliative care team, having shared understandings or knowing of the family context, enhanced support for people and family at home.

Wishes and beliefs, sometimes but not always embedded in cultural perspectives and language, meant individuals within families held key information that was not shared.

“He was dying and he never told his family ... he just said, I am very sick. He had chosen not to tell his family and they didn’t know what to expect” (M.1, P.12). The district nurses and wider palliative care team involved all honoured the man’s wishes, trusted in his decision, and his family was never told he was dying. A further example relayed by a group member, when in caring for an elderly woman and her family, her family members *“wouldn’t let her know ... we weren’t allowed to say the word ‘cancer’ or ‘tumour’ ... in her presence. Even though, the family knew she had cancer and was dying, but she wasn’t allowed to know what she had”* (M.1, P.14). The family’s wishes were honoured. The group members acknowledged these were difficult places to be with people. While this approach could be viewed as complicit, the nurses trusted families were making the right decisions for them and their loved one.

While the group acknowledged challenges in terms of honouring culturally different values and perspectives, they saw these as *“an ever changing process ... I don’t think things remain firmly cultural”* (M.2, P.17), *“it’s about need ... it’s about the need at the time”*, *“it changes”* (M.2, P.18). This stance reflected an embedding of cultural safety in their nursing practice. The group believed cultural perspectives, values and differences in approaches by people and families were not ethnically based. Abiding by and honouring the person’s wishes and/or family wishes was a priority for the district nurses in their practice, determining the district nurses actions. In seeing themselves as guests in people’s lives, in their homes, the group reinforced they did not work in isolation of the family. It was understood by going against these wishes demonstrated mistrust in decisions made by the person or those made by family on behalf of the person. The end result could be a complete rejection of the district nursing service by those in the household.

The ripple effect of the person’s declining health

Potential risks and possible flow on effects for family members, particularly in crisis situations were identified. In relaying an episode from practice, one member spoke of visiting an elderly woman in the evening who lived with her daughter. The elderly woman had become acutely unwell during the day and the district nurse had been advised prior to visiting the woman could be admitted to the hospice. However this option later proved not to be the case.

The group member had not met the woman or her daughter before and in fact, they “*weren’t expecting a visit from a district nurse*” (M.1, P.6) that night. On visiting, the member was concerned not only for the woman herself, but also for her daughter, whom the member believed might have had some cognitive impairment. The woman’s daughter was unable to help her mother stand or assist with any physical cares, could not recall what medications she had given her mother and was unsure if and when her mother had last had anything to eat or drink. “*I was going through the notes and the information that I had there at hand, but it would have been really helpful if that could have been given to me by family members who we often rely on, but in this case I couldn’t. The daughter also needs someone ... I didn’t know what it was about her, she couldn’t process information*” (M.1, P.6). The member expressed concern as to whether the daughter would be safe at home alone as s/he believed the elderly woman “*needed to be in a more supportive environment, certainly not at home*” (M.1, P.8). Despite considerable effort and time committed by the member, liaising with after hour services, the elderly woman remained at home overnight.

It seemed the two women had managed their day-to-day lives and needs together and the delicate balance of their existence was thrown into disarray when the elderly woman’s physical health deteriorated. The interconnectedness of people’s lives was a consideration for the district nurses in negotiating ongoing support to manage any future planning and events that may unfold.

The essence of honouring through communication

The ability and opportunity to discuss with the person and family, their needs, wishes and desires were essential for members to authentically provide palliative care nursing support. To ensure informed choices, the person and family being able to vocalise what they wanted and what they needed was seen as a mechanism to facilitate the district nurses role. “*It’s just easier ... when it’s someone who’s able to verbalise what’s going on*” (M.4, P.20). The group saw their role as supporting family to articulate these wishes when working with other health providers, being described by one group member as “*the vehicle to get it across*” (M.1, P.11) especially once the person was no longer able to communicate their wishes. Another member spoke of working with a person who changed “*from a very vocal communicative person, to somebody who could no longer communicate*” (M.1, P.11) on entering the palliative

phase of a slow degenerative condition. The member detailed the family's commitment, in supporting of their loved one to maintain control and preserve the person's dignity for as long as possible. The person's ability to communicate their wishes and choices early in their illness enhanced district nurses ability to support the person and family when deterioration in their physical condition occurred and they were no longer able to speak.

Differences in spoken language proved challenging on occasion. Relaying how, in developing a relationship as the primary district nurse, a group member discovered the person and most of their family had lived in New Zealand for a long time however they did not speak English. The person had not taken the prescribed medication, as they could not read the days of the week on the medication dispenser. The district nurse engaged an interpreter and asked them to write on the dispenser in the family's written language the days of the week and times. This intervention appeared to work well "*That was just one aspect of it*" with the member enlisting the support of the interpreter "*everyday*" (M.1, P.12). However, as the relationship with the person developed, the group member identified and was able to understand the "*motions*" the person made and respond.

Consistency of the nurse, in being with the person was an essential element to facilitate this. Family members who spoke English worked long hours were not available when the district nurse visited. The group viewed the Interpreter service as an investment (paid for by CHS when called upon by district nurses) to ensuring the voices and choices of the person and their family are clearly heard, while also a mechanism to clarify and confirm the district nursing care being provided was acceptable to, and meeting the needs of the person and their family. Family members' acting as interpreters was not expected by the group.

Issues of access and flexibility in meeting the needs of the person and family

Balancing and accommodating family expectations of what district nurses could provide created tension at times. Opportunity to plan, consult, negotiate and discuss choices around care, and if need be, clarify whether district nursing service could meet the person and family expectations was seen by the group as essential. This appeared more easily negotiated when there was an existing relationship between the person,

their family and the primary district nurse with visits and support negotiated throughout the journey of care.

Particular issues arose when the person and family were previously unknown to the district nursing service and required urgent support due to an acute physical deterioration, or following discharge from an inpatient unit where there had not been direct dialogue and negotiation between family and the district nurse. A group member spoke of receiving a new referral requesting a district nurse first visit assessment on a Saturday for a person discharged from the hospice. *“The daughter burst into tears when I walked in the door and [her] expectations of what I was going to do and what she had been told I would do, didn’t marry up with what the referral to the service said [the referral indicated the person was independent however had been assessed as hospital level care] and I felt terrible. I felt terrible not being able to provide the care that she’d expected”* (M.1, P.19) due to time and workload demands. The district nurse negotiated to attend to the person’s immediate requirements that day and return the following day to attend more fully to the care the family had been anticipating and expecting.

Differences in flexibility and responsiveness during weekdays when other colleagues were available and on weekends and evenings, when skeleton staff were rostered on duty were evident. Group members’ ability to respond in a timely manner, and service flexibility to respond to family need and choices was challenged after hours. This required creative problem solving and when able, seeking alternative methods of support, which were very limited. However, when the person and family was known to the district nursing service, the primary district nurse would take responsibility for setting in place additional supports. The group discussed planning of care between agencies and recommended in the letter of action that when the local hospice was planning to discharge someone who was known to CHS home, the primary district nurse attend the discharge meeting. This would ensure clear communication pathways and understandings and highlight gaps (if any) of care, with the person, their family and the other members of the palliative care team. This practice would avoid any additional stress or dissatisfaction for people and family already under immense stress. This practice would hopefully reduce unanticipated and unplanned for demands on CHS.

Forward planning

The group discussed their responsibility to forward plan as an integral part of their practice, due to the unpredictability of palliative care, viewing this as an essential pathway for supporting the person and family which was never static and ever changing. Members clearly placed a high priority in considering possible future implications for the actions taken. In describing a plan negotiated with a person in response to concerns expressed by their family member caring for them, one member commented that *“For a lot of other people it probably isn’t as appropriate but for that family it seems the appropriate solution”* (M.4, P.10). The plan of action was individualised and in response to the need of that particular family in their situation.

An action plan for all palliative people and their families the group believed would provide additional support, direction and reassurance for family particularly during times of crisis or uncertainty. Only one article reviewed in the literature outlined in Chapter 3, when articulating issues raised by families, discussed action plans (Jarrett et al., 1999). This need for planning could reflect a localised issue in that particular geographical area and location, and may explain why this issue was not evident in the other literature reviewed. Having clear processes or pathways, with clear outlines of after hours’ access to health providers, was identified as critical to supporting the person and family to manage crisis or acute deterioration. This was undertaken on an ad hoc basis to manage specific catastrophic events. The group recommended in the letter of action the instigation of a provisional individualised action plan from the time a person was deemed palliative.

The group described issues when accessing appropriate support, particularly for people with no action plan in place. In the event an ambulance was called, the person would be taken to the public hospital rather than the hospice. One member described this as *“frustrating, that some get letters, to the ambulance saying that they’re to go straight to the hospice if the call comes. But others don’t, so, they end up in the hospital system, when you know that that’s where they need to go – directly, is to the hospice”* (M.2, P.4). A challenge would remain for those people, who may have a palliative prognosis, been ‘well’ and were unknown to palliative services or CHS.

Group members saw their visits as a moment in the day of the person and family and believed it was important family knew what to do if a crisis occurred. However, just as important was a pathway for supporting colleagues in the district nursing team. *“You’re thinking of your patient, but you’re also thinking of your colleague ... you’re thinking of your colleague who’s on afternoon shift and on call, and knowing that they could have a terrible night, that they could be called out more than once, that’s horrible”* (M.1, P.15). The group discussed their practice in clarifying with family from the beginning of the relationship, the district nursing on call service offered. *“When we first meet them, saying that we have this service ... it’s an acute after hours service, where the person is on call, but they are home asleep”* (M.3, P.21). One family rang the local hospice for advice *“because she knew that they were awake ... and she was aware that if there was a problem where ... the district nurse needed to be involved, the hospice would tell her that ... we would be the ones that would go to the house”* (M.3, P.22). Specific issues and tensions of access to other services after hours were a significant group concern.

Forward planning and negotiating with family possible pathways to access ongoing support required teamwork and clear communication on the part of the whole wider palliative care team. Teamwork was an essential essence distilled in the praxis group meetings.

The essence of teamwork within Community Health Service

Commitment to working together as a team at the local base enhanced the groups’ ability to provide quality palliative care nursing at home. Teamwork included ready and open access to *“a large body of knowledge amongst our own colleagues that we can tap into”* (M.2, P.11). Members emphasised the value they placed on particularly the postgraduate Palliative Care Certificate, offered over four modules. *“It’s also quite valuable to do the modules isn’t it?”* and *“I mean I’ve only done one module, I’d like to do more – I’m very aware that I need to do more”* (M.2, P.27). The learning gained through the palliative care modules was reinforced by their work in the community *“kind of hand in hand really”* (M.2, P.21), *“you need to see it. And you need to touch it”* (M.2, P.22). Another member went further *“I think they should be a co-requisite – I think they’re very helpful and valuable”* (M.2, P.22). Adriaansen, Achterberg and Borm (2005) view palliative care postgraduate study as making “a

significant contribution to nurses' knowledge and insight, as well as their self-efficacy in providing palliative care" (p. 96).

It was "*really important*" (M.2, P.11) to be able to recognise and ask for help. Support within the district nursing team at the local base was acknowledged along with possible support able to be enlisted from district nurses at other bases. However this support was dependent on the workloads in those other areas. In practical terms members of the district nursing team would try to free up a colleague who needed additional time to care for a palliative person and family. This at times impacted on consistency for other people and families. This was a short-term compromise often in the last few days of life. "*It's the whole team ... it was being able to yell out to other team members and say help ... it's supporting one another*", "*That's why it's good to have such a good team*" (M.4, P.21), "*We're able to do that, that's great*" (M.4, P.22). There was flexibility and support within the immediate district nursing team during working hours and was viewed by the group as enhancing the palliative care the primary district nurse was able to provide. This flexibility was not available after hours or on weekends. "*Week days when there's other staff available to help*", "*but not in week ends*", "*After hours it's quite a different thing*" (M1, P.20).

Managing workloads and responding to the unpredictable nature of palliative care and supporting people and their family through crisis situations meant for the group members "*that realistically ... you just keep working until such time as you've done it*" (M.3, P.3), "*you get on ... and do and it could still mean that you're off at midnight and still on call until eight o'clock the next morning ... we tend to just cope*", "*when you're in the thick of a situation ... you have to*" (M.3, P.11). Working past the designated finishing time for the shift to ensure best outcomes was a reoccurring issue, more so in the evenings and on the weekend than during regular working hours. Workload management issues included "*being on afternoons and having a whole lot of already pre-prepared work to do that isn't palliative and then having to manage the unexpected*" (M.3, P.1), "*it happens a lot ... because it's the unpredictable of someone deteriorating rapidly*" (M.3, P.2). The group regularly experienced workload challenges in responding to and balancing the needs of palliative people and families when providing an acute hospital in the home service.

Having clear documentation provided a supportive framework for the group when managing these unexpected events. The group discussed their trust in other district nurse colleagues' assessments, especially at night. *"It's hard when you're on call to know somebody [person] from somebody else's area [primary district nurse] but if that person's been doing regular visits and regular assessments, then there should be a reasonably good picture of what that person's like from their notes – if you've got the luxury of having their notes"* (M.2, P.12). This was *"often"* not the case after hours, with the district nurses going *"on the hop"* and *"what you're basing it on is your assessment over the phone at the time or on your first meeting"* (M.2, P.12). The group viewed their ability to accurately assess and seek out reliable information to inform their assessment as essential, not only for the primary district nurse but also to support the wider team being able to respond to the person and their family in an informed, meaningful way. The group also identified teamwork and relationships within the wider palliative care network as essential elements in enhancing care and support for palliative people and family at home.

The group identified managing workloads after hours, weekends and some public holidays as an issue in the letter of action. Members offered solutions drawing on existing practices in other Capital and Coast DHB district nurse bases. On call issues were also identified with a recommendation for service wide discussion to take place to clarify Community Health's position in continuing to offer this service. Dialogue with the local hospice provider may follow on from this clarification process.

The essence of teamwork in the wider palliative care team

Members clearly acknowledged *"We work in partnership"* (M.2, P.11) with provision of quality palliative care at home dependent on working as a team with health professionals from other agencies. The group was clear they could not support people and family at home without this input and these relationships. *"It's all about support. Whether it's from each other or from other people ... making sure that we're there to support each other [and] also that that we're getting support from outside areas"* (M.2, P.14). The roles of the local hospice, the community based palliative care physician and the care coordinators were highlighted as essential in working with the

group to support choices made by people and family. *“We can’t do it on our own”, “we need the support of other people who can help us in our roles”* (M.2, P.25).

Regular meetings and sharing of information between the community hospice team and CHS was seen as beneficial and being able to access the inpatient hospice staff after hours *“I’ve always found them very supportive and helpful”* (M.2, P.16). Particularly robust communication links between the community hospice team and the inpatient hospice unit proved invaluable for the group members after hours during times of crisis for people and families. This was viewed as a feedback loop where *“there’s also an onus on us to feedback to the hospice particularly after hours at weekends”*, with *“anything that we’ve encountered or that we feel is a big change in the patient’s condition”* (M.4, P.10). The group members acknowledged their responsibility and reciprocity in the exchange of information. To enhance these relationships the group recommended offering nurses at the local hospice inpatient unit the opportunity to work with district nurses as part of the orientation process.

Group members acknowledged the valued support of the Cancer Society funded and agency sourced night nursing hours. A maximum of 72 hours is available for each person and family. The provision of night nurses to support people and families was a service the group agreed was *“absolutely brilliant. Really brilliant”* (M.3, P.9). Difficulties were experienced at times, in being able to readily access the scarce resource of registered nurses interested and able to provide this overnight nursing support. Only those people with a cancer diagnosis can access this service. The group recommended in the letter of action offering agency nurses interested in providing night nursing care regular palliative care in-service sessions, in partnership with the local hospice.

Members believed people and families often considered district nurses to be part of the local hospice. The members did not view invisibility or visibility of the district nurses by people and family as an issue. The group did acknowledge tensions and inherent risks involved in the decisions they were often asked to make after hours in diagnosing presenting health issues and articulating these to other health providers in order to access appropriate support. They appeared to shoulder enormous responsibility outside regular working hours. Issues of district nurse invisibility did become

apparent when attempting to access additional back up after hours support in crisis situations.

When attempting to access appropriate after hours support, members described requests often made of them to define *“if it’s a medical problem rather than a palliative care”* (M.1, P.7) issue. The group questioned if this was a triaging tool used by other health providers, or a method for other health services to say *“we don’t have the means right now to deal with your problem that you’re talking about ... they don’t have the full capacity to deal with it at the time, so they deal with it the best way they can ... and that’s not necessarily to keep me happy, and to make me feel reassured”* (M.2, P.9). There was also a sense other health providers may believe because the district nurse is *“a registered nurse”* there was a possible misconception that the district nurse *“can stay with the person”* (M.2, P.10). A further view was other health providers may not get a true sense of what is happening despite district nurses best attempts to articulate the picture *“they’re not there in the situation ... we might see the person as being really unwell, but they can’t identify that necessarily from what we’re saying in the phone conversation”* (M.2, P.10). The situations described occurred after hours and did not appear to be an issue during normal working hours when regular services were available.

Ready access to GPs after hours for symptom management, was acknowledged by the group as enhancing their ability to support the choice of the person and family to remain at home. Or not. There was wide variation in this service provision and dependent on the individual GP. *“We have to forward plan for our patients ... and work with the GPs to say, well we don’t know what’s going to happen after hours if this person becomes unstuck”* (M.2, P.5), *“We usually have what I call the witching hour between midnight and 2 o’clock when they (patients or families) invariably ring in”*. While the group were unanimous in the need for back up from other health providers, the role and availability of the GP, particularly after hours was pivotal. *“We could do as much forward planning as we want, but it we don’t have that medical support ... we’re not going to make a difference”* (M.2, P.6). The positive difference in outcomes for people and family when the GP was available after hours was clear to the group, however *“lots of them [GPs] aren’t available”* (M.2, P.4). Tensions existed for one member in attempting to arrange an after hours medical assessment

where the GP wasn't available, although *"The hospice were supportive, the man didn't want to go to the hospice, he wanted to die at home"* (M.2, P.5).

The group experienced challenges in accessing after hours the required medical assessment and appropriate symptom management for the person at home. The closure of the local After Hours medical centre and the opening of the new Accident and Medical facility at Kenepuru Hospital does not address this challenge. For the group members, this issue *"doesn't only affect our work with the palliative patients, but also... other patients"* (M.3, P.11). Despite knowing little action may be able to be taken on this issue, the group believed the gap in this service was significant. This point was raised in the letter of action.

At times, availability of GPs after hours was not clearly known. One group member described how *"I just thought, I'd ring, I'd try and ring his GP, even though there's no way ... the guy's going to be there. And I rang up, and the GP was there, at his rooms on a Sunday afternoon, he was there! So he came to see him"* (M.1, P.3). The commitment of some GPs was reflected also by the commitment of the hospice doctors *"a hospice doctor ... lived just down the road and he said that ... he would be available"* (M.2, P.5). There were tensions in accessing GP services for those people whose family doctor practiced away from where the person lived. In contacting the now closed after hours medical centre, one group member recalled *"The doctor said he wouldn't be able to come [but asked] has this patient got their own GP, and then I said ... the GP was in Wellington, this person lived in ... the Porirua area, and he [the on call doctor] said that's crazy, why don't they have a doctor, GP in the area that they live in, and I said ... this isn't helping the situation at the moment, this person needs to be seen, and when I asked the doctor ... his or her name, they gave me their name and their attitude changed, and [the on call doctor] said, maybe [he] could come"* (M.1, P.3).

There are issues currently for people living in Porirua being unable to register with a GP in the area, due to a local and national shortage of GPs. Local people have no choice but to register with a family doctor elsewhere. In providing home palliative care, group members needed to be assertive when communicating with other health professionals in order to advocate access to the most appropriate services and

interventions on behalf of the person and family. The group members described, particularly during times of crisis, being required to direct other health professionals to acutely facilitate appropriate action or pathways to be taken, to avoid people “*being taken to A and E and dying in A and E*” (M.2, P.15). The group believed the provisional action plan described earlier may prevent these events from unfolding.

On occasion hospital assessment was the most appropriate pathway. One member described being “*rapped over the knuckles*” for deciding over the telephone to call an ambulance (as opposed to visiting and assessing) for a person experiencing chest pain who had rung in late at night. This intervention had been negotiated and agreed to by the person and family. The member stood by his/her decision, articulating their rationale and drawing on their long medical and surgical experience that supported the stance taken “*I still wouldn’t change what I did*” (M.2, P.13). At times, particularly when challenged by others of decisions they had made and the risk management approach they had adopted after hours, the members continued to reflect on these episodes long after the event had occurred.

The essence of caring for ourselves and each other

The group acknowledged while there were no clear answers or defined pathways, the members continued to reflect on and question decisions they had made. “*I ask myself afterwards have I done the right thing as far as the process is concerned ... questioning ourselves all the time*” (M.2, P.8), “*You get home and you think ‘god’ did I do the right thing? Did I say the right thing; have I made the right calls? You know, and you don’t get back to sleep for a couple of hours ... it’s hard*” (M.2, P.9), “*I wonder whether ... everything that should be done, has been done, to the best way that you can at the time*” (M.2, P.11). The situation was further complicated when acute needs of non palliative people on the district nurses books arose and “*deciding which situation to attend first, whether palliative ... or if there was an acute case, how would you decide ... I’ve been in a situation like that and have had to think very carefully ... what time and what opportunities you’ve got*” (M.3, P.10). Decisions under these circumstances are made quickly, requiring the ability to accurately and promptly read the situation, decide what action need to be taken and the action undertaken (Eraut, 1994). Reflective spaces in these moments are very limited.

Group members particularly recollected incidents that occurred late at night. One group member recalled, when visiting a dying person, coping with *“the family’s reactions – one of the sons was vomiting in the hand basin ... for me, leaving there after that, you know it’s about midnight and I’m driving home and thinking, who do I talk about this with?”* (M.2, P.9). In relaying an episode of care that had occurred *“three or four years”* previously another group member described being called to a person during the night and waiting for an after hours doctor to come. The person the district nurse was called to *“was in acute pain, and he was acute and short of breath and I just couldn’t do anything. It was the most terrible three hours of my life probably and he died ... he was only a young man, but it was a hideous experience. It was ghastly”* (M.1, P.5).

Informal debriefing with colleagues was helpful to work through these and other practice experiences and issues. *“You can personally identify with the situation, or for whatever reason, it’s quite draining, it’s quite hard. And sometimes, if it’s in the afternoon or something, you need someone to talk to”* (M.2, P.25). This proved difficult in the evenings and overnight when the district nurses covered the area alone, although there was acknowledgement of being able to contact the district nurses working from the other two bases up until 10pm. The group also acknowledged there was an after hours supervisor available at Kenepuru hospital. Members rarely accessed this supervisor to discuss practice issues and did not appear to have established relationships with them.

In articulating the personal impact of palliative care nursing, one member described a person they had been working intensively with, had died on a Friday afternoon prior to the nurse then going on leave. *“I spent my whole ... it’s really unhealthy, I spent my entire holiday thinking about this guy, thinking about what I’d done, what I hadn’t done, you know, just thinking about it ...I came to work on the Monday after I’d been on holiday and I was talking to my colleagues and then ... I felt better”* (M.2, P.9). When reflecting on the personal costs they experienced following the death, the member acknowledged, *“this guy, he’s about the same age as my husband, and he’s got a young family”* (M.2, P.10). There were experiences in their palliative care practice when the group members more closely identified with the person and family, than on other occasions.

Being able to share these issues in a timely appropriate manner with colleagues was an essential element to support self care, for group members. Issues of self care focused on looking after ‘ourselves’ but also looking after ‘each other’. The group, while articulating a deep sense of commitment to supporting palliative people and family, were also clear “*we have to look after ourselves*” (M.2, P.27). They discussed challenges in achieving and maintaining this balance at times. Clinical supervision, although available, is at a cost met by the individual and structured, regular debriefing was not a routine established within Community Health Service. Members initiated informal discussions with colleagues from within the district nursing team to share issues from their practice.

In acknowledging “*the family need someone to talk to*” at any hour of the day and night and at times, “*They’re frightened*” (M.4, P.9), members viewed the district nursing on call service as one way of providing support, believed it was generally used appropriately and made a difference for people who were palliative and their families. Providing this service came at some personal cost articulated by the group. A sense was expressed that the personal cost of providing palliative care at home, particularly after hours, was not often acknowledged within the service. “*We get that call in the middle of the night and we get ... good feedback about the way we deal with things, but no one wants to know about how we are actually doing or what we’re doing with all that ... we’re expected just to soldier on*” (M.2, P.26). The opportunity to debrief as a team was a recommendation from the group in the letter of action. This action would support practice development in sharing creative solutions from each others’ practice, provide a forum for team members to discuss and move issues on as they arose. Debriefing was also viewed as a positive, reflective way to acknowledge a person’s death.

Summary

Issues, essences and elements highlighted in this chapter demonstrate some of the complexities and, at times, the messiness of district nursing practice. The authenticity and genuine commitment by the group to support people who are dying and their families was enacted in their practice through the essential essence of the development of the relationship between the person, family and the district nurse. Key elements in

developing these relationships were consistency, reciprocal trust, timing and presence. Role of family was pivotal to enabling the person to remain at home. The group drew on specific district nursing knowledge in their problem solving approaches, underpinned by an over arching focus of being with people and family, supporting their choices and respecting their wishes. Essences of teamwork within the district nursing team and the wider health providers required key elements of close collaboration with strong communication links to ensure positive outcomes for people and family. Accessibility and flexibility of services and forward planning between agencies were also contributing factors. When all of these essences and elements were present, outcomes were positive. If any of these were absent, outcomes for the person and family were less clear.

The groups' ability to support positive outcomes were challenged by issues including unclear pathways to timely access of appropriate after hours support, uncertain processes to manage variation in district nurse workloads and ongoing changes within the immediate workplace context and other health providers. For example, uncertainty amongst the members about changes following the closure of the local medical centre that had provided limited after hours support in the local community. How the vacuum created by this closure would be filled and what the potential impacts may be on district nurses ability to support people and family, particularly over night was unclear. Concerns of access and availability of support from members of the multidisciplinary team were not identified as an issue during normal working hours.

The group demonstrated their ability to reflect on their practice and an openness and respectful approach in considering perspectives and practices different to their own. Providing quality palliative care at home came at some personal cost to the group members. However a positive difference through supportive team relationships, including relationships with other services was viewed as reducing this impact.

CHAPTER 7: Concluding comments and reflections

The intention of this action research project was to articulate common experiences of a group of district nurses delivering palliative care in a specific community. Five district nurses came together to formulate a practical plan of action to address issues and challenges they experienced when providing palliative care at home with the focus of improving outcomes for people and family. The issues that emerged were not new for the local area nor in relation to the international literature reviewed. However, new knowledge emerged of what these nurses saw as the essences of their district nursing practice. Kelly and Symonds describe this identity construction as nurses articulating the “real nature of their role” (2003, p. 110). Common group understandings, insights and interpretations resulted in the action taken in this research. This chapter commences with a summary of the key findings of this research related to district nurses providing palliative care. Also detailed are implications and recommendations for nursing practice from this research. This chapter outlines conclusions and recommendations reached when utilising action research in a practice based discipline, in this instance district nursing. Highlights and limitations experienced in this research project are also summarised.

Commitment of the district nurses who joined me on this research journey was a humbling experience for me. Without this commitment, the research would not have been possible. The groups’ trust and openness provided rich insights into their everyday practice world. Members who volunteered were experienced district nurses, generally established in their community practice. Issues, elements and essences exposed may have been very different, if members had been less experienced and less familiar with this particular community context. Novice district nurses may not have been as confident to openly discuss their practice. The experience of the group resulted in the group being able to discuss a number of issues that impacted on the day-to-day work of the district nurses delivering palliative care.

Articulating and acknowledging research outcomes

Proposed practical solutions to the issues raised during the praxis group meetings were agreed to and proposed in the letter of action sent on behalf of the group to the Community Health Service Leader. These included district nurses’ active participation in discharge planning, clear processes and pathways through the

development of provisional action plans and the development of a pamphlet of care to support the palliative person and family at home. These highlight the focus of the group members to actively make a difference for people and families. Constructing practical approaches to develop and enrich relationships with other providers were outlined. Addressing workloads and strengthening self care was viewed collectively, with the group taking a wider approach (as opposed to caring only for themselves). Group commitment and focus was actively demonstrated when, within weeks of the research process drawing to a close, debriefing sessions within the whole district nursing team were instigated at the base. I cannot assume this was as a direct result of the research, however I believe the energy generated during the project may have contributed to this development. This research also created the opportunity to clarify processes following a change in service policy for syringe drivers.

The district nursing team at Kenepuru Community Health has undergone further significant staff changes since this research was completed. These changes have temporarily stalled further action being taken. The team once more is in the process of re-employing, rebuilding and re-establishing itself. The issues presented in this research continue to remain largely unresolved. The group and I hope once things are more settled, dialogue can commence again with Community Health Management to move the actions recommended out of this research forward.

In the meantime, I plan to submit a summary report of the research articulating the common positive aspects highlighted by the group members along with the group recommendations. It is my intention that this summary will create a space for dialogue amongst the practice leadership at Community Health and also between Community Health Services and their palliative care partner.

Implications and recommendations for nursing practice

This research reinforced the value of establishing a person-centred relationship that acknowledges and honours the uniqueness of the person and family, with a commitment to enhance outcomes. This research also highlighted the genuine commitment of the group to ‘go the extra mile’ to provide quality palliative care at home and make a difference. The value of teamwork, respecting and acknowledging what each other brings in their practice was evident, in working together to support

choices of people and family and enhance outcomes. Elements such as improved access, flexibility and availability of services after hours were identified in this research as potentially enhancing outcomes for people and families. Solutions were proposed for those factors able to be addressed. Actions recommended by the group are localised. The issues, elements and essences revealed may resonate with other nurses working in any community.

This research also provides insight and perspectives for nurses in other practice settings and other health providers working in partnership, to consider, and possibly challenge historically held perceptions of district nurse roles and practice. While this research focused on localised issues and formulating responses to these when providing palliative care in this community, identifying what contributed to positive outcomes may also enhance outcomes for other people and families being supported by these district nurses. Continued demand for increasingly complex community care and the reducing GP workforce nationally mean the issues presented in this research will continue to challenge nurses working with people and families in any community. Creative responses to address these issues must be developed. Further research must also be undertaken on a national scale to reveal the currently invisible – district nurses’ own interpretation of their role and their practice and what they view their contribution to be when working with people and families.

Future research focused on the experiences and perspectives of people and families either currently receiving palliative care services at home in this community, or families who have received palliative care services is recommended. This research could focus on perspectives and experiences of peoples highlighted in the *Disparities of Health* report (Ministry of Health, 2002). The researcher suggests the commencement of robust dialogue amongst palliative care providers and their partners of possibilities and potential contributions of nurse practitioner roles in the community. One possible development could be district nurse ‘Nurse Practitioners’, with a palliative care focus. These developments and research could provide further evidence to inform Capital and Coast DHB in developing the future direction of local palliative care provision, following the release of the final palliative care review document (Capital and Coast District Health Board, 2005).

Conclusions and recommendations for nurses undertaking practice based action research

Undertaking action research can be a daunting prospect, even more so for a neophyte researcher. Action research is, I believe, a great research vehicle for eliciting individual and common group understandings and perspectives of practice while creating a space to develop localised, practical, responsive outcomes and change. Some of the many immediate and wider ethical considerations and implications to navigate have been presented in this thesis. These are particularly important when undertaking action research in your own practice discipline and in your practice setting. Action research demands authentic commitment from the researcher to ensure the research is undertaken in an honest, safe and collaborative manner. The researcher needs to respond ethically to the unexpected moments of messiness, and trust the focus directed by those collaborating, in that moment which may or may not be the researchers. While action research is a lot of work, the outcomes and successes are rich, tangible and shared. These include enhanced understanding and acknowledgement of common and diverse perspectives in established relationships, making a difference in the immediate workplace context, and articulating the essences of nursing practice. The essences of the nurses' roles may never have been revealed before or been buried by ongoing health service restructuring. Action research is also a great vehicle to support reflection on practice.

Benefits of praxis groups as focused forums to explore practice

Praxis group meetings provided a forum for these practitioners to reflect on their experiences in their real world. Through focused group reflection (although the focus was not always clear at the time) members explored challenges they experienced in their current practice context, specifically when providing palliative care at home. Coming together as a collegial group provided the opportunity to share individual and common perspectives and experiences in a structured way and created a new space for group support. While this new space had a serious focus, there was ample evidence in the transcripts of laughter, jokes and a sense of trust within the group. This new space was voiced as being much valued by the praxis group members at the end of the research project. The praxis groups also provided a place for members to acknowledge each other's practice wisdom, expertise and to honour the work each other did. This was a new experience for most of the members in simply coming

together as a group to explore issues – most practice sharing was in an informal, ad hoc basis when time permitted. I did not collect data to elicit if the praxis group members had participated in a research project before but suspect this may have been a new experience for some members of the group. I recommend that where possible, research involving practitioners should be conducted during normal working hours as this reduces access barriers for potential participants and makes the organisation of group research more manageable for group members and the researcher. In addition, this strengthens the authenticity of the research findings - to be listened to and thus implemented into practice.

Sharing and testimony of the group revealed previously invisible practice with each member bringing with them a wide range of perspectives and experiences. Sharing of practice experiences “is for another just as much as it is for oneself [in]... that it recognizes but values the teller ... [with the potential] ... to change one’s own life by affecting the lives of others” (Frank, 1955, p. 17). Multiple voices coming together created a climate for, what one group member described as, ‘triggering’ within the meetings. Action agreed on by the group was reached by consensus at the end of the research, and signalled the coming together of multiple voices to create one single voice. Reflection and critical thinking by the members were embedded in a distillation process towards action.

Number of group members and group meetings

Numbers of district nurses consenting to collaborate in the research supported inclusive praxis group meetings, with everyone having a chance to speak. In a larger group, the trust and openness evident may have been lost alongside reduced opportunity for everyone to share. Significant data was collected, providing meaningful information for the group to determine the priority issues in their practice and the action required to respond to these issues. Recruitment within one base strengthened the research, with established relationships between the district nurses, an authentic understanding of the specific local everyday issues and genuine commitment to enhance outcomes for people and families living in this community. This commitment and common understanding may have been absent had recruitment spanned all three bases. Future action research enquiry could be undertaken to elicit similarities or differences, if any, for the district nurses working at the other two bases

in providing palliative care, with a focus of instigating action appropriate to meet the needs of people and families living in those communities.

Relationships in practitioner based research

Established relationships and trust amongst group members and myself had considerable benefits, reflected in the richness of what was shared and positive group processes. My past relationship emanated from my having regularly worked with members in our practice and the shared insights gained through these experiences. Existing trust and positive relationships was evident within the group. Together there was a group understanding of the nuances of working in this community, the complexity embedded in everyday district nursing practice and the culture of the immediate team and wider service. I implemented strategies to manage my existing friendships with other colleagues within the service and in other services to ensure confidentiality, non-disclosure of the research content and maintain confidence of the group members. I recommend practitioner action research that is addressing local practice issues be facilitated by a researcher with established relationships inside the workplace context.

There were advantages and disadvantages in my no longer being employed in the immediate workplace. Advantages included the removal of any power dynamics associated in my previous leadership role and the availability of time. I would have struggled to co-ordinate the praxis groups and complete the writing up of this research due to continued staff changes and shortages alongside workload pressures. Had I been able to complete the research and remain in a leadership role, there would have been a greater opportunity to highlight and agitate for implementation of these actions as a service priority.

Non-identifiability and confidentiality

The Team Leader and other district nursing colleagues were aware of those collaborating in the praxis group meetings due to the group members' unavailability at the times the meetings were running. This may have been avoided if the meetings had been held out of work time and away from the base. However, I knew the time and energy the district nurses already committed during their working day and did not want to encroach on their personal time. The best that could be hoped for in this research was ensuring speakers were not identifiable and a group commitment to

confidentiality. These were dependent on researcher conduct (including the writing up of the research), data management to ensure safekeeping and reliance on the researcher and group members to abide by the ground rules in what was discussed in the course of the research was not discussed outside the research without agreement by the group as a whole. I recommend researcher's contextually situate and seek consent to include the voices of those who participated in writing up any research project.

Maintaining action research momentum

Group commitment, interest and support, and meetings being scheduled in close succession in this project, enhanced maintaining the research momentum. Reduced meeting time frames may have encouraged an even more focused approach by group members. Interest and support for the proposed research from within the immediate district nursing team and Community Health Services management had been established some time prior to the invitation to collaborate and as a result recruitment was not an issue. This was pivotal to the action research project being commenced and completed. Completion of the modified cycle within a short time frame supported research momentum and focus, avoiding potential disruption of staff changes.

Establishing clear communication processes to ensure those collaborating in action research are kept up to date and informed of progress is essential. This was an area I could have improved, particularly once the research process had drawn to a close. There was a considerable time lag between the praxis group meetings and my meeting with Community Health Service management. Although I remained in contact with most of the group members during this time, there were some who I missed in my communication links. This communication would have demonstrated continued honouring and respect of those who collaborated.

Lack of timely written communication between myself and the group members during this time may have left those who collaborated, feeling let down by the researcher and left not knowing where their proposed action was sitting. From my own past experience in participating in research, I was aware that when engaging in research with an expectation of action, if action does not eventuate, volunteers might turn away from future research involvement. Ongoing communication with those who have

collaborated is essential in cultivating enthusiasm and interest in continuing current research and committing again to research projects in the future.

Strengths and limitations of this study

The great strength of this study lay in the commitment and focus of the group. Despite pressured workloads, the members worked thoughtfully, quickly and with focus. An extended break between the second and the third praxis group meeting of four weeks appeared to have been useful for group information gathering. It seemed to provide time for members to reflect on possible solutions, and possibly rekindled enthusiasm or momentum for the rest of the research. The group members consenting to the content of Chapters 5 and 6, to ensure my account honoured their work is a further strength of this study.

Although, initially I considered I was confident in facilitating a group conversation, there were nuances that occurred during the group meetings that I failed to recognise and follow up. They were not always evident to me at the time and only became clear to me in writing up the process. On reflection, inclusion of ‘ums’ and ‘ahhs’ was not particularly helpful and I would recommend removing them in the future. However, their inclusion did raise awareness about language and articulation for all of those involved. This awareness would have been lost had they been removed. The informal conversation with the group member following the second meeting, caused me to reflect upon and critique my ability, not only to articulate the research and facilitate the meetings, but also in undertaking the research in the first place. Critically, I saw this research as articulating others’ practice and I wanted to do it the ‘right’ way and the ‘best’ way possible. This reflection continued for me, throughout the research and writing up.

Difficulties experienced with transcripts following the second and third praxis group meeting impacted on group members’ ability to validate and reflect on what had been discussed. I hadn’t anticipated this messiness and although the group members agreed to go ahead without the transcripts, had I considered this possibility in my planning, I would have arranged a second transcriber ‘just in case’, rather than proceed. Proposed timeframes between meetings were tight, creating additional pressures in cleaning

transcriptions and getting these back to the group with enough time for members to read and reflect what had occurred.

Agendas may have been useful to begin conversations but I used them in a distracting manner that broke conversation flow from time to time. Agendas could have stifled the conversation direction of the group. There are tensions between remaining true to the collaborative nature of action research and the focus of the researcher. This was reflected in process issues that unfolded earlier in the research. I almost have a sense I made it up as I went along, while believing I was engaging in a collaborative process. An example was my decision to substitute group member's names for pseudonyms in the first transcripts. I would negotiate how to manage inclusion of names, reaching group consensus at the beginning of any future research.

A further limitation was the reduced time frame for the four praxis group meetings. While one hour provided time for focused discussion, I wondered whether issues could have been explored further and if there were things left unsaid. However, this was what was manageable for the group with the research an additional demand on their already full working day. The issues, essences and elements revealed by the group were rich and complex. The outcomes from one action research cycle were fruitful and are work in progress. Once again, I acknowledge the commitment of the group members who joined me in this research and thank them for their candid participation. I look forward to working with you again in the realm of district nurse practice in the future.

Wellington Ethics Committee

Ministry of Health
10th Floor
180 Molesworth Street
PO Box 5013
Wellington
Fax 04 496 2360

15 June 2004

Wellington Ethics Committee Ref No: 04/06/042

Please quote this reference number in all correspondence relating to this research

Donna Voice
C/o Kenepuru Community Health Service
Kenepuru Hospital
P.O. Box 50-215
Porirua

Dear Donna

04/06/042 - Palliative care in the community: An action research study of the issues of concern, as experienced by a group of District Nurses providing palliative care in a particular community setting

The above study was considered by the Wellington Ethics Committee at its meeting of 8 June 2004.

The study was approved subject to the following points being addressed:

- 1 The research question focuses merely on negative experiences/issues associated with nurses delivering palliative care. It is suggested that you could direct some questions in your praxis meetings to elicit positive experiences as well. Affirmation of positive experiences/areas of satisfaction would provide clear justification for addressing the problems or constraints that nurses experience in delivering in palliative care.
- 2 Suggest a wider dissemination of results would be beneficial i.e. to other primary care providers such as G.P.s, hospices etc.
- 3 3.3 first praxis meeting should include broad introductory questions on nurses' background and level of interest in palliative care. This would provide a context for better understanding and interpreting the data. The group that volunteers for this study may be the keener, more informed nurses in this field of practice.
- 4 3.4 what happens if more than six nurses volunteer? Will first six be taken? Needs to be explicit in information sheet.
- 5 Casual short-term staff may not be ideal participants, as they may not have an in-depth 'handle' on the issues.
- 6 4.1 Please provide a copy of the schedule of broad questions to be used in meetings.
- 7 4.3 members of the group should be provided with transcription of previous meeting to verify content. This provides a process of data validation.
- 8 5.2 we suggest the lead researcher should be responsible for analysis- too unwieldy involving all participants.
- 9 8.1 How will transcriber be funded?

10 General Information Sheet

- Needs to strike a more positive/definite note, ie, "I am planning to undertake a research project...". (first sentence).
- Could include statement that managers have approved the project.
- Suggest times chosen for meetings are too restrictive and may exclude some volunteers on this basis. Could this be more flexible within the work timetable? (suggest a lunchtime with lunch provided)

11 Participant Information Sheet

- Organise information into subheadings, ie, introduction, data collection, voluntary participation and procedures, expected outcomes, further queries.
- Para 1, replace "looking at" with "exploring".
- Para 2, replace "look at" with "reflect on"

12 Consent Form

- Remove contradiction concerning identity being confidential as quotes used may easily identify a participant. Need to consider whether single quotes that could identify an individual will be used.

When the above issues have been addressed, ethical approval for this study will be granted.

Yours sincerely

Claire Yendoll
Co-Administrator

Claire_Yendoll@moh.govt.nz
Phone: (04) 496-2405

15 April 2005

Donna Voice
68 Gloomington Hill Rd
Titahi Bay
Wellington

Dear Donna

**WGT/04/06/042 - PALLIATIVE CARE IN THE COMMUNITY: AN ACTION RESEARCH STUDY OF THE
ISSUES OF CONCERN, AS EXPERIENCED BY A GROUP OF DISTRICT NURSES PROVIDING
PALLIATIVE CARE IN A PARTICULAR COMMUNITY SETTING**
Donna Voice

The above study has been given ethical approval by the Central Region Ethics Committee Ethics Committee.

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, March 2002.

Final Report

The study is approved until April 2006. A final report is required at the end of the study and a form to assist with this is available from the Administrator. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date. Report forms are available from the administrator.

Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

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

Yours sincerely

Claire Yendoll
Central Ethics Committee Administrator

Email: claire_yendoll@moh.govt.nz

Appendix 3: Invitation to participate in research

Project Title: Palliative care in the community – district nurses' experiences.

Researcher: Donna Voice, Master of Arts (Applied) in Nursing student

I am planning to undertake a research project with members of the district nursing team at Kenepuru. This project is looking at the experiences of district nurses in providing home based palliative care. I have received approval from Capital and Coast District Health Board Hospital Services management and from the Wellington Ethics Committee to undertake this research. This research is being completed as the thesis component of my Master of Arts (Applied) in Nursing degree. The project is being supervised by Dr Kathy Nelson, Graduate School of Nursing and Midwifery, Victoria University of Wellington.

The project calls for volunteers to participate in a group to discuss experiences in providing palliative care nursing. Using an action research design, the group will explore experiences and issues in a structured way and will identify strategies that can creatively address ways of improving the services provided. This type of research is called action research.

The study is open to all District Nurses working at Kenepuru Community Health Service base who want to participate. Ideally I would like to recruit up to six nurses to form the group. I am looking for volunteers to participate in the study. The first six nurses who consent to participate will be included in the group meetings.

The research project group would meet three or four times for a maximum of two hours each session, possibly between 2pm-4pm at Kenepuru Community Health Base. Tentative dates proposed would be Tuesday 3rd May, Tuesday 17th May and Tuesday 31st May, with the option of Tuesday 14th June if the group decided a fourth meeting was required.

If you are interested in receiving further information about the project or participating in it, please contact me by telephoning 237 3100.

Kind regards
Donna Voice

Appendix 4: Participant Information Sheet for a study of palliative care in the community – district nurses' experiences.

Researcher: Donna Voice, Student, Graduate School of Nursing and Midwifery, Victoria University of Wellington.

INTRODUCTION

I am a Master of Arts (Applied) student at Victoria University of Wellington. As part of this degree I am undertaking a research project exploring the experiences of district nurses in providing home based palliative care. Ethical approval for the project has been gained from the Wellington Health and Disability Ethics Committee. The management of Capital and Coast District Health Board have approved the study proceeding.

AIM

The aim of the study is to use a group-based approach in which district nurses can share their experiences in delivering home based palliative care. It is intended that this study identify issues that impact on district nurses ability to deliver quality palliative care. The group will be supported to reflect on strategies nurses and the service may utilise to address issues raised, enabling improved outcomes for patients and their families. The study is open to all district nurses working at Kenepuru Community Health Base who want to participate. The first six volunteers who consent to participate will be included in the group meetings.

HOW, WHERE AND WHEN

The research will be undertaken at the Kenepuru Community Health Base and will consist of 3 or 4 group meetings. The meetings will provide opportunities for practitioners to participate in focused discussions around particular practice issues. The research project group would meet three or four times for a maximum of two hours each session, between 2pm-4pm and tentative dates proposed would be Monday 2nd May, Monday 16th May and Monday 30st May, with the option of Monday 13th June if the group decided a fourth meeting was required.

DATA COLLECTION AND ANALYSIS

Each session will be tape recorded and transcribed by an independent transcriber who will sign a confidentiality agreement. The tape recordings will be destroyed after the project has been completed. In the first meeting nurses will be invited to share a palliative care story from their practice. In the second meeting nurses will be invited to share their reflections on the issues raised. In the third meeting nurses will be invited to look at strategies that could be used in their practice or by their Service to address issues raised. The research will report generally on the discussion of the group sessions, and quotations may be used to demonstrate the issues raised. No

identifiable information will be used in the thesis to link individual research participants to the quotations.

VOLUNTARY PARTICIPATION

Participation in the study is voluntary and should any participant feel the need to withdraw from the project, they may do so at any time. The group will contract to maintain confidentiality and minimise the use of names of patients, families and other health professionals.

The project will be written up as a thesis, which is due in December 2005 and deposited in the Victoria University of Wellington Library. In addition, the project may be presented at professional forums or in publications.

CONSENT AND FURTHER INFORMATION

Participants will need to sign a consent form if they agree to participate. At the end of the study, the results will be summarised and decisions made as to who to share the findings with. If you have any questions or would like to receive further information about the project, please either contact myself or my supervisor.

Thank you.

Donna Voice
Telephone 2373100

Supervisor
Dr Kathy Nelson
Graduate School of Nursing and Midwifery
Victoria University of Wellington
Telephone 463 6138

Appendix 5: Consent to participation in research

Title of project: Palliative care in the community - district nurses' experiences

Researcher: Donna Voice, Master of Arts (Applied) in Nursing student

- ☐ I have been given and have understood an explanation of this research project.
- ☐ I have had an opportunity to ask questions and have them answered to my satisfaction.
- ☐ I understand that I may withdraw myself from this project without having to give reasons and without penalty of any sort.
- ☐ I understand the published results will not use my name, and no opinions will be attributed to me in any way.
- ☐ I understand that the tape recordings of the group discussions will be electronically wiped at the end of the project.
- ☐ I understand I will receive transcriptions of meetings throughout the research project and I will receive a summary of the research results at its conclusion.
- ☐ I understand that the information I have provided will be used only for this research project and related publications and presentations, and that any further use will require my written consent.

I hereby consent to take part in this study.

Signature: _____

Name: _____

Date: _____

Cc To participant

Appendix 6: Transcriber Confidentiality Form

I _____ (**Transcriber**) agree that the information I am about to transcribe involving interactions with a group of nurses for Donna Voice's research project is strictly confidential.

At all times the research information (tapes and transcripts) will be inaccessible to other persons. I have agreed to meet with the researcher following each interaction (group meeting) to address any issues that transcribing the interaction arise for me.

I agree to the conditions of transcribing for Donna Voice's research and understand that the research is a requirement for the completion of a Master of Arts (Applied) in Nursing which is being supervised by Dr Kathy Nelson, Graduate School of Nursing and Midwifery, Victoria University of Wellington.

_____ Date _____

(TRANSCRIBER)

_____ Date _____

(RESEARCHER)

Appendix 7: Letter of Action

24th August 2005

<name>

Service Leader

Community Health Services

Capital and Coast District Health Board

Private Bag 7902

Wellington

Dear <name>

I am writing to provide feedback on behalf of the participants from the recent praxis group meetings I have convened at Kenepuru Community Health services. This group was convened as part of my Masters of Arts (Applied) thesis research looking at what is involved in district nurses providing palliative care in a particular community. The research data is currently being analysed but as part of the group process a decision was made by the group that I write to you regarding the four broad issues - supporting people and their families, managing workloads, working in partnership with other providers and debriefing – raised by the participants during the research. The research process also involved participants looking for solutions and possible pathways to address these issues. I must acknowledge the commitment shown by the group members in this process, with all of the members attending all the group meetings. I believe this reflects the degree of interest and commitment by district nurses to providing quality palliative care for people and their families.

The group acknowledges the palliative care contract is currently under review and the tender process underway, which may have significant impact on district nurses continuing to provide these services. However, a number of the issues raised by the group impact not only on those people and their families receiving palliative care but the wider population served by the district nursing service.

1 Supporting people and their families

The group raised and explored the issue of general care planning between agencies, ensuring people and their families have a firm understanding of what district nurses can provide prior to discharge. At present, this is undertaken in selective situations. This would avoid any additional stress or dissatisfaction for people and their family. It would also avoid some of the unexpected and unplanned demands on the district nursing service. The group proposes that in the event of a planned discharge from Mary Potter Hospice, the primary district nurse attend the discharge planning meeting with the person and their family to ensure there is clarity and understanding regarding ongoing care at home. This has occurred in the past but has not been a widespread practice.

In the instance of palliative care, the notion of a provisional action plan was also discussed by the group. This would be instigated from the acknowledgement of a person's palliative prognosis. At present, action plans are in place for those at risk of a catastrophic event, but we would like consideration to be given for all people having such a plan. The action plan could include a clear outline for people and their families of after hours access to other health providers, in an effort to manage unexpected deterioration or changes in the person's symptoms,

which could be planned for and addressed (by the use of patches for example). The group proposes exploring this issue further with Mary Potter Hospice.

A further method of supporting families explored was in the form of developing a pamphlet targeted at families caring for people at home. The pamphlet could outline basic care requirements such as mouth care, as well as space for more personalised details of care to be added. This would acknowledge the potential for multiple carers and provide families with some guidance as to how to provide physical care for their loved one. A section could also be included outlining when to contact your health professional or key points to tell your district nurse. The group would be interested in exploring similar tools that may be in use in other areas. The group proposes a working party of interested district nurses be set up to develop this tool. The tool could be translated in other languages and could prove useful for the wider population served by Community Health Service.

2. Managing workloads

A theme repeated in our meetings has been the ongoing challenge in managing workload, especially after hours, weekends and some public holidays. The group acknowledges much work has been undertaken by the service to explore these issues, such as the triage group and the work undertaken in the recent Community Health Service review. There remains outstanding, a firm process to manage the unexpected and the variances associated with rapidly changing health circumstances, in this instance, people in the community with a palliative diagnosis. The group are aware there are variables of how other bases within the service manage this issue, such as having a second person on call and available in the evenings, in the event of unplanned for, increase in demand. This is an ad hoc arrangement and appears to be reliant on staff good will. They also acknowledge the ability to access other bases for nursing support. However, this is dependent on the already planned workload of those nurses working at the other bases. The group proposes an exploration of possible solutions and clarity in processes at Kenepuru base, which may reflect the action currently undertaken at Kapiti base.

The group also recalled the proposal from the 2004 Community Health Service review, which outlined the notion of a second person being on the roster for afternoon shifts and wondered if this proposal would be implemented at any stage. The issue of ongoing on call arrangements by the district nurses was also raised, as this issue remains outstanding from the 2004 Community health Service Review, which indicated that this service would cease. There appears to remain a misconception by some people and their families that district nurses are awake and up working during the night and this issue may need to be clarified further with other health service providers. The information regarding on call contact continues to be collected and the group is unclear of how this information will be utilised. In the example of palliative care, the group would be interested in revisiting the concept of families ringing the hospice first, for advice in this instance. The group acknowledges that district nurses resoundingly rejected this some years ago however for some individual families this has been a planned part of their care and this has appeared to work well. The group proposes a service wide discussion again on this issue and depending on this outcome, further discussion with Mary Potter Hospice.

3. Partnerships with other providers

A further theme repeated in our meetings has been the ongoing challenge in accessing medical support after hours. With the recent changes in the provision of local after hours medical service, which now ceases at 11pm, access to medical assessment relies on the availability of the family doctor or on a telephone assessment by the hospice doctor on call. While the group

acknowledges the newly opened Accident and Medical centre at Kenepuru, the doctor based at this department will not be able to assess the person in the home. The group also acknowledges that this has been a long-standing issue and one that has been identified in the recent palliative care review undertaken by Capital and Coast District Health Board. While the group acknowledges there is little action the service may be able to take in this matter, they felt the impact of this service gap is so immense for people and their families, it must continue to be raised.

In terms of working alongside other health providers in palliative care partnerships, the group proposes clarifying with those nursing agencies currently providing night support, the level of interest in nurses providing night care. This level of interest may be enhanced by offering ongoing in-service to support these nurses to provide this care. This in-service could be undertaken in partnership between Community Health Services and Mary Potter Hospice.

The group also proposes an offer to Mary Potter Hospice be made for new staff employed in the unit to spend a day working alongside district nurses. The offer could also extend to existing unit staff who indicate an interest. This would enhance relationships between the service partners and provide valuable insight for both hospice and district nurses in their roles of walking alongside people and their families in quite diverse environments.

4. Debriefing

The issue of debriefing at the base was raised. The group felt that this would be a useful process for the team to explore. A method of taking this forward was discussed and the use of a supervisor to facilitate in the initial stages suggested. This would enable team members to become comfortable with the process and allow those interested to develop the skills required to take over the facilitation role. The group believes debriefing would support reflection and practice development. Debriefing would support the nursing team members to 'let go' of issues as they arise, provide a forum for future learning and provide a space for members to acknowledge care that has gone well.

While the issues I have outlined may be localised, the group acknowledges these issues may be service wide. The group also raised many positive aspects and the proposals outlined in this letter could further enhance the care provided by the service while also ensuring existing resources are managed as effectively as possible. The group would be happy to be invited to meet with you, to discuss how to move these issues forward. I would be happy to arrange this meeting. I can be contacted by telephoning 237 3100 extension 3901. I look forward to hearing from you.

Kind regards

Donna Voice
MA (Applied) student

Cc Kathy Nelson
Lecturer
Graduate School of Nursing and Midwifery
Victoria University
PO Box 600
Wellington

Phone: 64-04-463 6138

Fax: 64-04-463-5442

Appendix 8: Consent to Include Group Members Voices

<Address>

29th November 2005

Dear <name of group member>

I am writing to update you on the action research project you recently collaborated in, exploring the issues of concern of district nurses providing palliative care. As you are aware, a letter was forwarded to Community Health management on behalf of the group members, following consensus being reached on the action to be taken at the final praxis group meeting. I apologise for the delay in formally advising you of the status of the research.

In the letter of action, the suggestion was for the group members to meet with management to discuss the issues raised and the strategies put forward to address them. Community Health management indicated some concern for group members retaining non identifiability in this process and requested to meet with me. There was some delay in this meeting taking place but we eventually met on 19th October 2005. I am awaiting a letter from Community Health management outlining the content of this meeting, which I will forward to you as soon as it arrives. A request was made by the service leader to discuss the issues raised by the group with the Practice Development team from the service to elicit whether these issues were experienced at the other bases. I gave permission on behalf of the group and hope this meets with your approval. A request was also made to raise these issues with Mary Potter Hospice management, however the service leader requested some feedback be included outlining the positive aspects of partnership in palliative care delivery. I have undertaken to do so, once I have received the above mentioned letter. Once again, I hope this meets with your approval and will forward to you a copy of my proposed response for you to consider and provide feedback on.

As you are already aware, within weeks of the group disbanding, group debriefing opportunities had commenced at Kenepuru base, led and facilitated by one of the district nurses from the team. I'm sure these sessions are proving useful in supporting group reflection on practice.

Enclosed is a draft of Chapter 5 and Chapter 6 from my thesis. They contain sections taken from the transcripts of our praxis group meetings. You may recall in the consent form you signed prior to the group convening I undertook to gain your consent to include your 'voice' in my thesis. Although these chapters are in draft, they contain the sections from the transcripts I would like to include and undertake not to add any further sections. While, my writing will continue to be reworked over the next two months, the proposed context in which your words are used will not change. I am requesting that you review these chapters and if you agree to my including these sections, could you please sign the attached section of this letter and return to me in the self addressed envelope enclosed, by 15th December 2005.

You will also note in Chapter 5, page 121, I have paraphrased the discussion regarding the Palliative Care review and I would like your permission to include this

section. If you do not give permission or in the event of any your own statements you would like deleted from these two chapters, could you note them on the drafts and contact me and I will collect these from you and make the changes you have requested.

If you have any questions or if there is anything you would like to discuss with me regarding the research, the action, or the content of these chapters, do not hesitate to contact me on 237 3100 extension 3901. Please leave a message if I am out of the office. Alternatively, you can contact me on <home telephone number>.

Once again, thank you for collaborating with me in this project and hope you have found it a positive experience. I will forward you a copy of my thesis, once it has been examined and lodged in the university library. There was a suggestion by group members regarding input into the title of the thesis. As it currently stands, "Everyday essences revealed through a journey of distillation". However, I welcome your feedback regarding this as I view my thesis as honouring and acknowledging your work, your practice.

Kind regards

Donna Voice
MA Applied (student)

Title of Project: Palliative care in the community – district nurses’ experiences.
“Everyday essences revealed through a journey of distillation”.

Researcher: Donna Voice, Master of Arts (Applied) in Nursing student

I have read the draft Chapters 5 and 6.

I understand the transcriptions identified in these chapters will be included in the final thesis.

I give permission for the informal discussion outlined in Chapter 5, page 121, to be included in the final thesis.

I hereby consent to the above information being included in the final thesis.

Signature: _____

Name: _____

Date: _____

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