Management of Patients on Chemotherapeutic Treatment for Advanced Cancer with Acute Conditions in the Emergency Department.

A thesis presented in partial fulfilment of the requirements for the degree of Master of Nursing at the Eastern Institute of Technology Taradale, New Zealand.

Lynne Marie Gray June 2013
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Abstract

Chemotherapy is increasingly used in people with advanced cancer, with the aim to palliate symptoms and to improve survival. Patients may live longer but quality of life may be affected by treatment-related events. New Zealand provides medical oncology services in a Hub and Spoke model, with an increasing emphasis on delivering treatment at out-patient ‘satellite’ services. The reality is that these services do not provide around the clock care, so after hours and urgent care is provided by the local Emergency Department (ED). There is evidence to suggest cancer patients on chemotherapy are clinically high risk, presenting more frequently to the ED and with more complex clinical needs than the general population.

This study sought to answer the question “How do ED nurses manage patients on chemotherapeutic treatment for advanced cancer presenting with acute conditions?” The research objectives were to explore the factors that influence clinical decision-making and nursing care provision to this group of patients. A qualitative, exploratory study was undertaken. A voluntary, purposive sample of 5 ED nurses from three satellite hospitals underwent semi-structured telephone interviews, each lasting from 30-40 minutes. The interviews were transcribed and the raw data thematically analysed via an exploratory descriptive approach.

Analysis yielded three main categories: Context, Communication and Collaboration, and Awareness. Care delivered within the context of the ED is presentation-driven and urgency-driven. Chemotherapy treatment and goals of care may have little influence on the interventions provided. Challenges arise through patient complexity, lack of oncology specialist availability and low volumes that preclude the maintenance of specialist skills and knowledge. Care may be more influenced by local Hospice teams due to well established relationships with the ED. A more collaborative relationship between Oncology and the ED may be the key to future models of care that support ED staff to provide acute and emergency care within the context of the patient’s disease, their chemotherapy and their goals of active treatment.
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This project would not have been completed without on-going support and commitment on a number of fronts:

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CHAPTER 1

Background

1.1 Introduction

A decade in cancer care is a long time. Under the pressure of multiple factors the cancer landscape keeps changing, and health care professionals and policy-makers have had to adapt. One of the more significant of these pressures has been advances in the pharmaco-therapeutic options for treating advanced cancer. These have altered the trajectories of what were once inexorable malignant processes. Workforce pressures, changing population demographics and fiscal pressures have also contributed to changes in cancer service delivery both in New Zealand and overseas. This has and will, increasingly, extend the scope of practice of, and expectations on, the oncology nursing workforce. Convergence of these factors is also likely to increase the challenges for all acute health care providers involved in the care of people receiving disease-modifying treatment for advanced cancer, particularly ED staff that are required to respond urgently to acute health care events.

In this chapter I will provide the background to this thesis, starting with operational definitions. I will then discuss the New Zealand policy and professional response to this altered cancer landscape and the impact these factors have had on cancer nurses and acute health care providers alike. From this will emerge the identified research problem and study purpose. Research design and methods will be discussed including sampling strategies, data collection, analysis and ethical considerations.

1.2 Operational Definitions

Operational definitions have been provided for the following terms that are central to this thesis that will enable the reader to grasp the context of the study.
Medical Oncology

A recognised specialty (Medical Council of New Zealand, 2012) that undertakes medical treatment of malignancy using systemic cytotoxic, hormonal, and targeted drug treatments which seek to modify the disease itself. There are numerous terms in use in the literature to describe this, and which will be used interchangeably in this thesis: ‘active treatment’; ‘disease-modifying treatment’; ‘systemic anti-cancer treatment’; ‘palliative chemotherapy’.

Oncology nurse

A registered nurse working primarily with a focus on the care of patients with cancer undergoing disease-modifying treatment.

Palliative care

The term palliative care (all lower case) will be used in this thesis as an adjective to denote a philosophy of support and symptom management that may permeate all aspects of health care so is not just the domain of a Palliative Care or Hospice Service. Where reference is made to an actual Palliative Care or Hospice Service or Team this will be indicated by the use of upper case for the first letter of each word.

Palliative Care nurse

A registered nurse working primarily within a defined Service or Team providing palliative support and symptom management.

Emergency nurse

A registered nurse working primarily in an ED specialising in the management of acute and emergency events.

1.3 Background

1.3.1 New Zealand Government Strategy

Cancer care in New Zealand is specifically guided by the Ministry of Health’s Cancer Control Strategy set down in 2003 (Minister of Health, 2003). This strategy is supported by a number of specific reviews, reports and recommendations around future models of care, oncology workforce, and
predictive analyses of future demand. These will be discussed in this section. The Cancer Control Strategy takes a broad view across the continuum from cancer prevention to palliation. Its overall purpose is to “reduce the incidence and impact of cancer” and to reduce inequalities in respect to cancer” (Minister of Health, 2003, p. 1). To achieve this, the strategy has identified six goals as follows (Minister of Health, 2003, p. 1,2.):

- To reduce the incidence of cancer through primary prevention.
- To ensure effective screening and early detection to reduce cancer incidence and mortality.
- To ensure effective diagnosis and treatment to reduce cancer morbidity and mortality.
- To improve the quality of life for those with cancer, their family and whanau through support, rehabilitation and palliative care.
- To improve the delivery of services across the continuum of cancer control through effective planning, co-ordination and integration of resources and activity, monitoring and evaluation.
- To improve the effectiveness of cancer control in New Zealand through research and surveillance.

The Cancer Control Council of New Zealand is an independent advisory body mandated by the New Zealand Public Health and Disability Act 2000, appointed by the Minister of Health, and responsible for turning this strategy into action. Four Regional Cancer Networks (Northern, Midland, Central and Southern) have been put in place to work across organisational boundaries, with District Health Boards (DHBs), consumers and non-governmental agencies, to provide regional leadership for the Ministry’s Cancer Control Programme. Goals three, four and five are particularly pertinent to oncology nurses and teams undertaking the care of cancer patients on active anti-cancer treatment.

The 5th goal of improving service delivery and patient outcomes through planning, co-ordination and integration is influenced by many of the previously noted pressures such as increasing cancer incidence, complexity, and the move to more outpatient treatment. Care co-ordination has been
defined as “a multi-faceted approach to achieving continuity of care which is best viewed as an outcome of care as experienced by the patient” (Midland Cancer Network, 2008, p.2). Timely access to services and communication between these providers are seen to be essential to effective care co-ordination. Care co-ordination itself is not seen to be specific to an individual role but rather a function of the whole system. Therefore this goal needs to be addressed at more than an individual, oncology-specific level and requires informational, management and relational strategies (Midland Cancer Network, 2008).

1.3.2 Models of Medical Oncology Care in New Zealand

Oncology workforce and fiscal challenges, along with an ageing population and increasing survivorship have led the Ministry of Health (MOH) to commission a review of medical oncology services in New Zealand. This report favours the current hub-and-spoke model of service delivery with increasing devolution of clinical services to the spoke (Cranleigh Health, 2011). The hub-and-spoke model is a “service structure that involves key sites (hubs) representing the central base that are connected to satellite sites (spokes). These central bases provide supporting services to satellite sites” (Cranleigh Health, 2011, p. 7). The six Regional Cancer Centres, situated in Auckland, Waikato, Palmerston North, Wellington, Christchurch and Dunedin, provide medical oncology inpatient, day stay chemotherapy and outpatient care and act as the hub. At the spoke, the smaller hospitals function as satellite services and may provide ambulatory chemotherapy and/or visiting specialist outpatient clinics. Even if chemotherapy has to be administered at the hub, wherever possible the patient will return home between treatments. There are large variations around the country in the distances between the person with cancer and their satellite treatment centre and between the satellite centre and their specialist cancer centre.

The Cranleigh report recognizes a number of important factors impacting on future service delivery: the disease trajectory may be prolonged and punctuated by acute, treatment or disease related events; and there is an expected trend towards chemotherapy of greater complexity being given to more people with advanced cancer, more frequently, and to an older
population overall. There is anticipated to be increasing devolution of chemotherapy administration to the satellite units (Cranleigh Health, 2011). Nationally, chemotherapy sessions increased by nearly 4,000 in 2009/10 to just over 57,000 outpatient sessions. This growth is not due to increasing cancer incidence as much as patients receiving more treatments, and there being more options for treatment (Ministry of Health, 2011c).

1.3.3 Oncology Nursing

Under the auspices of the Cancer Control Strategy, the Palliative Care and Cancer Nurses Education Group (PCNEG) was initiated to develop a sustainable nursing workforce for people with cancer (Ministry of Health, 2009). The framework developed defines the term cancer nursing not just as nurses working within oncology services, but broadly encompassing all nurses providing care at any stage in the continuum. This wide-ranging definition of cancer nursing is reflected in a model of nursing competencies in cancer control that range from level one core competencies demonstrated by all, through to level four, which defines the specialist competencies and post-graduate education of the few who work in advanced practice roles. These level four competencies acknowledge the increasing complexity and intensity of the treatment regimens and supportive care requirements that demand specialist knowledge and skills; the pivotal role oncology nurses play in interdisciplinary care; and the international recognition of cancer nursing as a specialty (Ministry of Health, 2009). From an oncology nursing point of view, the specialist competencies require an advanced practice role that must influence care not only at client and team level, but also at a service and policy level. The hub and spoke model of care also places the specialist oncology nursing role at the heart of cancer service delivery in the smaller centres. These factors have had a major influence on the development of this research question and proposal.

In this researcher’s experience of integrating and co-ordinating cancer care in a small district health care setting at the spoke, the impact of the increase in treatment options for advanced cancer has been felt. It is increasingly the practice locally to maximise supportive care and symptom management with early referral to Palliative Care/Hospice Services for
patients with incurable malignancies, even though there may be multiple options for disease-modifying therapy. From personal experience this has required closer collaboration and clearer communication to integrate the dual philosophies of active treatment and palliative care between two distinct services. Expectations of care and goals of treatment need to be negotiated and re-negotiated between these services and the patient/whanau in response to dynamic disease processes and responses (or lack of) to treatment. The ambiguity of this interface is apparent from this researcher’s experience, as is the difficulty in prognostication and goal-setting with this group of patients. This is challenge enough to those working within these specialties, but it is this researcher’s observation that many acute health care professionals continue to hold traditional views of palliative care as ‘end-of-life’ care and struggle to reconcile the dual philosophies of active treatment and palliative care.

As the Ministry of Health draws these numerous strategies together to address the future challenges in cancer care, and local and regional services adapt and respond, it appears to this researcher that a critical point in the patient pathway remains unaddressed. It is a reality that in New Zealand small centres will not be able to provide an around-the-clock specialist oncology service. Nor will they all have ready access to specialist oncology advice. Advanced cancer patients, more numerous, older, with greater complexity and receiving a greater range of disease-modifying treatments will be directed to their local ED for management of acute events. In the ED, under the impetus of an acute event, significant clinical decisions may be made upon which the whole patient trajectory will pivot. These decisions of necessity are made under urgency, possibly without a clearly defined goal of care and frequently without access to the oncology team who know the patient well. The proposed models of service delivery place increased expectations on the nursing workforce at the spoke. Local oncology expertise will be invested in a few key staff and in many cases this will be nursing only. It is in the smaller, more rural centres that our more vulnerable populations live and where the cancer burden is relatively high compared with the metropolitan areas.
1.4 Authorial Declaration

The motivation for this research topic has come after more than 20 years of full time cancer nursing, the majority as the sole oncology nurse in a small, relatively isolated region. My current oncology nursing role bears little resemblance to that which I started in 1990 and is a reflection of many influences. Firstly, the factors already discussed and secondly my own professional and personal growth in this specialised field of health care that has been wrought by experience, the lessons learned of patients and oncologists, as well as the timely addition of very relevant post graduate studies. Political and professional forces have enabled the development of an advanced clinical practice role for nurses and supported my efforts to extend my scope of nursing practice and influence. With the increased experience, expectations and specialisation of the role has come the increasing frustration of being unable to influence the medical and nursing care provided by acute health care services that people with cancer invariably have to traverse.

I started this study from the point of view that I needed to find out why don’t they (ED staff) get it? However, after much reading, analysing and reflecting I came to better understand the bias that specialty practice had engendered in me and the difficulty in maintaining the neutrality required of the researcher role. I had initially viewed the problem from my own position of specialised knowledge and experience and the undoubted privilege of being able to provide longitudinal care for individuals with cancer and their family/whanau. This is possibly the best position from which to understand the ambiguity inherent in the situation and to negotiate with the patient the sometimes very fine line between active and palliative goals of care; and what a position from which to glare over the fence at the medical and nursing staff in acute care.

As my reading and reflecting progressed it dawned on me that I was doubly guilty, not only of judging my colleagues too harshly, but of not working with the acute care staff to make both them and people with cancer safe. The issue at the heart of this thesis is as much a tendency of specialist cancer nurses, me included, to manage the patient within our own specialist paradigm and our failure to address patient needs across the whole care
continuum, as it is an exploration of the issue from the acute care nurses’ point of view. Thus, this will be a self-conscious exploration that will always strive to be mindful of the vastly different contexts and specialised knowledge bases of these nursing sub groups. In our increasingly specialised oncology world we may have failed to appreciate how it must be to make appropriate decisions for these patients under conditions of urgency and high ambiguity such as in the ED. Therefore this has become an exercise in climbing the fence and asking of a colleague “how are you managing this?” An opening gambit in what I hope will be an on-going dialogue between oncology nurses and emergency nurses that will eventually lead to an on-going, sustainable and mutually supportive relationship that works to our and our patients’ benefit.

1.5 Problem Statement

The challenge for ED nurses is to respond urgently, possibly without specialised knowledge, without insight into an individual’s goal of care and without access to the staff and services who know the patient well. Whatever clinical uncertainties and dilemmas arise with regard to chemotherapy for advanced cancer may be aggravated by the involvement of the palliative care team in the patient’s care as that involvement has traditionally signalled end-of-life care. There is the potential for both the under diagnosis and under treatment of disease or treatment-related sequelae, and the institution of inappropriate treatments. This has consequences for the patient in terms of outcome, quality of life and experience of healthcare, as well as potentially creating clinical and moral dilemmas for the ED staff.

1.5.1 Purpose of the Research

There is a need to understand just how ED nurses manage the complexities of advanced cancer patients on chemotherapy when they present acutely, and to explore the factors influencing clinical decision-making and provision of care. Therefore the purpose of this research is to explore how the ED nurses plan and implement nursing interventions for patients on chemotherapeutic treatment for advanced cancer who present with acute conditions in an ED. Some insight will be gained through the experience of
the ED nurses regarding the factors that influence the clinical decision-making of the whole team in the ED.

1.5.2 Research Question

How do ED nurses manage nursing interventions for patients on chemotherapeutic treatment for advanced cancer presenting with acute conditions?

1.5.3 Study Aim

The aim of this study is to describe the experience of a group of ED nurses caring for advanced cancer patients on chemotherapy, when they present with acute health problems, in the context of the ED. As the researcher and interviewer, specialist oncology knowledge and skills cannot be suspended for the duration of the project, but instead every attempt has been made to make that influence and position transparent.

1.5.4 Objectives

- To explore the factors that influence nursing interventions for patients on chemotherapy treatment for advanced cancer presenting with acute conditions in the ED.
- To explore the factors that influence clinical team decision-making for patients on chemotherapy treatment for advanced cancer presenting with acute conditions in the ED.

1.5.5 Significance of the Research

Understanding how people with advanced cancer on chemotherapy are managed in the ED is of importance to people with cancer, to ED nurses and to oncology nurses. Firstly, palliative chemotherapy decision-making is frequently a delicate balance of risks versus benefits. Adverse events due to treatment need to be promptly and appropriately managed to optimise quality of life. Undermanaged side effects will erode the benefits of treatment and have a negative impact on quality of life and/or survival. Secondly, ED nurses are in the position of providing care to this population under conditions of urgency and ambiguity and will be in a position to influence the clinical decision-making if they have the tools to do so.
Understanding how they currently plan interventions for this population is a beginning step in understanding exactly what tools are currently used and what are required. Thirdly, from an oncology nurse perspective it is very relevant to the provision of effective treatment, reduction in morbidity and coordinated cancer care as outlined in the Ministry of Health’s Cancer Control Strategy (Minister of Health, 2003). Of particular relevance here is goal three which is “to ensure effective diagnosis and treatment to reduce cancer morbidity and mortality” (p.21); and goal five which is to improve service delivery across the whole cancer continuum through “effective planning, co-ordination and integration...” (p.21).

Care co-ordination is defined as “a comprehensive approach that seeks to achieve continuity of care and support, drawing on a variety of strategies that strive for the delivery of responsive, timely and seamless care across a person’s cancer service pathway” (Ministry of Health, 2010, p. 48). Cancer nurses who undertake such co-ordination roles must not limit themselves to the pathways and processes within and between specialist cancer services, but must acknowledge the role of primary health and acute services that people with cancer may be accessing. In New Zealand the Health and Disability Commissioner Code of Patient Rights, Right 4, specifically legislates for services of an appropriate standard, “provided with reasonable care and skill”, consistent with the consumer’s needs and in a manner that “minimises the potential harm to, and optimises the quality of life of, that consumer” (Health and Disability Commissioner, 2009). Under this code healthcare workers have a duty to uphold these patient rights. Therefore advanced practice oncology nurses have a duty to invest their specialist knowledge and experience in the care provided to these patients throughout the pathway, including the ED and other acute-care settings.

1.5.6 Limitations

This was a small study and is intended to provide an insight from the point of view of the ED nurses working in the spoke away from the six regional cancer treatment hubs in New Zealand. Four satellite DHBs of a single regional hub which services a wide geographical area were chosen to provide a range of sites situated at some geographical distance from the
hub. Due to the project time frames and locality approval delays it was limited to three DHBs out of the four. As such, the findings are expected to reflect the experiences of the ED nurses in those geographical areas but may be generalizable to all ED nurses at the spoke. The experience of the nurses working in the ED at the hub may be distinctly different given their ready access to specialist oncology advice and resources.

1.5.7 Exclusions

ED nurses from the researcher’s home DHB were excluded from the study, as were ED nurses from other than the DHBs noted.

1.6 Research Method

A qualitative methodology was used, using an exploratory, descriptive design. Exploratory descriptive research is philosophically aligned to the field of naturalistic enquiry, three key tenets of which provided the philosophical foundation for this study. These three principles are that the reality of the ED nurses’ experience will be complex, subjective and context-driven; that the inquirer will influence and interact with that which they are inquiring about; and that no a priori theory will suffice to explain that reality (Thorne, Kirkham & O'Flynn-McGee, 2008).

1.6.1 Research Design

1.6.1.a Population and Sampling

A purposive self-selecting sample of ED nurses working in four ED’s within DHBs from the spoke were invited to participate via email through the College of ED Nurses electronic database; through recruitment by the Oncology Nurses in those DHBs; and through engagement of the ED nurse managers in those localities. Once email or phone contact was made with the researcher a participant information sheet and consent (Appendices V,VI) were posted out with a reply-paid envelope, and the emailed consent was signed and returned to the researcher. On return to the researcher an appropriate time and place for the telephone interview was scheduled. The aim was to recruit between six and eight ED nurses from the four localities. However due to slow uptake by ED nurses in most areas and a lengthy
locality ethics approval process in one DHB, only five nurses were recruited from three DHBs.

1.6.1.b Data Collection

Data was collected directly via phone interviews using semi-structured open questions to guide the interview process. Phone interviews are considered an appropriate method of qualitative data collection if the focus is clearly defined and participants are purposively selected because of knowledge and experience (Smith, 2005). Phone interviews are considered as likely to generate rich qualitative data as face to face interviews (Musselwhite, Cuff, McGregor, & King, 2007; Novick, 2008; Smith, 2005; Sturges, 2004) when carefully conducted, and have some advantages in overcoming geographical distance, cost and time resources (Musselwhite, et al., 2007). An interview schedule was devised to guide the discussion using the following open questions:

- How would you know a patient presenting with an acute condition is receiving chemotherapeutic treatment for advanced cancer?
- How does the ED team determine the level of intervention that is appropriate for the patient who is receiving chemotherapeutic treatment for advanced cancer?
- How are the clinical decisions of the ED team on treating the acute conditions influenced by the patients’ cancer and chemotherapy treatment?
- How is your intervention influenced by the patients’ cancer and chemotherapy treatment?
- In your opinion how often do you see patients receiving chemotherapeutic treatment for advanced cancer?

Closed questions were used to establish basic demographic and professional information such as gender, years of nursing experience and years of ED experience. This was to provide a brief description of the sample to assist transferability of the data.
1.6.1.c Data Analysis

The data analysis has been a free form analysis of the raw data from which emerged the themes and concepts that described the phenomenon, as is appropriate for an exploratory descriptive study (Schneider, Whitehead, & Elliott, 2007). In keeping with the aim of this study this has not proceeded beyond an exploratory, descriptive analysis of the data.

1.6.2 Ethics

Ethical approval was given by the Eastern Institute of Technology (EIT) Research Ethics and Approvals Committee (REAC), Reference Number 29/12 (Appendix IV). Locality approval has been granted by the individual DHBs (Appendices VII, VIII, IX, X). Cultural oversight and support has also been given in writing from the researcher’s home DHB Kaiwhakahaere Hauora Māori. (Appendix III). Early in the project engagement was sought via the College of ED Nurses regarding the purpose and methods of the study. This was an endeavour to assure those members of the validity and justification for the research in which they would participate. This engagement is reflected in the consent of the collective provided by the elected representatives on the College of Emergency Nurses – NZNO (Appendix II), and their on-going support of the project.

Participants were recruited without coercion and written informed consent was obtained (Appendices V, VI). Privacy and anonymity has been upheld by de-identification of the DHBs, the participants, and the data at the point of transcription. Data has been securely handled and stored with only the researcher, supervisor, and associate supervisor having access to the raw data. Anonymity has been further enhanced by carefully anonymizing and numbering of direct quotes used to illustrate the findings in Chapter Four.

1.6.3 Outline of the Study

This was a qualitative descriptive study using semi-structured telephone interviews with a purposive representative sample of ED nurses reflecting the ‘spoke’. Data has undergone free form analysis for themes and these themes were then described and explored. Chapter One has provided the background for this research study. Chapter Two is a description and
discussion of the relevant literature related to the study topic. Chapter Three provides a thorough discussion of the research methodology used throughout the study. Chapter Four reports the findings of the study. Finally, Chapter Five provides a discussion and interpretation of results with respect to the study question, discusses study limitations and makes recommendations for further research.

1.6.4 Literature Control

In keeping with a qualitative study design, which is a contextual and dynamic process, literature searches have been undertaken in response to the findings of the study. This literature has been incorporated into the discussion in Chapter 4 to illustrate and substantiate the research findings, and to highlight deviations between the findings of this and other research studies. This process is expected to enhance the study findings.

1.7 Summary

This chapter has explored some of the factors influencing care provision to people with advanced cancer on chemotherapy, and described the recommendations and models of care that have arisen in response to these challenges. In particular it has introduced the New Zealand response and the proposed model of care, and expressed a concern about the unknown impact of this model of care, especially on the communities domiciled away from the major metropolitan centres. This background research has validated the researcher’s personal experiences and identified actual and potential challenges with regard to the care of this population group in the ED. It has also identified and discussed the role of specialist cancer nurses in relation to the problem. A research question has been formulated and research objectives and methodology offered. It is hoped that an understanding of the nature of the phenomenon will inform further research and represent an opening gambit in an on-going dialogue between Oncology and ED nurses that will be mutually supportive and lead to improved patient outcomes. Literature reviews in the context of this study will be discussed in Chapter Two.
CHAPTER 2
Review of the Literature

2.1 Introduction

Chapter One has provided the background context and rationale for this study and the proposed research design. It contains the trends in current and future cancer care that have reinforced personal experience and concerns about the impact on the care and outcomes of patients with advanced cancer on chemotherapy. In this chapter the literature relating to the context of the study is discussed and analysed. In keeping with the qualitative research design, this has been a wider view of the issues surrounding this topic, rather than an exhaustive and detailed commentary.

2.2 Strategies for Literature Review

A literature search was undertaken in the CINAHL, PUBMED, PSYCHINFO databases using the key words: “chemotherapy”, “cancer”, “nurs* attitude” “physician attitude”, “integrat* oncology palliative care” “acute-care” “cancer patients”, “emergency service”, palliative, “supportive care”. Results were filtered by date, (2000 to present) and English language. Abstracts were assessed for relevance of the paper to acute care situations. Relevant papers were retrieved and reference lists checked for the more recently published papers, and “cited by” links pursued for the more dated papers.

As previously noted it is difficult to separate the subject of chemotherapy for advanced cancer from concepts of palliative care. This became apparent during the literature search which was undertaken initially using narrow search key words such as ‘emergency care’ and ‘advanced cancer’ and ‘chemotherapy’ that reflected the research question literally. It became apparent that the more clearly defined and definable ends of the cancer trajectory – the diagnosis, treatment ‘active oncology’ end of the continuum, and the ‘end-of-life’ end of the continuum have, in and of themselves been the subject of much enquiry. This initial search strategy returned little and had to be broadened to include the concepts palliative
care and models of oncology care and the relationship between the two. Perhaps it should not be surprising that the published research reflects the traditional dichotomy between these distinct specialties, as harder to find was literature specifically related to the increasing area of overlap between the two.

The first sections of this literature review address the topic within the context of the Treaty of Waitangi. The findings of a large study in the United Kingdom (UK) (National Confidential Enquiry into Patient Outcome and Death (NCEPOD), 2008) are felt to be highly relevant to the situation in this country given the similarities in models of medical oncology service delivery, therefore are discussed in some detail. Further sections describe the international literature and policy development in relation to the integrated models of oncology/palliative care and the factors influencing this relationship, followed by discussion and analysis of the primary research in relation to acute and emergency care provision to people with cancer. Finally, literature relating to the interface between Palliative Care and the ED is discussed.

2.3 Treaty of Waitangi

Māori as tangata whenua hold special status in New Zealand. Māori also have the poorest health status of any ethnic group in this country (MOH, 2002). The negative impact of colonisation on Māori has been recognised via the Treaty of Waitangi which underpins the Crowns relationship with Māori. A commitment to reducing the inequalities and improving health outcomes for Māori are evident in the Treaty principals of partnership, participation and protection espoused in He Korowai Oranga (the cloak of wellness) Māori Health Strategy (MOH, 2002). For this reason the impact of cancer on Māori requires specific discussion and will be covered in this section.

Māori have a higher incidence of cancer overall than non-Māori (MOH, 2011b), and a 29% higher mortality on average than non-Māori. (Soeberg, 2012). Although the difference in survival between Māori and non-Māori has not changed significantly from 1991 to 2004 there is a widening gap in survival between lower and higher socio-economic status (SES). (Soeberg,
The 2009 data continues to show a significantly higher number of cancer registrations and deaths in areas of greatest socioeconomic deprivation (MOH, 2012a). In 2005, as part of the implementation of the Cancer Control Strategy, the Ministry of Health commissioned a review of access to cancer services for Māori. This report reviewed the disparities in cancer incidence, staging at diagnosis and survival. While stage at diagnosis does account for some of the disparity of outcomes, the conclusion is that there are likely to be disparities in “timely access to definitive diagnostic procedures, staging procedures, and optimal treatment or management of cancer” (Cormack, Purdie, Ratima, & Brown, 2005, p. ii) and the “entire treatment pathway requires serious attention” (Cormack, et al., 2005, p. 30).

Patient and provider factors may both influence access and outcomes. Patient factors noted by Cormack et al. (2005) included SES, level of deprivation and transport. A number of factors related to the actual health care system and processes were also seen to impact on access for Māori. These included how the service was configured and located and how services worked with other services. Health care provider factors impacting on access included the providers’ level of expertise, perceptions and biases. Cormack et al. (2005) suggest health professionals’ perception of Māori treatment preferences and non-compliance potentially influences care and treatment decisions. The complexity of the cancer pathway and the multiple providers involved was noted and timely communication and coordination between these multiple providers was identified as an issue (Cormack, et al., 2005). In the graphs below, Figure 2.1 shows the five most deprived deciles by domicile code concentrated at the spoke. Figure 2.2 shows the greatest population density of Māori also concentrated within the spoke with the exception of Waikato. (MOH, 2011a). Māori will make up a higher proportion of those with advanced cancer on chemotherapy who will be receiving chemotherapy at the spoke and who may seek acute care from their local hospital ED.
Figure 2.1: Deprivation by Domicile Code, 2006-2008. (Ministry of Health, 2011a, p.3)
Figure 2.2: Percentage Māori by DHB region of Domicile, 2006-2008. (Ministry of Health, 2011a, p.4)
2.4 The UK Experience

The New Zealand hub and spoke model is similar to that of the UK which also has a hub and spoke approach to service delivery and similar trends towards chemotherapy administration as close as possible to the patient’s domicile. In the UK, prompted by concerns about the care of cancer patients on chemotherapy, the National Confidential Enquiry into Patient Outcomes and Deaths (NCEPOD) was commissioned and funded by the National Patient Safety Agency in the UK (National Confidential Enquiry into Patient Outcome and Death (NCEPOD), 2008). The NCEPOD findings have implications for provision of care to people with cancer in New Zealand, particularly those receiving chemotherapy, and therefore has been deemed worthy of discussion in this section in some detail.

Entitled ‘For Better, for Worse’, this enquiry focussed on the care of patients who died within 30 days of receiving systemic anti-cancer therapy (SACT) and was a detailed qualitative and quantitative analysis of: the cause of death (disease progression, treatment-related or other cause); initial clinical decision-making to treat; SACT prescribing and administration; subsequent clinical care; resources, clinical pathways and clinical governance. The researchers took pains to point out that the study was deliberately designed with a bias towards exploring the clinical decision-making that led to a fatal outcome, and did not represent the total population that was receiving SACT, and therefore did not reflect the benefits of such treatment (National Confidential Enquiry into Patient Outcomes and Deaths, 2008).

One of the specific objectives of the NCEPOD study was to examine the follow up care, toxicity and death of 659 patients who died within 30 days of receiving chemotherapy. The majority were receiving chemotherapy with palliative intent. Most patients sought help from their General Practitioner or the ED; were acutely unwell at presentation; and 85% required admission to hospital. A pattern of delayed presentation was noted, even when patients were experiencing severe toxicity, and there was evidence that patients did not always seek advice in the manner in which they had been advised. The authors questioned the appropriateness of these patients...
being managed by general physicians in general wards and suggested that emergency care was best delivered by cancer specialists within a specialist cancer centre (National Confidential Enquiry into Patient Outcomes and Deaths, 2008).

The recommendations from NCEPOD (2008) were welcomed by senior cancer nurses in the UK who saw communication as key to service improvement and called for the development of an acute oncology service that integrated the clinical expertise of oncology, emergency medicine and general medicine at both a governance and an operational level (Lennan, Roe, Young, & Crowe, 2010). On a governance level they advised the development of policies and procedures that “took account of the complexities of the referral pathway and facilities” (Lennan, et al., 2010, p. 39). On an operational level they advised the availability of 24 hour acute oncology services. They also called for resources for further education and training across all disciplines. Senior cancer nurses envisaged that this “should be welcomed as the foundation of future cancer services both in organisations and across professional boundaries” (Lennan, et al., 2010, p. 39). The tendency of cancer services to focus on the administration of chemotherapy rather that the entire chemotherapy pathway is noted in the UK National Chemotherapy Advisory Group’s recommendations (National Chemotherapy Advisory Group, 2009). This best practice guidance also saw the development of an acute oncology service as a key priority for service improvement and stated that (p. 3):

The provision of emergency care not only for cancer patients who develop complications following chemotherapy, but also for patients admitted suffering from the consequences of their cancer. It recommends that all hospitals with an Accident and Emergency (A&E) department establish an “acute oncology service” (AOS), bringing together relevant staff from A&E, general medicine, haematology and clinical/medical oncology, oncology nursing and oncology pharmacy.
While there are notable similarities between the models of service delivery, New Zealand differs from the UK in the relative isolation of many of the spoke treatment centres which makes admission to a specialist cancer service for management of acute complications impossible. In a small centre such as the spoke described in the hub and spoke model, specialised knowledge around active cancer treatments is the domain of a few key staff and patient numbers are relatively small. Infrequency does not mean that adverse treatment-related events are not significant. Acute care is provided by the ED and admission will be to generalist wards by health professionals without 24 hour access to the specialist team who knows the patient well. Therefore, when the NCEPOD authors state that “it is vitally important that mechanisms are put into place in every hospital so that clinicians admitting patients with complications of SACT have access to sufficient patient details that appropriate decisions can be made” (National Confidential Enquiry into Patient Outcome and Death (NCEPOD), 2008, p. 105) this may be even more important in New Zealand given our geography.

2.5 Integrated Oncology/Palliative Care

The guidelines advocating an integrated model of oncology and palliative care published by several countries are informed by an international body of research, mostly undertaken over the last 10 to 12 years. Much of this research has been conducted in the context of large cancer treatment services with integrated palliative care units and the ability to provide 24 hour and acute/emergency services. Many of these studies were felt to not reflect the reality of generalist nurses in acute settings managing these patients as is the case in New Zealand and are therefore not presented here. The literature that is presented in this section describes the challenges in defining palliative care, prognostication and the changing relationship between services. In particular it describes the perceptions and confusion that underlie the interface between these two philosophies of care and how this may impact on acute and emergency care provision.

Lack of a formal definition for the term palliative care is noted in the literature (Hui et al, 2012). Palliative care is a recognised medical specialty with multidisciplinary expertise in symptom management and relief of
suffering (Meier & Bishop, 2012). In 2002 the World Health Organisation (WHO) defined palliative care as:

an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention of and relief of suffering by means of early identification and impeccable assessment, and treatment of pain and other problems – physical, psychosocial and spiritual (WHO, 2002, p. 84).

This recognises the need for expert supportive care and symptom management early in the disease process and is significantly different to the WHO definition of a decade earlier which placed the emphasis on end-of-life care. The term palliative care is also in use as an adjective and a philosophy of support and symptom management that may permeate all aspects of health care so is not just the domain of a Palliative Care Service or Team.

Perceptions about the role of these services, however they are named and defined, exist even within specialist cancer services. Many equate the term palliative care with terminal care and hold the perception that this is for patients without any active treatment options (Fadul et al, 2009). Similarly, oncology nurses may perceive that palliative care relates to end-of-life care rather than throughout the disease continuum (Pavlish & Ceronsky, 2009). If these preconceptions exist within specialist oncology practice, it is reasonable to assume that they will be even more prevalent among non-specialists in acute care settings.

The reason for this lack of definition and bias towards end-of-life is that historically oncology care and palliative care have been seen as two distinct entities (Meier & Bishop, 2012). The first, focussed on prevention, early detection and active treatment to modify the malignant disease process, the second focussed on symptomatic and supportive end-of-life care. Over the last decade and a half that traditional dichotomy between active and palliative treatment for cancer has been replaced by an integrated model of oncology and palliative care (Abernethy & Currow, 2011; Ferris et al, 2009; Whedon, 2002).
Figure 2.3 below depicts the traditional dichotomous model of care alongside the new recommended ideal of integrated care. This figure shows the previous model of disease progression with a clear cut transition to palliative care at the end of life prolonging care alongside the new integrated model of shared care throughout a prolonged period of disease progression modified by therapy, with increasing involvement of Palliative Care Services in response to increasing need and the decreasing involvement of active treatment services towards the end of life.

Figure 2.3: Models of Healthcare Delivery. (Meier & Bishop, 2012).

Internationally, integrated oncology/palliative care is becoming the accepted model of care. In the United States (US) there are a number of high level initiatives including policy and guideline development (National Comprehensive Cancer Network, 2012); clinical integration of oncology and palliative care services; education programs for health professionals, with the ultimate vision of full integration and provision of comprehensive cancer care from the point of diagnosis by 2020 (Ferris, et al., 2009). Similar efforts exist in Europe (Cherny, Catane, Schrijvers, Kloke, & Strasser, 2009)
and the United Kingdom (UK). The National Institute for Clinical Excellence (National Institute for Clinical Excellence (NICE), 2004) takes the position that palliative care should be instituted early in the disease process alongside life-prolonging treatments.

Integration of comprehensive cancer care is supported by evidence to suggest that early referral to palliative care improves both quality of life and survival outcomes, at least for metastatic gastro-intestinal cancer (Ahmed, Ahmedzai, Vora, Harrison, & Paz, 2004), and non-small cell lung cancer (Temel, et al. 2010). The ideal is that palliative care services be involved from the point of diagnosis with an advanced cancer, with increasing involvement in response to changing needs as the disease progresses (WHO, 2007). In New Zealand, recommendations suggest that referral to supportive services is appropriate alongside cancer treatment with palliative or life-extending intent (Ministry of Health, 2007), although in the recently updated Guidance for Improving Supportive Care in Adults with Cancer (Ministry of Health, 2010) the role of Palliative Care is not made explicit.

The shifting relationship between medical oncology and palliative care reflects the changing role of chemotherapy (Baszanger, 2012). Sixty years ago chemotherapy was given solely as a palliative treatment for advanced and incurable malignancy. As therapies were developed, researched and refined, some conditions became curable and active oncology began to distance itself from palliative care, which became the domain of the Hospice movement. That relationship is once again undergoing a shift towards integration driven by drug innovations in anti-cancer therapy. The majority of these innovations are used towards the death end of the disease continuum (Baszanger, 2012), and some cancers in effect become chronic conditions by virtue of the sequential use of effective treatments. Reflecting this is the fact that of the eight anti-cancer drugs approved for funding in New Zealand in the 2010/11 year, five are given with non-curative intent. Two of the other three are already in use for advanced cancer but have been approved for use at an earlier stage (Pharmaceutical Management Agency, 2011). While the integrated model depicted in Figure 2.3 above may seem straightforward, the reality of the disease continuum and the transition from curative to palliative is, in practice, “a fuzzy and constantly
shifting boundary that chemotherapy and palliation would patrol together, that always moved closer to death” (Baszanger, 2012, p. 869).

2.6 The Changing Disease Trajectory

Advances in medical oncology have improved survival of some advanced cancers (McCall, 2007; Von Roenn & Temel, 2011), and the use of new cytotoxic regimens and targeted therapies is increasing. Life expectancy can impact on the treatments offered and referral to palliative care. The typical cancer trajectory has been described as “a reasonably predictable decline ... over a period of weeks, months, or, in some cases, years” (Murray, 2005, p. 1007). Understanding the disease trajectory assists clinicians to predict, plan and negotiate goals of care with patients. But predicting survival in patients with advanced cancer can be challenging and clinicians frequently get this wrong, showing a tendency to overestimate survival (Glare et al, 2008). Therefore, previous descriptions of the cancer trajectory may not reflect the new reality of some cancers, as increased treatment options prolong survival. Models to predict prognosis have been tested on advanced cancer patients in the last few months of life (Maltoni et al, 2005; Stone & Lund, 2007) and on those no longer receiving disease-modifying treatment (Gwilliam et al, 2011). However, a complex array of variables, including the significant impact of anticancer treatment, determine survival for those recently diagnosed with advanced cancer (Hauser, Stockler, & Tattersall, 2006), and the disease trajectory may be punctuated by acute, reversible disease-related or treatment-related events.

2.7 Acute and Emergency Care for People with Cancer

The literature reviewed in this section addresses acute and emergency care of the cancer patient in general and includes some with a focus on end-of-life care in the acute care setting. The primary quantitative research found to be most relevant was overseas research describing patterns of ED presentation of people with cancer. This included one systematic review, five descriptive studies and small studies related to pathway and process implementation in the ED. The primary qualitative studies related to acute care nurses perceptions and attitudes to cancer patients generally, attitudes
to palliative chemotherapy and nurses’ experience of end-of-life care in the acute care setting.

The complexity of cancer care and specialised skills and knowledge required for appropriate care creates significant clinical risk to the cancer patient on chemotherapy presenting to the ED (Considine, Livingston, Bucknall, & Botti, 2009). Up to 50% of patients receiving outpatient chemotherapy may have an ED presentation (Craike, Livingston, & Considine, 2010). These presentations are sometimes delayed with patients having been symptomatic for several hours (Nirenberg, Mulhearn, Lin, & Larson, 2004). Compared to the general population these patients have higher clinical complexity, higher admission rates and higher morbidity and mortality at that admission (Considine, et al., 2009; Yates & Barrett, 2009). Uncertainty, lack of information, fragmentation of care and delays in diagnosing febrile neutropenia and commencing antibiotics all contribute to this risk (Considine, et al., 2009). Clinical pathways can improve the time from presentation with febrile neutropenia (Nirenberg, et al., 2004; Salter, 2005), although those with extensive cancer and or comorbidities tend to wait longer (Nirenberg, et al., 2004).

Acute and emergency presentations are not always due to treatment side effects and can be due to disease progression or other medical conditions. Patient experience of care may be enhanced when continuity is maintained and admission is to the specialist oncology unit or review by their oncology specialist occurs (Yates & Barrett, 2009). These authors also comment that if care is given by other than oncologists “residual prejudices about the lack of value of active management for these patients must be overcome” (Yates & Barrett, 2009, p. 232). Nurse-led initiatives such as the recurring admission patient alert (RAPA) have been trialled to improve the clinical pathway and outcomes of the cancer patient presenting acutely to the ED (Stowe, 2011). This has shown cost savings and a decrease in patient length of stay but also had the unexpected consequence of enhancing care pathways through the collaborative relationships that were initiated by the presence of the oncology nurses in the ED (Stowe, 2011).

The experience of acute care staff managing patients with cancer has been explored in terms of the entire cancer trajectory and specifically around
end-of-life care in the acute in-patient setting. The emotional nature of the care, lack of specific knowledge, expertise, and time impact on the care provided and it is suggested that the acute care, non-specialist environment is not conducive to providing for the complex needs of the cancer patient (Gill & Duffy, 2010; Mohan, Wilkes, Ogunsiji, & Walker, 2005; Sheward, Clark, Marshall, & Allan, 2011). Personal, professional and cultural beliefs and values impact on team dynamics and transition of care and cause nurses stress (Sheward, et al., 2011). Ambivalence towards palliative chemotherapy may be linked to personal experience (Andrew & Whyte, 2004). Negative perceptions of cancer and misconceptions about cancer treatment may be detrimental to the patient (Gill & Duffy, 2010).

2.8 Palliative Care and the Emergency Department

The changing interface between Palliative Care and Emergency Care has also been recognised. In the United States there are moves to integrate the palliative care philosophy into emergency departments and to promote clinical engagement between these two distinct specialties (Lukin, Douglas, & O’Connor, 2012). The apparent cultural differences between the priority-driven, resuscitation, intervention focus of the ED and a palliative philosophy of care have been explored (Bailey, Murphy, & Porock, 2011), as has the role of the ED as a gateway to hospital services and as a critical point for resetting the patient’s disease trajectory (Grudzen, Stone & Morrison, 2011). Research by Grudzen et al. (2012) into the perspectives of ED physicians regarding palliative care in the ED identified a number of barriers to this care including lack of knowledge and training, complexity of the decision-making especially under urgency and without knowledge of the goal of care. That ED physicians have to address goals of care during acute events was not seen by some in the ED as their responsibility and reflected a failure of the primary care physician or oncologist to undertake such discussions. Others in the ED saw it as an opportunity to activate palliative care and appreciated the availability of specialist palliative care teams in the ED to support that process. Other factors impacting in the ED were the inability to access medical records, advance directives and the non-availability of the primary health care providers who could communicate
essential information about the patient’s disease trajectory and goals of care (Grudzen, et al., 2011; Smith et al, 2009).

2.9 Summary

The literature discussed highlights the confusion and perceptions around palliative care and the ambiguity inherent in the relationship between oncology and palliative care. In spite of deliberate policy attempts to integrate the two, and the proven benefits of such integration, in reality it can be an uncomfortable and ambiguous interface. Not surprisingly perhaps, integrating palliative care into the emergency care setting is also fraught. Again ambiguity and lack of communication about the patient’s disease trajectory and goal of care are seen to impact. This increased uncertainty is likely to add to the clinical dilemma presented to health care professionals managing acute and emergency events in patients on chemotherapy for advanced cancer. Critical decisions about the level of intervention or lack of intervention may have to be made under urgency in a situation of clinical ambiguity.

In relation to the acute care of cancer patients on chemotherapy the literature discussed and in this chapter speaks of a complex, high clinical risk population requiring specialised knowledge. In the acute setting, patients with advanced cancer on chemotherapy present without the context of their individual goals of care and within a disease trajectory of uncertainty and ambiguity. The commonalities within the literature reviewed were the acknowledged complexity of the cancer patient; the experience and specialised knowledge needed to provide appropriate care to this patient population; and the uncertainty and lack of a clear plan of care or relevant patient-specific information that would enable the provision of appropriate and safe care. For nurses in acute care this was a source of professional distress and dissatisfaction. For the patient there were noted clinical risks, including higher mortality, as well as sub-optimal symptom management and lack of continuity of care. Communication was noted by all authors as a key need.

Clinical decision-making for this group in the ED may be influenced by health care professionals’ perceptions about the role of palliative
Chemotherapy and involvement of the Palliative Care Service may add to the confusion regarding the goal of care. Given the increasing use and complexity of chemotherapy in advanced cancer and the prolonged disease trajectory the incidence of these acute presentations is likely to increase. Over treatment or under treatment is a real risk and can have devastating impacts on individual’s quality of life, outcomes and experience of health care. This literature highlights the need for a better understanding of the care of this patient group in the ED, and supports the intention of this thesis to gain an understanding of how clinical decision-making and nursing care is undertaken for this population group, especially in peripheral centres away from the regional cancer treatment hub.
CHAPTER 3
Research Methodology and Process

3.1 Introduction
The previous chapters have provided the background and a discussion of the literature in relation to this thesis which sought to explore the care of patients on chemotherapy for advanced cancer from the perspective of nurses in the ED. The aim of the study was to describe the subjective reality of these nurses in caring for this population. A voluntary, purposive sample of ED nurses underwent semi-structured telephone interviews. The interviews were transcribed and the raw data thematically analysed. This chapter provides an explanation and a justification of the sampling methods and processes of data collection and analysis. Ethical considerations and the processes of ethical consent are described. A clear and detailed description of research methodology allows for the research process to be audited and is a necessary component of the reliability and replicability of the findings. Particularly important for qualitative research are the concepts of researcher reflexivity and the researcher-participant relationship. These concepts are discussed in detail as they are critical to the value and rigor of this study.

3.2 Nature of the Study
This study was undertaken via a qualitative approach using an exploratory descriptive design. A qualitative approach broadly “focuses on the way people make sense of their experiences and the world in which they live”, by exploring people’s “behaviour, feelings and experience” (Holloway & Wheeler, 2010, p. 3). Exploratory, descriptive research has “evolved as one such articulation of a qualitative approach to clinical description with an interpretive or explanatory flavour” (Thorne, et al., 2008, p. 2). Exploratory descriptive research is philosophically aligned to the field of naturalistic enquiry, some key tenets of which have provided the philosophical foundation for this study. These were described originally by Lincoln and Guba in 1985 and cited by Thorne et al. (2008, p.3) as follows:
• “There are multiple constructed realities that can be studied only holistically. Thus, reality is complex, contextual, constructed, and ultimately subjective’.

• ‘The inquirer and the object of inquiry interact to influence one another; indeed, the knower and known are inseparable’.

• ‘No a priori (known by reason alone) theory could possibly encompass the multiple realities that are likely to be encountered; rather, theory must emerge or be grounded in the data’.” (i.e. a posteriori, dependant on evidence or experience).

Based on these tenets, this study aimed to describe the subjective reality of a group of ED nurses in caring for advanced cancer patients on chemotherapy experiencing acute health problems, in the context of the ED. Free form analysis of the raw data was undertaken, from which emerged the themes and concepts that described the phenomenon. Lack of an exact theoretical framework is considered appropriate when a description of the phenomenon is required and does allow for a free-form analysis of the data (Schneider, et al., 2007). As is appropriate for a qualitative study, research processes were dynamic, flexible and non-sequential (Frankel & Devers, 2000; Holloway & Wheeler, 2010). Data collection and analysis were undertaken simultaneously, findings were emergent and new literature searches were conducted as the data analysis proceeded. Relevant studies were woven into the findings to validate or highlight the insights found there.

3.3 Context of the Study

Qualitative research recognises that truth is subjective and context-driven. In keeping with this, the nature and context of this study, the primacy of the data, and the emic perspective are paramount. This study recognised that the phenomenon being explored would be influenced by the culture, training, values and experience of the ED nurses participating, and the environment in which they practiced. The researcher’s relative distance from and lack of familiarity with the ED environment need not be seen as a negative in this setting as the researcher may be more able to function as a naïve observer, free of the culture and conventions of the ED. A too
intimate knowledge of the participants’ world can lead to valuable cues and considerations being missed (Holloway & Wheeler, 2010). Although this researcher has had some prior emergency nursing experience, having worked for several years in the ED in the 1980’s, this topic has emerged from many years of current oncology-specific training and experience. This oncology-specific specialist knowledge was not able to be suspended for the duration of the study but every attempt has been made to remain sensitive to the context in which the ED nurses experience the phenomenon, and to make the researcher’s influence and position as transparent as possible. This has required a careful process of self-consciousness and reflexivity that will be further discussed in section 3.5.

3.4 Research Questions and Objectives

Defining the research question proved difficult and the question underwent several revisions. This may have been a reflection of the broadness of the topic and the ambiguity of the interface between active and palliative care described in Chapter 2. Due to the varying interpretations and biases evident in relation to the term ‘palliative’, this term was not used. The circumstance of a patient on chemotherapy for advanced cancer presenting with acute problems became the default scenario that captured that ambiguity and complexity. The ED was chosen as a setting in which these complexities may be keenly felt and as a pivotal point in clinical decision-making for this population group. The ED nurses’ experience was sought, and from their perspective the team’s clinical responses explored. The research question therefore was refined to “How do ED nurses manage nursing interventions for patients on chemotherapeutic treatment for advanced cancer presenting with acute conditions?” The objectives were: to explore the factors that influence nursing interventions for patients on chemotherapy treatment for advanced cancer presenting with acute events; and to explore the factors that influence team clinical decision-making in the ED for patients on chemotherapy treatment for advanced cancer presenting with acute events.
3.5 Role of Researcher and Others

Qualitative research is a subjective process especially in comparison to quantitative research where the methodology is designed specifically to limit the researchers influence, thereby providing greater objectivity (Sandelowski, 2011). In a qualitative study such as this, the researcher exerts influence at every step of the process, from formulating the question and proposing the methodology, to the collection, analysis and interpretation of the data (Caslin & Scott, 2003). In effect the researcher is the research tool, therefore the engagement between the researcher and subjects is highly significant and valued in qualitative research as a means of uncovering the truth (Ryan-Nicholls & Will, 2009). ‘Truth’ in a qualitative descriptive study such as this is the outcome of that relationship and may be more correctly described as “an intentional shaping of recalled reality toward a particular purpose” (Thorne, et al., 2011, p. 447).

The researcher’s influence on the study needs to be understood by the researcher and managed in order to maintain the integrity of the findings (Thorne, et al., 2011). Researcher reflexivity is the means by which the researcher appreciates their own influence, therefore reflexivity becomes essential to the rigour and trustworthiness of the study (Bulpitt & Martin, 2010). Used effectively, reflexivity can expose the perspectives, the presence and the biases of the researcher and is a way of accounting for the researcher’s position in relation to the study, throughout the data collection, interpretation and analysis (Finlay, 2002a). For the researcher this requires a level of ‘introspection’ - a self-conscious awareness of their values, experience, knowledge and the position from which they view the topic, and an awareness of the relationship between themselves and the participants (Finlay, 2002b). Used appropriately reflexivity promotes insight, and supports the study’s integrity by enabling the reader to make their own judgments about the validity and applicability of the findings (Finlay, 2002b).

This research question has been derived from specialist knowledge and experience in cancer nursing that has led to a growing professional concern about the acute care of this group of patients. From a broad observation of a phenomenon it has been refined through analysis of the literature,
through discussion with colleagues, consideration of methodologies, gut feelings, intuition and grappling with what should be done as opposed to what could be done within the limits of this project. In the authorial declaration in Chapter One, initial biases and attitudes of the researcher were disclosed. Formulating a neutral research question took some effort between researcher and supervisor. In grappling with the seemingly simple task of formulating the question this novice researcher came to understand that early bias. Over this time, with much reflection it has become an exercise in climbing the fence and asking of a colleague “how are you managing this?”

Exploratory, descriptive methodology also does not absolve the researcher from the obligation to provide an analysis and interpretation of the data (Sandelowski, 2010). Qualitative research is a subjective, relativist process and a neutral interpretation of the data may not give credit to the researcher, to the participants, or to the findings. This project is the work of a novice researcher with specialised oncology knowledge and experience. The challenge has been to make the researcher’s position thoroughly transparent throughout the process. This has been achieved through a deliberate self-consciousness, but not to the point of a self-centredness that would have detracted from the research question itself and the experience of the ED nurses that was the aim of the study.

Ultimately the findings are a collaborative consequence of the relationship between researcher and participants. From the point of view of these participants there may have been some suspicion of the researcher’s motives and a sense of having their practice scrutinised and critiqued by an ‘outsider’. This dynamic has been further discussed in relation to the ethics underlying the study in section 3.12. Alternatively information may have been given that set the participant in the best light or was what the participant thought the researcher wanted to hear. In the practice interviews with local ED staff there was an impression that, at least initially, information was provided that flattered the researcher and may have reflected the long collegial relationship that existed. Over the course of the practice interview this dynamic changed and overall the data collected was felt to be relevant and rich. It was also felt by interviewing participants at a
distant DHB, unknown to the researcher and with the anonymity afforded by telephone interview, that these effects would be mitigated.

The thesis supervisor has played an essential role throughout the process, from assistance in formulating the question and the methodology, to data collection and analysis through investigator triangulation and peer debriefing. This has provided an alternative perspective to the data and acted as an external check and challenge to the researcher’s processes and interpretations. Peer debriefing and investigator triangulation are a means of improving credibility of the research findings (Polit, Beck, & Hungler, 2001).

3.6 Sampling

A purposive sample of 6-10 ED nurses working in four DHBs from the spoke was sought. These sites represent the satellite DHBs of one Regional Cancer Treatment Service (RCTS) hub. This hub serves a widespread geographical area and provides specialist clinics and distant oversight and support of chemotherapy administration. The more distant satellite DHBs provide on-site outpatient chemotherapy administration. These particular DHBs were chosen on the presumption that they would be representative of the satellite or spoke services described in the hub and spoke model (Cranleigh Health, 2011). Purposive sampling from a number of different sites is likely to enhance the representativeness of the study overall (Polit & Beck, 2010). All after-hours acute care for patients on chemotherapy is managed by primary health practitioners or the ED. To facilitate after-hours care, all patients on cytotoxic chemotherapy in these DHBs would have been provided with a ‘chemotherapy alert card’ and instructions to access their local ED for acute and emergency care.

A purposive sample is necessary to provide the researcher with the in-depth data required to explore the phenomenon and the number of participants required for a qualitative study may vary from 8 to 15 (Schneider, et al., 2007). Recruitment of the target population was via the College of ED Nurses electronic database which has approximately 400 signed up members nationally. One concern and a potential limitation of the study was the representativeness of the sub-set of ED nurses who were enrolled in the
College of ED Nurses and how their characteristics may differ from ED nurses who were not members. Therefore a second method of recruitment was facilitated by the Oncology Nurses from each region. These nurses were asked to visit their local ED to provide an invitation to participate. Thirdly, a total of 3 information packs containing participant information sheet and consent was posted out with a reply-paid envelope to the ED nurse manager at each of the DHBs. Once returned to the researcher, contact was made with the participant to schedule an appropriate time and place for the telephone interview.

The invitations were followed up by the researcher with phone contact with the Nurse Managers at these departments so that any questions or concerns about the researcher’s intentions could be clarified. Care was taken not to provide too much information about the background to the study and therefore influence the sample itself, or jeopardize the findings. As an exploratory study it could not be assumed that the nurses in the ED did perceive the patient group in question as problematic. This contact was an important first step as recruitment proved difficult and it was the identification and efforts of a key person within the ED who took a personal interest in the research question that became the means by which participants were eventually recruited and signed up.

The locality ethics approval process for one of the DHBs took over three months and approval was not received until the end of November which left little time for recruitment in the time allowed, so a decision was made to forgo participation from that DHB. The final analysis is based on the audiotaped interviews of five nurses from three of the DHBs. These nurses were all female with total years of nursing experience and years of ED experience shown in Table 3.1 below. The five participants have been randomly assigned the letters P Q R S T. In order to preserve anonymity, all future reference to individual participants in this document will be through the randomly assigned letter.
Table 3-1: Participants’ nursing experience

<table>
<thead>
<tr>
<th></th>
<th>Total nursing experience</th>
<th>ED nursing experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>12</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>3</td>
<td>40</td>
<td>35</td>
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<tr>
<td>4</td>
<td>20</td>
<td>11</td>
</tr>
<tr>
<td>5</td>
<td>32</td>
<td>23</td>
</tr>
</tbody>
</table>

3.7 Data Collection

Data is that which is deemed retrievable by the researcher, upon which the findings of the study will be based (Sandelowski, 2011). In this case the data deemed collectible were the experiences of the ED nurses, created as a product of the interview and the field notes of the interviewer. Therefore, even the raw data was a construct of that relationship and had already undergone some transformation and influence by the researcher. Data was collected over three months from late September to late December 2012 directly via recorded phone interviews using semi-structured open questions to guide the interview process. Phone interviews are considered an appropriate method of qualitative data collection if the focus is clearly defined and participants are purposively selected because of knowledge and experience (Smith, 2005). Phone interviews are considered as likely to generate rich qualitative data as face to face interviews (Musselwhite, et al., 2007; Novick, 2008; Smith, 2005; Sturges, 2004) when carefully conducted.

The advantages of telephone interviewing are its ability to overcome geographical distance in participant selection, an issue for this particular study, and effective use of resources in terms of cost and researcher time (Musselwhite, et al., 2007; Novick, 2008; Smith, 2005). The increased anonymity of phone interviewing may provide for more open responses (Sturges, 2004). The disadvantages are seen to be the absence of visual cues and how a lack of non-verbal and contextual information may affect the data collected (Novick, 2008), although there is scant evidence that this
distorts the data or compromises the quality of the findings (Novick, 2008). Musselwhite et al. (2007) recommend effective communication and processes such as interview practice, preparation, privacy and scheduling for the convenience of the participant to promote valuable data collection.

The questions developed for the telephone interview schedule were tested to ensure they were appropriate and generating rich descriptive data related to the research question and to provide necessary practice for the interviewer (Schneider, et al., 2007). Nursing experience itself does not necessarily equip one with the necessary skills to conduct research interviews (Skene, 2007). In preparation the researcher conducted and recorded practice phone interviews on ED nurses within her home District Health Board (DHB) and submitted the audio to the supervisor for critiquing of the researcher’s interview technique. This may compensate partly but not entirely for the researcher’s lack of experience and training in conducting interviews, which would be preferred given the complexity and importance of interview technique in gathering high quality narrative data (Schneider, et al., 2007). Reflecting on her early research attempts, Skene (2007) also noted the value of writing up field notes as soon as possible after the interviews as an essential step in the process to support the rigour and applicability of the findings.

The telephone interviews were conducted within the researcher’s work environment on a teleconferencing phone. The use of a speakerphone can create a more professional atmosphere (Smith, 2005) and left the researcher hands-free to take notes as the interview progressed, but required a private space. An Olympus Digital Voice Recorder with an in-line recording connection provided excellent audio quality for transcription. The participants were at a place of their choice by prior arrangement. The interview started with an introduction, a reminder of the research topic, and a reiteration of the recording of the conversation, privacy and confidentiality undertakings. All interviews took between 30 to 40 minutes. The telephone interviews were supplemented by field notes taken during and directly after the interviews. The audio was transcribed by the researcher within a few days of the interview which provided an opportunity to strengthen field
notes. At the point of transcription, participants’ names and practice locality were de-identified and the audio files were deleted.

The interview schedule underwent some minor adjustments after piloting and practice. The following five open questions were used to guide the discussion:

- How would you know a patient presenting with an acute condition is receiving chemotherapeutic treatment for advanced cancer?
- How does the ED team determine the level of intervention that is appropriate for the patient who is receiving chemotherapeutic treatment for advanced cancer?
- How are the ED team’s clinical decisions on treating the acute conditions influenced by the patients’ cancer and chemotherapy treatment?
- How is your nursing care planning influenced by the patients’ cancer and chemotherapy treatment?
- In your opinion how often do you see patients receiving chemotherapeutic treatment for advanced cancer?

The purpose of the interview is to enter the other person’s perspective on the assumption that their perspective is meaningful, knowable and explicable. The interviewing approach is on a continuum from a fully flexible, conversational “go with the flow” type interview through to a highly structured process with formally worded questions (Patton, 2002). The interviewer can maintain an easy conversation style within the pre-determined subjects. What is gained with an increasingly structured interview is a better use of time, a tighter focus and a structure that provides comparability across different sites. It provides a more exact instrument of evaluation that is available to those using the findings of the study and facilitates analysis of the data. What may be lost with increasing structure is the flexibility and the opportunity to uncover relevant experiences by not asking the right questions (Patton, 2002). In practice any interview is likely to be a blend of these methods.

In the middle of this continuum is the use of the Interview Guide with prepared subject areas within which the interviewer is free to probe and
explore. This was the approach used in this project. Patton (2002) suggests it is important to ask open questions, but in practice this was difficult. Truly open questions are: How do you feel about...? What is your opinion of .....? What do you think of...?. Patton (2002) suggests that if the initial question fails to elicit a thoughtful response the use of illustrative examples (and illustrative extremes) can prompt the interviewee. It is vital though that these examples remain neutral so as not to provoke a response bias. For example, asking what dilemmas arise in determining appropriate intervention to this group of patients in the ED communicates the researcher’s belief that there are dilemmas. For example, to provoke a thoughtful response about the ambiguity of the situation using the illustrative extremes format the prompt used by the researcher was “Some ED nurses I have talked to have described their concern about inappropriate over treatment of a patient with advanced cancer while others have expressed a concern about under treating someone who ought to have been treated more aggressively”.

Closed questions were used to establish participants’ basic demographic information such as gender, years of nursing experience and years of ED experience. This was to provide a description of the participant sample and will enhance transferability by allowing the reader to make judgments about the relevance of the study findings to their own practice situation.

3.8 Data Analysis

The aim of the data analysis is to reduce the descriptions of the experience captured in interview down the ‘essence’ of the experience of the phenomenon (Caslin & Scott, 2003). The data gathered was subject to free form analysis as is appropriate for an exploratory descriptive study (Schneider, et al., 2007). This involved an initial reading and rereading of the transcript as a whole followed by interpretation using a common strategy for qualitative data analysis, that of “fracturing, grouping and gluing” (Schneider, et al., 2007, p. 143). Paragraph by paragraph analysis was undertaken in relation to the research question; defined codes e.g. “discrete objects events and other phenomena” (Graneheim & Lundman, 2004, p.107) related by context were developed and described. Data was
fractured into these codes, codes categorised and analysed for underlying themes and relationships. Groupings were initially tentative and altered as the data analysis progressed and was subject to further interpretation (Schneider, et al., 2007). These mutually exclusive categories may be seen as an “expression of the manifest content of the text” (Graneheim & Lundman, 2004, p. 107) and themes “an expression of the latent content of the text” (Graneheim & Lundman, 2004, p. 107). This was a cyclic rather than a linear process and continued as the data from telephone interviews was added. The aim was to reduce the data to the least number of categories and ceased when it became clear to the researcher and supervisor that the process was complete (Schneider, et al., 2007). In keeping with the aim of this study this process did not proceed beyond an exploratory, descriptive analysis of the data.

Transcribed and anonymized data was maintained and managed via a word document. This enhanced data security and allowed for investigator triangulation and debriefing by the supervisor, both means of improving credibility of the research findings (Polit, et al., 2001). It also provided an alternative perspective to the data and acted as an external check and challenge to a single researcher’s processes, thereby enhancing reflexivity of the researcher. The research findings were not subject to member check for two reasons. Firstly there is some caution required in respect of member checks. Ryan-Nicholls & Will (2009) suggest that differing perspectives can result in discrepancies, but these do not necessarily invalidate the researcher’s interpretation. Participants’ perceptions may also change over time and in response to the interview process (Burnard, Gill, Stewart, Treasure, & Chadwick, 2008). Secondly, member-checking is extremely time consuming (Burnard, et al., 2008; Holloway & Wheeler, 2010) and not practical given the time constraints of this project. At the time of interview however, paraphrasing was used by the interviewer to clarify the participants meaning.

By its nature descriptive research "cannot yield facts but rather constructed truths” (Thorne, et al., 2008, p. 6). Just how credible and fit for purpose those constructed truths are will be dependent on the transformation of the raw data in a way that sheds new light on the phenomenon creating
meaning and utility for the reader (Thorne, et al., 2008). This has required a very deliberate and systematic, yet creative analysis of the raw data and every attempt has been made to maintain credible transparent data analysis to add to the rigour of the findings. Ultimately the utility of the findings and applicability to practice situations will be determined and tested by the reader.

### 3.9 Coding

The data analysis yielded three main categories: *(i)* Context, *(ii)* Communication and Collaboration, and *(iii)* Awareness. The themes and sub-themes within these main categories are summarised in Table 3.1 below and provided in greater detail in Appendix I. The table should be read from right to left in order to follow the researcher’s coding processes.

#### Table 3.1 Categories, Themes and Sub-themes

<table>
<thead>
<tr>
<th>Categories</th>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CONTEXT</strong></td>
<td>ED Context</td>
<td>Clinical decision-making</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Nursing Interventions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Challenges within the ED</td>
</tr>
<tr>
<td>Patient Context</td>
<td></td>
<td>Characteristics of patient group</td>
</tr>
<tr>
<td>Disease Context</td>
<td></td>
<td>Assessing acute event in the context of the individual’s disease trajectory</td>
</tr>
<tr>
<td>Chemotherapy Context</td>
<td></td>
<td>Awareness of immune-compromise</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Intervention independent of chemotherapy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Knowledge of chemotherapy-related side effects.</td>
</tr>
<tr>
<td><strong>COLLABORATION &amp; COMMUNICATION</strong></td>
<td>With Patient &amp; family/whanau</td>
<td>Collaboration</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Communication</td>
</tr>
<tr>
<td></td>
<td>Within the ED team</td>
<td>Collegiality</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Advocacy</td>
</tr>
<tr>
<td></td>
<td>Beyond the ED team</td>
<td>Hospice Interface</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Oncology Interface</td>
</tr>
</tbody>
</table>
3.10 Literature Control

The literature search has been an on-going process throughout the data analysis and discussion. New literature searches were conducted in response to the themes that emerged from the data and were integrated into the findings and discussion as a means of validating those themes and to highlight issues that did not arise in the process of this study (Holloway & Wheeler, 2010).

3.11 Qualitative Criteria

Quantitative research measures its worth through concepts such as rigour, reliability and validity. These concepts have not necessarily translated well to qualitative research and have been argued back and forth in the literature for decades. Opinions on the use of these traditional methods of establishing credibility range from the redefinition of these positivist concepts to meet qualitative, naturalistic criteria (Golafshani, 2003), to the denouncing of these concepts as irrelevant in qualitative research (Stenbacka, 2001). However, there is no argument about the need to establish credibility in qualitative research in order to convince the reader of its value and applicability to professional practice. The redefinition of the quantitative concepts of validity and reliability for the qualitative paradigm has led to terms such as trustworthiness, dependability, credibility, transferability and confirmability (Holloway & Wheeler, 2010) which are described as follows:

- Dependability is achieved through consistency and accuracy and by providing the reader with enough detail and context that they can follow the researcher’s processes of discovery to see how the conclusion was reached.
Credibility is seen to correspond to internal validity, which in qualitative research such as this may be jeopardised by wrong or incomplete data and an interpretation that does meet the stated aim of the research or accurately portray the experience of the participants (Holloway & Wheeler, 2010). One of the means to provide internal validity according to Holloway and Wheeler (2010) is through member checking to ensure the findings are compatible with their perceptions. Other authors have sounded a note of caution regarding member checks, arguing that they may actually invalidate the interpretation of the researcher who is tasked to synthesize and intellectualize the data from a number of participants (Morse, Barrett, Mayan, Olson, & Spiers, 2008).

Transferability, equating to the positivist concepts of generalizability and external validity, is difficult to achieve in qualitative research (Holloway & Wheeler, 2010). Transferability refers to the ability of the findings to be applied to other participants and situations (Holloway & Wheeler, 2010), and may be irrelevant in a study such as this that has set out to describe the experiences of a unique group of ED nurses. This has been alluded to in the study limitations. In qualitative research a detailed ‘thick’ description of the context, participants and researcher’s processes are necessary to enable the reader to make inferences from the findings (Polit & Beck, 2010), or to form alternative interpretations which can then be applied to practice (Polit & Beck, 2010). This level of description is seen to promote transferability and will increase trustworthiness (Graneheim & Lundman, 2004).

Confirmability, according to Holloway & Wheeler (2010), replaces objectivity in qualitative methodology. Confirmability seeks to ensure the study answers the research question rather that serving up the researcher’s preconceptions and again requires an audit trail to enable the reader to see how the conclusions were reached.

The findings of this study have been reported using extensive quotes from the participants to provide a detailed and thick description. Appendix I is provided as a means of revealing the link between the descriptions and the
researchers conclusions and categorisation. Throughout, the data analysis has remained focussed on the initial study aims.

The variety of viewpoints regarding methodology and measures to assess quality and credibility may be a reflection of the subjective and creative nature of naturalistic enquiry. However, there must be some assurance to the reader of the research that it contains some truth, or at least a version of the truth based on the circumstances and context of the research. This research therefore consists of the recalled experiences of a small group of ED nurses in providing acute health care to advanced cancer patients on chemotherapy, as described and analysed by an oncology nurse colleague. Honouring this lens, or rather, these lenses, requires intellectual transparency and sensitivity to the topic under investigation, and an audit trail for readers to be able to “follow the path of the researcher” (Holloway & Wheeler, 2010, p. 303). This has been achieved through the liberal use of direct quotes to support the findings and the provision the thematic analysis in Appendix I. As previously noted, peer debriefing provides an external check and challenge to a single researcher’s processes by identifying bias and subjectivity. This role was fulfilled in this study by the thesis supervisor and served to enhance the reflexivity of the researcher.

3.12 Reporting the Research

The findings of this study, while limited to the experience of a small sample of ED nurses working in just three satellite DHBs, are likely to be of interest to oncology nurses who work in similarly isolated DHBs. One feature of the findings, and possibly reflected by the difficulty in recruiting ED nurses to participate in this project, is that advanced cancer patients on chemotherapy presenting acutely make up a very small part of the ED caseload. This group of patients does not stand out within the ED milieu. The initial intention of this project was to illuminate the experiences of ED nurses in the care of these patients and to promote reflection and discussion by both ED and oncology nurses with regard to their care. The findings of this study will need to be reported via a medium appropriate to ED nurses in order to fulfil this intention.
3.13 Ethical Considerations

Ethical codes guiding research are essential to ensure the protection of participants and have been developed nationally and internationally in response to numerous human rights abuses. Individual participants’ rights are upheld through respect for autonomy, privacy and anonymity, respect for personal integrity and concepts of beneficence, justice and fairness (Schneider, et al., 2007). The starting point of any research project has to be the justification that the outcome of the research is likely to be a worthwhile addition to the nursing profession’s body of knowledge and will indirectly or directly enhance health outcomes. This justification has been made within the background and literature review of this topic. The value of the project must outweigh the potential harms or even inconvenience to the participants (Schneider, et al., 2007). Early in this project engagement was sought via the College of ED Nurses regarding the purpose and methods of the study. ED nurses had to be assured of the validity of this research project and the outcome of the study needs to be worthy and relevant to these nurses and their practice, as well as that of oncology nurses, i.e. both sub-groups must gain knowledge from the exercise. This engagement is reflected in the consent of the collective provided by the elected representatives on the College of Emergency Nurses – NZNO (Appendix II), and their on-going support of the project.

A clear explanation of the risks and benefits forms the basis for the informed consent of the participants (Schneider, et al., 2007). Information about the study with an invitation to initiate contact with the researcher was provided and allowed for voluntary participation in the study without coercion. The right to withdraw from the process was made explicit and signed consent of participants was completed and sent to the researcher prior to interview. Participants had a two week period post interview in which they could withdraw their data however none of the five participants did. There was also the potential for harm to respondents through the recall and disclosure of what may have been distressing events with adverse clinical outcomes. Participants would have been directed to their local Employee Assistance Programmes if necessary, however no participant expressed any distress during the interview. It was possible that the
participants benefited from the opportunity to explore any issues they may have had, and from contributing to a greater understanding of the phenomenon.

Privacy and anonymity were upheld by de-identification of the data at the point of transcription (participant and locality), and by ensuring careful use of direct quotes in the writing up. Data was securely handled and stored and will remain in a locked filing cabinet at the researcher’s home for 10 years before being destroyed. Only the researcher and thesis supervisor and have had access to the raw data. Data transcription was undertaken by the researcher.

Ethical approval for this research project was given by the Eastern Institute of Technology (EIT) Research Ethics and Approvals Committee (REAC) on the 27th July 2012, reference number 29/12 (Appendix IV). Locality approval was sought from the individual DHBs. Significant changes in the process of research ethics approval occurred at the time this thesis proposal was accepted and the ethics approval was sought. This change seemed to have an impact on the timeliness of the ethics approval as new forms and processes were enacted. There was a marked difference in the processes for locality assessment and approval in place in each of the four DHBs involved. In one, the approval was granted within a week, the second and third approvals were granted five to seven weeks from application and the fourth approval took three months. The delay in the fourth approval meant that there was little time left for recruitment at that DHB so a decision was made to forgo representation from that DHB. In one area there was opposition from medical staff in the ED but the approval was granted with advocacy from the ED nurse manager. The invitation to participants, consenting, and data collection were initiated at each of the DHBs once full written consent was obtained. Data transcription and analysis commenced as the interviews were completed and new raw data was added to the process as it was obtained. This non-linear, cyclical process of data collection and analysis has been described earlier in this chapter and is entirely appropriate for this particular research methodology.
3.14 Treaty of Waitangi

This research was not targeting Māori nurse participants in particular. It is unknown what mix of ED nurses were recruited to interview as the question of ethnicity was not asked. However, maintaining the minimum standards of Whakapapa (consultation), cultural responsibility (Manaakitanga) and Justice (Mana) within this mainstream research design, as described within the Māori Ethical Framework (Health Research Council of New Zealand, 2010) was the key to a respectful and collaborative research relationship. Treaty of Waitangi principles of partnership, protection and participation, have provided the framework for a culturally safe interaction. This has been achieved through partnership with the individuals and the collective (CEDNNZ); and protection, not only of identities, but of the validity of the participants’ views. These principles have been maintained throughout the data collection, analysis, and writing up of the findings.

It is anticipated that the results of this study will potentially benefit Māori patients with cancer as has been discussed in more detail in Chapter Two. The arguments to be made for this are: The higher incidence of cancer overall in Māori (Ministry of Health, 2011b); the higher mortality from cancer for Māori (Soeberg, 2012); the discrepancy in survival based on socio-economic status (SES) (Soeberg, 2012); the concentration of Māori living at the spoke; and the concentration of lower SES deciles at the spoke.

3.15 Summary

In this chapter the research methodology and processes from inception to data analysis and reporting have been discussed in detail. As a qualitative, descriptive enquiry, this is essential to enable auditability and to enhance the reliability and transferability of the findings. The value of such a project largely lies in the confidence the reader has in the findings, and their ability to incorporate them into future practice in a meaningful way. Given the stated intention to use this project as an opportunity to initiate an on-going dialogue with nursing colleagues in the ED, for the benefit of the people in our mutual care, great attention has been paid to maintaining the fidelity of the relationship between researcher and the participants.
CHAPTER 4
Findings of the Research

4.1 Introduction

The previous chapters have provided the background, discussion of the literature, and research methods undertaken to explore the acute care of patients on chemotherapy for advanced cancer seen in the ED. In this chapter the findings of the study will be discussed. The data analysis yielded three main categories: (i) Context, (ii) Communication and Collaboration, and (iii) Awareness. The themes within these categories have been summarised in Table 4.1 below and are further detailed in Appendix I.

Table 4.1 Major Categories and associated themes

<table>
<thead>
<tr>
<th>Category</th>
<th>Theme</th>
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<tbody>
<tr>
<td>Context</td>
<td>ED Context</td>
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<tr>
<td></td>
<td>Patient Context</td>
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<tr>
<td></td>
<td>Disease Context</td>
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<tr>
<td></td>
<td>Chemotherapy Context</td>
</tr>
<tr>
<td>Collaboration &amp; Communication</td>
<td>With Patient and family/whanau</td>
</tr>
<tr>
<td></td>
<td>Within the ED team</td>
</tr>
<tr>
<td></td>
<td>Beyond the ED team</td>
</tr>
<tr>
<td>Awareness</td>
<td>Attitudes</td>
</tr>
<tr>
<td></td>
<td>Perceptions</td>
</tr>
</tbody>
</table>

These findings have been based on analysis and systematic coding of the raw data. The analysis and coding has been undertaken by the researcher from outside the ED, who has an insider’s knowledge of the patient group described in this study. Therefore every effort has been taken to provide a clear, objective description of the coding process supported by the participants’ narrative. Each participant has been randomly assigned a pseudonym initial from the alphabet from P to T and direct quotes are
linked to the participant by that initial and a number assigned to each participant’s quote; e.g. Q10 refers to participant Q, 10th quote cited. The findings will be discussed in detail according to the themes and sub-themes. As noted in Chapter Two, the literature search has been an on-going process and literature has been discussed theme by theme as a way of validating the themes described and to highlight issues noted in other research studies that are not evident in this study.

4.2 Context

Context was seen to be one of the dominant categories of the data analysis. This may not be surprising in that qualitative research itself is contextual. There were a number of sub-themes, or contextual positions recognised that led to the creation of Context as a distinct category. Each of the context-related themes appeared to have varying levels of influence on the ED decision-making and intervention. The sub-themes were related to the context of (i) the ED itself; (ii) the patient context, i.e. the patient characteristics; (iii) the context of the individual patient’s disease trajectory; and (iv), the context of the patient’s chemotherapy. Table 4.2 below contains a schematic explanation of Category 1: Context. The table should be read from right to left for the purpose of following the coding process.

<table>
<thead>
<tr>
<th>Category 1</th>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
</table>
| Context    | ED Context          | Clinical decision-making and interventions
                 | Nursing Interventions                                                     |
                 |                     | Challenges within the ED                                                 |
|            | Patient Context     | Characteristics of Patient Group                                          |
|            | Disease Context     | Acute event in the context of the disease trajectory                     |
|            | Chemotherapy Context| Awareness of immune-compromise and use of neutropenic pathway            |
|            |                     | Clinical intervention independent of chemotherapy                        |
|            |                     | Knowledge of specific chemotherapy-related side effects                   |
4.2.1   ED Context
Within the ED context the influences on the ED clinical decision-making and nursing interventions for advanced cancer patients on chemotherapy, including the challenges and constraints within the ED, are further described and explored. The relevant literature is discussed sub-theme by sub-theme and is incorporated at the end of each sub-theme section.

4.2.1(i) Clinical Decision-Making and Intervention
The most dominant description within this sub-theme is that the clinical decision-making and intervention in the ED is very much presentation-driven and determined by the urgency of the intervention required. This was described by all participants. This presentation-driven intervention was also described by more than one participant as little different to any other patient group presenting to the ED (Q). The fact that the patient had advanced cancer and was on chemotherapy had only a minor impact on the clinical decision-making:

...that’s what we do with everything, not only the oncology patients, we do the acute stuff and then hand them on for somebody to follow up and decide what happens next basically and that’s what we do all the time, and that’s the ED mind set (P1).

...we just treat the presenting problem and we don’t think about necessarily about what the underlying cause is, certainly not in the first half hour to an hour, like, if its nausea, it’s treated as nausea (R1).

I don’t want to say it is irrelevant because it is very relevant but compared to what we are doing for them right here and now, the fact they are on chemotherapy might influence some of our decisions like can we give them certain drugs or is that going to interact with the chemotherapy medications? (T1).

The intensity of the intervention required was also described as influencing the clinical decision-making. One participant saying it’s fairly clear there are minor interventions and there are major interventions (P2). At the level of a
major intervention she also stated that the clinical decision applies more often to patients who we don’t care are on chemo or not, it applies to patients full stop (P3). Another participant described a tendency to overtreat rather than undertreat:

We probably over-treat rather than undertreat because it is easier to pull back than to not start and wish that you had (R2).

In these situations participants described the role of patient and family/whanau in influencing the level of intervention:

I think here we are very much patient centred so we very much follow the direction of the patient (R3).

90% of the time it is patient-led about what they want and what their expectations are… (T2).

Descriptions reflected an initial, emergency response, followed by a more measured response once the situation was stabilised. At this point in clinical care however, most participants agreed that decision-making beyond the immediate intervention was frequently escalated to relevant and available specialists. According to Q: they just come into this complex group that they just refer on to medical (Q1). This response to the acute presentation and up-escalation was reiterated by all and was summed up as:

First of all you do anything necessary to stabilise the patient urgently, or not quite save their life because that is not going to happen down the track, but you do what’s necessary and then they usually get referred on to in the first instance the medical team on call depending on the time of day (P4).

None of the participants articulated any clinical dilemma in the ED related to the treatment of these patients, even when specifically asked. Just one participant recognised the potential for under or over treatment (R2), describing as well as decisions to admit or not, team reflection on the level of intervention:
Initially we just treat the presentation that comes through the door, but if it is an on-going thing more the decision is about do we admit? Whether to admit? Where to admit to? Then you hear the conversation going on, “should we be doing this?” (R4)

One participant described a high level of commitment to providing the appropriate care and escalation to the appropriate specialists (Q), even if that frequently required admission to facilitate specialist review at a later date.

4.2.1(ii) Nursing Interventions

All participants described having a very active nursing role in assessing the patient at triage and saw ED nurses as being in a unique position to recognise febrile neutropenia1 (FN) and to initiate appropriate care via predetermined pathways and protocols. However, beyond their initial triage role, all participants described the clinical decision-making as medically driven and that ultimately it comes down to what the Doctor wants and what the patient wants (T3). ED nurses were described as taking a more procedural role:

Nurses would see the patient, initiate the care, the lines, the bloods, the doctors would come and see the patient, I would say the nurses don’t have an awful lot of say (Q2).

Where the nurses did describe their influence on the decision-making, it was in advocacy for patient involvement in decision-making. This was achieved often by encouraging the doctors with “have you asked the patient that question?” (R5), or by prompting medical staff to escalate to a more appropriate clinician:

From an RN point of view it would not be an RN’s call, but they may prompt the doctor to “perhaps you should ring the oncologist or talk to the team looking after the patient” (Q3).

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1Febrile Neutropenia (FN) is defined as an oral temperature >38.5°C or two consecutive readings of >38°C with an absolute neutrophil count <0.5x10⁹/l. (de Naurois et al, 2010)
One participant discussed experiencing a lack of mandate at times when advocating for the patient; but described the ways in which she contrived to get around this, such as waiting for a shift change or escalating her concerns to a more senior medical clinician (S). This may have been a frustration less often felt by the more experienced ED nurses who participated, but they too described how they relied on their ability to influence the medical staff with whom they worked. Overall, participants described a very high level of team work and consensus around the decision-making. This will be further described and explored under the communication/collaboration theme.

Participants’ opinions on advanced cancer patients on chemotherapy presenting to the ED with acute events were varied. They were described as more complex (Q), requiring careful medical and nursing assessment (P,Q,T) and more holistic nursing care (R). Two participants put it this way:

*I think a cancer patient on treatment gets a little more thought than the general Joe Bloggs because they do think...they do think about, often what they are presenting with is not necessarily directly related to their primary cancer and so nurses do think a little more holistically...* (R6).

*...is this treatment related, is it drug related, is it disease related and it’s just assessing your patient properly and finding out...* (T4).

This complexity appeared to be the reason that once the presenting problem had been addressed and stabilised, further care was escalated to on-call teams (Q1).

4.2.1(iii) **Challenges and Constraints in the ED**

Within the context of the ED the participants described a number of challenges in caring for advanced cancer patients on chemotherapy when they presented acutely. These were described consistently. These were related to space constraints (S,T), time constraints (R,S,T), competing priorities (R,S,T), specialist availability (P,Q,S,T), delays in accessing
patient information ($P,R,T$), and low patient volumes that precluded the acquisition and maintenance of specialist competencies ($P,Q,R$).

The care of these patients in the ED was described as creating some logistical challenges especially in relation to immune-compromise. One of these was the practicalities of allocation of single rooms and staff to minimise infection risk described by T: *one of the hurdles is; do we have a side room?* (T5). Time and competing priorities were also described by the same participant:

*I’ve been in here for an hour with this patient, but I’ve also got 6 other patients...and that guy needed pain relief...how am I going to manage this?* (T6).

These stressors led to a sense of conflict and guilt voiced by R who said *there are not many days you walk away feeling good about yourself* (R7). Adding to these stressors was the additional expectation of meeting ED ‘6 hour’ targets, described by three participants (R,S,T).

Some participants also identified and described multiple expectations by numerous clinical sub-specialties, all with their own demands for specific management of their own patient groups within the ED. This issue is highlighted by the following quotes:

*Oncology patients are a very small proportion of what comes through our doors and if we set out to become expert in everything....we would be completely swamped* (P5).

*Yes, fast-track for this, door to needle time for lots of other things and each group in its own right, and rightly so, should be focussed on their condition but when you are in an emergency department and trying to balance all of that...* (R8).

Low volumes of this particular group of patients through the ED were also described as a constraint in their care. As T noted, *it is difficult because we don’t see them very often, about actually sometimes knowing what to do* (T7). Low volumes were also described as a problem especially around
gaining and maintaining competencies with regard to specialist procedures such as accessing Port-A-Caths®. As P pointed out, being competent in that involves doing x number of examples (P6). All participants described this as a constraint and most areas had resolved this particular issue within their ED by accessing other resources such as paediatric nurses (P) after hours or their specialist intravenous nurse when available (Q). None described using their local oncology nursing colleagues even when they were available during working hours.

The relatively low volumes of these patients presenting to the ED was reflected in the estimates of the number of presentations each month. The three participants from one DHB provided a very similar estimate of 2-4 per month, the other participants 3 per month and 5 to 6 per month respectively. Several participants also reflected on the impact of pro-active management of these patients by the oncology team:

Oncology care seems to be effective because they mostly keep away…it’s during the weekends (P7).

We are not seeing them cos [sic] they are being well looked after in the community under the oncology teams (T8)

Similarly, Q suggested that acute problems were likely to be managed within working hours by the oncology team. This may be more likely in a satellite oncology service with an on-site oncology medical practitioner. This would have the effect of reducing the ED staff’s overall exposure to this group of patients, but increase the likelihood of that being an after-hours occurrence. The participant estimating the highest volume (5-6 per month) came from the smallest DHB, whose local oncology resource was nurse-led.

Another constraint described by these ED nurses was the lack of availability of oncology specialist cover or advice after hours especially in relation to a tertiary hospital with a 24 hour on-site service (P,S,T). Pointing out the proportion of time a Monday to Friday working hours only resource was available, P said nothing’s much use to us that’s only available 23% of the

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2 Port-A-Caths® are implanted central venous access devices used for repeated venous access. (Smiths Medical, 2013)
time (P8). This is the ratio of ‘normal office hours’ to the open all hours cover provided by the ED. This limited availability may influence the likelihood of seeking that advice:

*It depends on the time of day, during the day they are more likely to ring the oncologist…after hours they are probably more reluctant…* (Q4).

When describing the need to escalate to the medical team on call, time delays to that higher level assessment and decision-making were noted (T). The need to admit the patient and wait for the specialist to be contacted the following day was also described: *we’d have a medical doctor, but they would probably wait for oncology in the morning* (S1).

Also impacting on the clinical decision-making in the ED, at least in the initial stages of the intervention, was the delay in accessing up to date information about the patient (P,R,T). In some cases, but not all, the clinical record could take some time to access and there was some variation in the amount and usefulness of electronic patient information. Thus the patient and family/whanau became an important source of information:

*Before you have got their case notes it’s relying on what the patient can tell us and how much they understand* (T9).

Reliability of the patient in this situation was recognised as variable depending on where they were at (Q5).

The exception to this situation was evident in one DHB, where the participant described the use of a patient-held record that had been initiated by their Hospice Service and was increasingly used by the oncology nurses. This record provided the ED team with some valuable information to support the clinical decision-making, although it did not include clinical correspondence from the oncologist. The record remained primarily the responsibility of the patient to maintain and provide at presentation.

Many participants also noted that the clinical notes were not routinely accessed and it was rarely the nurses who accessed them. Q said:
If you happen to go through the clinic letters and you can access that on computer but you don’t always do that, certainly the nursing staff tend not to (Q6).

Electronic records improved access to information but all areas described having to access hard copy notes as not everything they needed was available electronically. This seemed particularly to be the case with the clinic notes from the oncologist. Even when the oncology clinic note was available the information in that was described as variable as to whether, with plans and stuff (Q7). However, this was not always the case according to P:

Our doctors always read them and sometimes they are helpful if they have a lovely summary that is summarising where they are at and what is going to happen next because that’s quite good, then you can work out whether the patient is deteriorating or whether it is a problem that can be fixed (P9).

In summary, the care of advanced cancer patients in the context of the ED was described as presentation-driven and not greatly influenced by the patients’ cancer or chemotherapy. The decision-making was largely medically-directed, in collaboration with the patient or family/whanau. The ED nurses’ role was predominantly at triage and thereafter in procedural support and advocacy. ED nurses described this patient group as complex, requiring careful assessment, although low volumes precluded acquisition and maintenance of specialised skills and knowledge. Clinical decision-making beyond the acute event was frequently escalated to more appropriate teams. Challenges described in the ED related to competing priorities, lack of specialist availability and lack of specific clinical information about the patient.

4.2.1(iv) Literature Control related to the ED context theme
In the literature examining the role of ED nurses in management of patients on chemotherapy, the ED is noted to be the main point of access to acute inpatient care (Considine, et al., 2009). The ED is also seen as a high risk environment for these patients. Some of the reasons cited for the higher
Clinical risk is fragmentation of care and that clinical decisions must be made about unfamiliar patients, with minimal background information to inform those decisions (Considine, et al., 2009). This was one of the challenges described in this study (P,R,T, p.58). In the absence of appropriate clinical information, participants described a high reliance upon the patient or family/whanau to provide that information (R3,T2,T9).

The increased clinical risk in this population results from higher acuity as well as a lack of specialist assessment and care (Considine, et al., 2009). Higher complexity and limited access to specialists seemed to be recognised by the nurses and ED teams in this study (P4,Q1,R6,T4). This was also evidenced by the participants’ description of ED’s role to stabilise the acute problem and then escalate the decision-making to in-patient teams or specialists (P4,Q3,R4,S1). The ED is seen as a critical point in resetting the disease trajectory (Grudzen, et al., 2011). Complex decision-making may be undertaken by ED physicians under urgency often without knowledge of the goal of care (Grudzen et al, 2012). From the descriptions in this study it seemed more likely that pivotal decisions about the direction of care were escalated to on-call teams. The tendency of these patients to present to their familiar oncology unit when it was open (P7,Q, p. 57), and the ED after hours has been noted by other researchers (Nirenberg, et al., 2004).

Patients on chemotherapy treatment for advanced cancer represented a very small proportion of the ED caseload according to the estimates given in this study (p. 57). However, these patients make up about 50% of an oncologists workload (Hauser, et al., 2006) and provision of palliative chemotherapy for advanced cancer is predicted to increase in frequency and complexity (Cranleigh Health, 2011). Approximately 30% of people receiving outpatient chemotherapy will present to the ED at least once and over 40% more than once. Half of these presentations will result in admission (Livingston, Craike, & Slavin, 2012). Thus, there is likely to be an increase in the presentations of this complex group of patients to the ED.

McKenzie et al. (2010) also described a high rate of admission, nearly 90%, and speculated that patients were more readily admitted after hours when the cancer unit was closed. Admission to facilitate specialist assessment was
also described in this study (S1). Admissions to the DHBs in this study are to general wards as there are no oncology in-patient units, and limited after-hours access to specialist oncology advice was described (P8,Q4). Lack of specialist assessment and care and placement in general wards may also contribute to a higher risk of adverse outcomes in these patients (Considine, et al., 2009). Length of stay may be longer due to delay in seeing a cancer specialist (McKenzie, 2010). It is also likely to impact on continuity and patient experience of care (Yates & Barrett, 2009).

The specialised, episodic, emergency care that ED nurses are trained to provide to a very diverse population (Fry, 2008), does not always meet the needs of this highly specific patient group (Considine, et al., 2009). Pressure to meet imposed targets such as the “6 hour target” described by participants (p. 56) and the urgent nature of the ED environment may not serve complexity well. This was illustrated by Nelson et al. (2011) in relation to repeat attenders with complex health needs: “The presenting symptoms were responded to but there was often a failure to capture complexity within the time period of a rapid response system” (Nelson, et al., 2011, p. 536).

What is not known is if or how management of acute events in the ED in this population might influence outcomes, especially at the spoke. What is known is there are disparities in cancer survival in New Zealand that are not accounted for by stage at diagnosis (Cormack, et al., 2005). Access through secondary care, rurality and cultural factors may all contribute to less than optimal health-care (Hill et al., 2010; Jeffreys et al, 2005). Risk of dying from some cancers may be increased at a distance from a tertiary cancer centre, and with worsening SES (Haynes, Pearce, & Barnett, 2008). It has been suggested that it is small incremental differences along the cancer pathway that add up to the overall disparity between Māori and non- Māori survival rates (Hill, et al., 2010), and that the “entire treatment pathway requires serious attention” (Cormack, et al., 2005, p. 30).
4.2.2 Patient Context

4.2.2(i) Patient characteristics

There was a highly consistent description of the characteristics of this particular patient group. All participants described a highly compliant, proactive patient group. One described patients on chemotherapy like people who have kids with strange syndromes you’ve hardly ever heard of… (P10). Others confirmed that as a group they were well informed about their disease:

They are usually switched on about their condition (S2).

Their treatment:

Usually your chemo patients are well educated (S3).

And their prognosis:

Most of the ones I have come across have been pretty on to it about what their prognosis is (T10).

All participants also described their reliance on the patient and the family communicating their own understanding of their chemotherapy, goal of care and expectations to the ED team to guide the decision-making:

...we rely on the clinic letters or the patient’s knowledge (Q8).

...patient is giving us some info if they have been told specifically “make sure when you present they know this” (R9)

One of the constraints within the ED, previously discussed, was timely access to oncology clinic notes; which health professionals tended to access these; and how well these notes articulated the specific goals and expectations of the active treatment regimen (P9,Q6,T9).

Two participants added the caveat that the patient was not always compliant and proactive (P,Q). Q, acknowledging the value of the secondary assessment and direct questioning said:
But if they don’t necessarily come in with a fever you do get people who don’t say they are on chemo, and I guess then it becomes when you do a secondary assessment that that may come out, but again not always.... and the occasional person you actually have to say “are you receiving chemo at the moment?” (Q9).

There was also an acknowledgment that patients were not always in a position to take an active role in their care due to the acute situation, adjustment or health literacy:

Some are good; some are not, depending on where they are at (Q10).

It depends very much on the patient, some of them are absolutely clued up and others look blankly at you and say I don’t know, the Doctor told me to take this medicine and its making me sick... (P10).

One participant described this group of patients as having high expectations of ED staff. She described them at times as a bit more assertive, bordering on aggressive about they must be taken in and seen absolutely immediately (T11). She felt these expectations were driven in part by the instructions of the oncology staff: they’ve just been told if you are ever unwell you have to go straight to ED (T12); and partly by the patient’s fear and their understanding that they needed to be seen straight away. All participants described the high use of the chemotherapy alert card in use over this region, but one suggested it was misused by some patients as the revolving door card (T).

4.2.2(ii) Literature Control relating to Patient Context theme

Despite of descriptions by some participants in this study of an educated and compliant patient group (S2,3,T10), there is evidence that patients even with significant complications present late (National Confidential Enquiry into Patient Outcome and Death (NCEPOD), 2008; Nirenberg, et al., 2004). Nirenberg, et al. (2004) found that patients frequently delayed, on average, for 21 hours before presenting to the ED with fever and most of
those who delayed were patients with advanced cancer who have higher risks of sepsis.

Identification of individuals’ goals and expectations and involvement of the patient in clinical decision-making as described in this study (R3,T2) is highly appropriate; to not do so is in breach of consumer rights (Health and Disability Commissioner, 2009). However, too great a reliance on the patient and family/whanau (as described by Q8,R9), to provide the relevant information places the onus on the patient. Individual patients will have differing levels of understanding, adjustment and health literacy. This was noted by participants in this study (Q10,P11). There are recognised barriers and variables related to the delivery of information by health professionals and receipt of that information by the patient that may lead to divergent expectations (Moore, 2005). In a recent study of patients with advanced lung or colorectal cancer, 69% and 81% were found to have an incorrect understanding of the goal of their chemotherapy (Weeks et al, 2012). This appeared to be unrelated to education, but was more likely with ethnic minority groups. Most patients want an honest appraisal of their prognosis, but there are others who would not want to know (Alifrangis et al, 2011). There is also a difference between what oncology staff believe they have given in terms of education and what patient’s understand and act on (Leonard, 2011). This too was recognised in this study and is discussed further in the context of communication and collaboration with the patient.

Reliance on the patient to provide appropriate information to support the clinical decision-making was described in this study (Q8,R9). This may place those with poor health literacy at a disadvantage. Approximately half of the population have low literacy levels that might preclude such engagement (Ministry of Health, 2012b). This is particularly prevalent among Māori where 76% of urban Māori and 80% of rural Māori are known to have low health literacy skills (Ministry of Health, 2012b). A higher Māori population, lower SES and rurality are features of these satellite DHBs (Ministry of Health, 2011a). Given these factors, reliance on the patient’s ability to communicate clinical particulars to support the decision-making, in the absence of specialist information, may not be ideal.
4.2.3 Disease Context

4.2.3(i) Assessing the acute event in the context of the patient’s disease trajectory

All participants described the need to assess the acute event in the context of the patient’s position on the disease trajectory:

*It’s actually getting to the bottom of what is normal for the person at this time* (S4).

This was seen as an important step in distinguishing acute reversible events:

*Summarising where they are at and what is going to happen next….then you can work out whether the patient is deteriorating or whether it is a problem that can be fixed* (P12).

...*is it, you know, is this something that they die of, or you know...I am not sure that makes sense but is this simply part of the cancer process? Or is it something that we can treat* (T13).

The uncertainty and the difficulty of establishing that in a brief ED encounter triggered by an acute event were articulated by P:

*We don’t know what has gone on before, how bad they may have been and how much better they might be or how much worse they might be because we’ve not seen them before* (P13).

Often the presenting event had to be dealt with in the first instance and assessment of the context of the event within the individual’s disease process came later, possibly from a health professional already familiar with that individual’s disease trajectory:

*You start on the acute care then by then someone’s had a chance to look on the computer to sort out what’s going on with this patient and should we pursue it and you try and if*
you are lucky you’ll find a doctor who has actually, or somebody who has been involved with looking after this patient previously (P14).

As well as distinguishing acute, reversible events, many participants also described the need to distinguish disease-related from treatment-related events (Q,T); and described the possibility of acute events arising which were totally unrelated to either the advanced cancer or the chemotherapy (P,Q,R). Cancer was described by P as a chronic disease similar to other chronic health conditions that is treatable to a certain extent but possibly not to a massive extent (P15).

4.2.3(ii) Literature control relating to disease context theme

Accurate estimation of life expectancy in those with advanced and incurable cancer is difficult (Krishman et al, 2013). Distinguishing an acute and reversible event from a rapid and irreversible decline is a recognised challenge for clinicians (Glare, et al., 2008; Krishman, et al., 2013). Participants in this study were alert to the need to distinguish between disease-related, treatment-related and other acute conditions that may have led to the presentation (P,Q,R,T, p. 66). As a group, patients with cancer may experience of acute events for a variety of clinical reasons. In one study, 50% presented due to cancer progression, 20% due to treatment-related events and 10% due to other medical conditions (Yates & Barrett, 2009).

From the descriptions in this study it was also apparent that the ED nurses and the ED team sought to situate the acute presentation within the context of the patient’s disease trajectory in order to appropriately manage the event (P12,P13,T13). Primarily they relied on the patient and family/whanau to provide that context. Consultation with oncology team members who knew the patient well varied from DHB to DHB, depending on the resources available and on the time of day (P8,Q4,S1). Access to records, non-availability of staff who could communicate the goal of care and position on disease trajectory are identified challenges in the ED (Grudzen, et al., 2011)
Prognostication in people with advanced cancer is fraught. Oncologists get it wrong two thirds of the time and tend to overestimate. Patients themselves may be more accurate but also tend to overestimate. (Kao, Butow, Bray, Clarke, & Vardy, 2011). Predictive models are based on evidence relating to the last few months of life and not confounded by disease-modifying treatment (Gwilliam, et al., 2011; Maltoni, et al., 2005; Stone & Lund, 2007). When life expectancy is days to weeks, death is easier to predict but in those newly diagnosed with an advanced cancer, when life expectancy may be months to years, predictive models fail and co-morbidities and anti-cancer treatment have a major bearing on prognosis. (Hauser, et al., 2006).

Advances in systemic treatment for advanced cancers have meant that cancer has become a chronic disease in some individuals (Lage & Crombet, 2011). Recognition of this was noted in this study (P15). However there are some distinctions between cancer as a chronic disease and other chronic illnesses. Murray (2005) described the cancer trajectory as a “reasonably predictable decline” with “steady progression and usually a clear terminal phase” (p. 1007). This description may not reflect the improved survival of some cancers that has come from improved treatment.

It is clear that uncertainty exists, even to those experienced in cancer care with insight into an individual’s disease and specialised knowledge of disease-modifying treatment. However, there may be no way of the ED team knowing at which point in the disease trajectory an individual patient sits. While this may be more evident to the oncology team it may not have been clearly articulated, or if it is, may remain unavailable and unknown to acute care providers. This was evident in the descriptions given by this study’s participants (P13), and described as some of the challenges facing the ED staff in 4.2.1(iii).

4.2.4 Chemotherapy Context
Within the context of the chemotherapy itself, there were three distinct sub-themes uncovered. The first was a very high awareness and consistent use of established and mandated Febrile Neutropenia (FN) pathways across all areas; the second was a similar account by all participants that the
chemotherapy did not otherwise influence the ED decision-making or interventions; the third was a uniform description of minimal chemotherapy-specific information or resources available within the ED.

4.2.4(i) High awareness of immune compromise and FN pathway

In the context of the patient’s chemotherapy, all participants described the knowledge and use of an FN pathway or protocol and described a high awareness of the risk of immune compromise in this population group. Fever was a distinct trigger which prompted ED nurses’ recognition of the risk of FN at triage (P,Q,R,S) and placed the nurses in the forefront of the initiation of this clinical pathway: we are the ones who are going to recognise the problem at triage (T14). FN was also described as the most frequent reason for acute presentation (P,Q,S,T).

FN pathways were in place in all three of the DHBs involved and had either been initiated by the tertiary treatment centre and were modified and/or mandated by local guidelines or standing orders. Most participants agreed that the pathway was helpful, enabled a standardised clinical response (P,R,T) and enhanced their nursing role and ED team work (P,T). However, P, although noting that the pathway was effective and simple, expressed a wariness of pathways imposed on ED staff by other than ED clinicians, saying:

*I don’t think ED’s like pathways a lot because they are designed by people who have no idea how ED’s work, you get the oncology service saying do this for my patients and the diabetics say do this for my patient first and the orthopods [sic] say do the nofs [sic], we just treat people according to their clinical need, we do what we [participant’s emphasis] think should be done* (P16).

This participant also noted that there was a conflict between the Australasian triage guidelines and local protocols and again communicated a sense of imposition:
We are decreed that we have to make a triage code 2 a patient on chemotherapy, possibly neutropenic who has a fever (P17).

4.2.4(ii) Clinical intervention independent of chemotherapy

All participants described a high level of knowledge in regard to the potential for chemotherapy to cause neutropenia, and described a very clear clinical response to FN. However, beyond that specific chemotherapy-related clinical scenario, all participants stated that the chemotherapy itself had no impact on the clinical decision-making or on their nursing interventions. For example:

...it doesn’t change my management if they are on one type of chemotherapy to another because it does not change the management from an ED point of view (T15).

...It doesn’t really matter whether they are on chemo or not except for things like isolating them so they are not compromised by any infections hanging about (P18).

With regard to the actual goal of the chemotherapy, the majority of participants did not see that as greatly influencing patient management in the ED (P,Q,R). As T said, we don’t actually know when they front up whether they are palliative or other treatment (T16). Similarly, when describing the ED team’s understanding of the oncology team’s goals and expectations of treatment, R said, No to be fair, that would be a complete mystery to us, for the oncology team, not for the palliative team but definitely for the oncology team (R10).

There was a lack of information or knowledge available to clarify the oncology team’s clinical thinking, R saying we probably haven’t got a lot of information and support around that (R11), as well as the sense that knowing that would not change the ED decision-making:

We can look up a few things, if necessary. In actual fact we probably don’t do that much, we treat on what we see (P19).
### 4.2.4(iii) Knowledge of specific chemotherapy-related side effects

Most participants felt they had minimal knowledge of specific chemotherapy-related side effects other than immune compromise (Q,R,S,T) and readily described the need to isolate, assess and manage the presentation in the context of that. Chemotherapy specific resources available in the ED were described as minimal or out-dated (R,T). Many described the patient as their major source of information:

> We learn stuff from them, they tell us about the treatment and it’s like I have no idea what you are talking about (S5).

> I think we all understand the real basics – the hair loss and the nausea, as for all the other things we rely heavily on our patients telling us what is going on for them (R12).

In summary, FN was managed in an informed and clinically consistent manner. Other chemotherapy related side-effects were likely to be managed generically. Whether chemotherapy was curative or palliative did not influence the decision-making. The most valuable source of chemotherapy-specific information to support care was that which the patient was able to provide.

### 4.2.4(iv) Literature control relating to Chemotherapy theme

Triage is a process of prioritisation based on the need for time-critical intervention. In an assessment taking less than five minutes, the presenting problem and mostly visual cues are used to determine an ATS (Australasian Triage Scale) category (Australasian College for Emergency Medicine, 2005). The triage category describes the maximum wait time to assessment and treatment. Presentation with a fever in those immunosuppressed by chemotherapy or steroid therapy is categorised as ATS 3. This is at odds with the ATS 2 category in use at these DHBs, as noted by one participant (P17). Clinical pathways are utilised to improve the time from presentation to initiation of intravenous antibiotics. (Hawley, Loney, & Wiece, 2011; Lim

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3 ATS 3 is defined as potentially life-threatening event requiring treatment within 30 minutes. (Australasian College for Emergency Medicine, 2005).
4 ATS 2 is defined as imminently life-threatening time-critical events which require treatment within 10 minutes. (Australasian College for Emergency Medicine, 2005).
et al, 2012; Nirenberg, et al., 2004; Salter, 2005). In this study all participants were alert to the risk of immunosuppression in this population group and, using fever as a trigger, initiated an established and mandated FN pathway (p. 68).

FN is one of the more common side effects of chemotherapy. It’s impact on QOL may be underestimated (Methven, 2010). FN is considered an oncologic emergency which, if untreated, can lead to septic shock and death (Nirenberg, et al., 2004), but it may not always be accorded the same potential for sudden deterioration as other medical emergencies or trauma in the ED (Courtney et al, 2007). However, normal signs of an inflammatory response may not always be evident even in the presence of infection, especially in the elderly or those on steroids (Cull & Nolan, 2009). Fever appeared to be the single clinical trigger for recognising FN and commencing the FN pathway described by participants (p. 68). The elderly and those with co-morbidities carry a greater risk of neutropenia (Cull & Nolan, 2009). Those with advanced cancer and/or comorbidities are also likely to have a delay in starting intravenous antibiotics, possibly because of requiring more complex assessments (Nirenberg, et al., 2004).

FN is one of the more frequent causes for presentation to the ED in patients on chemotherapy, constituting between 15% (Livingston, Craike, & Considine, 2011) and up to 23% of presentations (McKenzie, 2010). It is also the presentation that is most likely, at 80%, to result in admission (Livingston, et al., 2011). Up to 20% of patients presenting with it may require Intensive Care and/or die. (Courtney, et al., 2007). In this study FN was recognised by most of the participants as the most frequent chemotherapy-related complication (p. 68).

FN, however, is by no means the only reason for ED presentations in this patient group. In an analysis of unplanned ED presentations of cancer outpatients who had received chemotherapy for solid tumours in a large hospital in Australia, the most frequent presentation was for nausea and vomiting (45%), followed by pain (27%), fever (23%), shortness of breath (19%), dehydration (12%), anaemia, fatigue and diarrhoea (each 9%) (McKenzie, 2010). ED presentation was more likely within two to four weeks
of receiving chemotherapy and twice as likely if the chemotherapy was given with palliative intent (McKenzie, 2010). Discussions about the side effects of chemotherapy in this study were focussed on fever and neutropenia. Nausea was noted to be a frequent presentation by just one participant (R), but other potential side effects of chemotherapy were not described by any participant. In fact there were acknowledgements from most that they had little knowledge with regard to other side effects (Q,R,S,T, p. 70).

This does raise the question about how chemotherapy side effects other than FN might be recognised and managed in the ED. It has been suggested that ED nurses need to gain specific knowledge of chemotherapy complications in order to manage the clinical risks associated with acute chemotherapy-related presentations (Considine, et al., 2009; Cull & Nolan, 2009). The participants in this study did not describe having the specific knowledge or resources to provide a more specialised level of care. Livingston, et al., (2011, p. 68.) also noted that “given the increasing range of skills and knowledge required to be emergency nurses, it is unreasonable and impracticable to expect emergency nurses to be experts in oncology care”. Achieving and maintaining such specialised skills was felt to be a constraint to care provision (P6,T7, p. 56-57) and may be an unrealistic expectation given the low volumes described (p. 57).

However, if complications of chemotherapy are not recognised and managed as such, this may tip the balance towards harm versus benefit of chemotherapy. Active treatment may be given to improve survival and “where the palliation/toxicity trade off from treatment clearly favours symptom relief” (Archer, Billingham, & Cullen, 1999, p. 470). Realising a net improvement in QOL arises not just from impacting on the cancer itself but also from minimising the side effects of the treatment given. Indeed, negotiating this trade-off is a critical part of the oncology team’s work with advanced cancer patients on chemotherapy (Buiting, Rurup, Wijsbek, van Zuylken, & den Hartogh, 2011).

To further illustrate this point, chemotherapy-induced diarrhoea (CID) will be discussed. CID is one of the chemotherapy side effects which, if
inappropriately managed, may negate the benefits of chemotherapy. Diarrhoea as an acute complication of chemotherapy necessitating emergency care was not described by the ED nurses in this study. This may be due to the low chance of an individual ED nurse having experienced this, but may be due to lack of knowledge and recognition of CID as a chemotherapy side effect. Diarrhoea constitutes up to 10% of ED presentations of patients on chemotherapy (McKenzie, 2010), but is one of the least likely to result in admission (Livingston, et al., 2011).

Chemotherapy-induced diarrhoea (CID) is a significant side effect with chemotherapy agents used for colorectal cancer, occurring in 50-80% of patients (Stein, Voigt, & Jordan, 2010). CID requires aggressive management in order to reduce morbidity and mortality (Benson III et al, 2004). CID may be severe enough in one third to require admission and may be catastrophic in a few individuals (Stein, et al., 2010). In advanced cancer, CID has to be distinguished from other causes of diarrhoea (Benson III, et al., 2004; Stein, et al., 2010). Management is guideline based and includes discontinuation of the offending agent (which may be oral) for any diarrhoea worse than Grade II$^5$ (Benson III, et al., 2004).

New classes of molecularly targeted drugs, tyrosine kinase inhibitors and epidermal growth factor receptor inhibitors also cause diarrhoea. This may occur in 60% of patients and may be severe in 10% (Krishnamurthi, 2013). Frequently these treatments are oral and taken continuously, as is a fluorouracil pro-drug used for colorectal cancer. Targeted drugs and oral chemotherapy agents may erroneously be assumed to be less toxic than intravenous agents (Moody & Jackowski, 2010). In a patient group motivated by their advanced cancer (Moore, 2007), there may be a reluctance to discontinue the oral drug despite toxicities. If uncomplicated, patients with Grade II CID may not require admission for rehydration, but this is the point at which the offending medication should be discontinued. This would need to be instituted in the ED in addition to appropriate assessment and supportive measures.

$^5$ Grade II diarrhoea is defined as an increase of 4-6 stools per day over baseline (National Cancer Institute, 2010).
Over the past decade, five year survival of metastatic colorectal cancer (mCRC) has increased to 20% due to new chemotherapy agents (Lage & Crombet, 2011). This improved survival has come at the cost of treatment toxicity, which is most often gastro-intestinal (Zafar et al, 2010). Therefore, although these patients have advanced cancer and are on chemotherapy with palliative intent, they may have a reasonable life expectancy but experience gastro-intestinal toxicities that require ED intervention. Using the example of mCRC, we see not only the impact of newer chemotherapy regimens on an advanced cancer trajectory; but also the potential costs to the patient’s QOL in terms of toxicity. A generic approach to the management of diarrhoea presenting in a patient on chemotherapy for advanced cancer may not address the specific clinical risks that it raises. It also seems likely from this study that the ED team would not always have access to specialist advice or resources, as discussed in 4.2.1(iii), to support appropriate intervention. They may not know what they do not know.

4.3 Communication & Collaboration

Communication and collaboration was another category identified from the descriptions given. This category has been divided into three distinct themes relating to the participants’ communication and partnership with (i) the patient and family/whanau; (ii) communication and interactions within the ED team itself; and (iii) how the ED nurses’ and ED team interfaced with services beyond the ED team itself, particularly Hospice/Palliative Care Services and Oncology Service staff who were also involved in the care of this patient group. Table 4.3 illustrates Category Two and its related themes.

Table 4.3 Communication/Collaboration themes

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<th>Category 2</th>
<th>Themes</th>
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<tr>
<td>Communication &amp; Collaboration</td>
<td>With patient &amp; family/whanau</td>
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<td></td>
<td>Within the ED team</td>
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<td>Beyond the ED team</td>
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Communication tends to pervade many of the more clinical themes discussed under the category of Context. Care within the context of the ED, chemotherapy, disease trajectories and of course the patient context cannot be entirely separated from it. Nor can it be fully discussed and given justice without a category of its own. Literature control related to each is addressed theme by theme with reference to previous sections as appropriate.

4.3.1 With Patient, family/whanau

Within this theme are found the interrelated notions of communication and collaboration. All participants described very patient-centred decision-making in the ED. As previously described there was a high reliance on the expectations and knowledge of the patient and family/whanau to guide the clinical decision-making (p. 53). Communication was described by several participants as essential to establishing and understanding the goal of care with the patient and family (p. 58). Most participants also recognised that there may be barriers to the patient’s ability to engage fully in this process under the circumstances of the acute presentation (p. 58). Where the patient was unable to participate fully the family/whanau (R,S,T) were utilised to support the decision-making. Some also described a possible dissonance between the patient’s understanding of the oncologist expectations, and the reality of the treatment being given (R,T), one participant saying:

There may have been discussion with the oncologist, but did the patient understand what the oncologist was saying? (T17).

Close communication with the patient and the family/whanau was described by most participants in relation to the ED team understanding the patient’s expectations, especially if the patient was unable to participate in this discussion (P,R,S,T). Two participants also described differing expectations between patient and family members that needed to be resolved in the ED:

They [the patient] generally have an idea what is going on but sometimes the family don’t...they want more done... (S6).
The family understandably were horribly distressed and saying it’s too soon, we’re not ready for this. I think she [the patient] was more accepting of it (T18).

In discussing communication with the patient and family in the ED, S also described the impact of differing levels of nursing experience, describing less experienced nurses as they’re trying to figure out how to deal with these things (S7), and also describing the impact of lack of time that was a factor for all patients in the ED:

...it kind of depends on the day – like if you are really busy you don’t have time to sit down ....there is kind of an ideal... (S8).

This participant also described the need for honesty and realistic goal setting in their dealings with this group of patients, giving an example of conversations with these patients such as:

This is the reality, this is where you are at and these are your options... (S9).

She also felt that some patients had unrealistic expectations, saying I think sometimes people come in and think they are going to get a miracle (S10).

4.3.1(i) Literature control related to Patient Communication/Collaboration

From the participants’ descriptions, communication with the patient and whanau appeared to be essential to appropriate assessment, nursing care and clinical intervention in the ED Context theme (p.53). Although there is a scarcity of research relating to the ED, there are studies exploring nursing care of people with cancer in the acute care setting. Communication is an inescapable element of care of patients with advanced cancer (Davis, Kristjanson, & Blight, 2003; Mohan, et al., 2005; Sheward, et al., 2011; Stajduhar, Thorne, McGuinness, & Kim-Sing, 2010).

In the acute care setting, nurses’ level of confidence in dealing with cancer patients may be compromised by their level of specific knowledge, access to accurate information about the individual (Mohan, et al., 2005); and lack of
a clear treatment plan (Davis, et al., 2003). These were issues described and discussed as constraints under the ED Context theme (4.2.1.iii). Insufficient time, which was described in this study (S9), and staff inexperience (S7) are also factors in poor communication in the acute care setting (Davis, et al., 2003).

Communication with the family of advanced cancer patients may present more challenges for nurses than communication with the patient, especially if there is family conflict or cultural-language barriers exist (Davis, et al., 2003). The need to manage differing expectations between family and the patient was described in this study (S6,T18). Davis et al. (2003) detailed the strategies that acute care nurses used to enhance communication. These were: assessment of social history; defining and communicating the treatment plan; better team work; opportunities for team debrief; and facilities that allowed privacy. Many of these strategies would be difficult to achieve given the ED environment and purpose, but may be mitigated by closer collaboration between the ED and oncology services.

4.3.2 Within the ED team

Most participants described a high level of collegiality and collaboration within the ED team (P,R,S,T). Team communication was seen to resolve any conflict and none of the participants described any clinical or ethical dilemmas arising in the care of this patient group in the ED. P described a high level of consensus especially in relation to high level interventions and decisions regarding the futility of treatment, saying:

> It’s a combination that develops within a team I think, I mean, I’ve seen patients who’ve come into resus [sic] and you think to yourself well this patient is not going to make it no matter what we do and by and large everybody in the team often including the relatives and sometimes the patient agrees (P20).

It has been noted previously within the ED context that the decision-making in the ED was described as medically driven and the nursing role described was focussed on assessment at triage and then procedural support (p. 54).
T felt that *Doctors have a greater understanding of what is happening than the nurses might* (T19).

The highly collegial team approach described by all was contradicted by a few participants who also described a lack of mandate in advocating for the patient at times. They described achieving their advocacy role via other medical staff passively, as described by S who said:

*If I can see that the family and the patient are not happy with things then I will try to push a bit further – wait for the next doctor to come on* (S11).

More active advocacy via a senior ED doctor or by initiating contact with medical and surgical on call registrars was described:

*Occasionally you are not happy with the medical decisions so you might push the issue but we are fairly lucky in that we have senior ED consultant cover* (Q10).

Another participant described a relatively long-serving ED nursing workforce with an ability to advocate saying *we’ve all been here about 20 years so we are not scared about coming forward* (R13).

**4.3.2(i) Literature Control related to ED Team Communication/Collaboration**

The description of highly collaborative team work (p. 77) appears to be at odds with subsequent descriptions of the ED nurses’ lack of influence over the clinical decision making, and the difficulty some nurses experienced in advocating for patients in the ED (S11). Power differentials between medical and nursing staff have been noted in the literature (Gott, Ingleton, Bennett, & Gardiner, 2011; Nugus, Greenfield, Travaglia, Westbrook, & Braithwaite, 2010; Powell & Davies, 2012; Salhani & Coulter, 2009). The expectation that doctors take responsibility for the clinical decision-making described (T19) is commonly held (Nugus, et al., 2010). In the acute in-patient situation fundamental decisions regarding the direction of care in this patient group may be driven more by the consultant than by consensus, with very limited opportunities for nurses to have input (Gott, et al., 2011).
This appeared to be the case in the ED according to some participants (T3,Q2) and has been discussed in relation to the ED context theme (p. 54).

Inter-professional boundaries may hamper effective communication and collaboration. Powell and Davies (2012) described a number of strategies nurses used to effectively work across the medical-nursing boundary; all of which involved “appealing to status” (Powell & Davies, 2012, p. 810). This may be done through appeal to senior medical staff, specialist teams or by invoking established guidelines and protocols. Nurses in this study described fulfilling their advocacy role through their relationships with the medical staff, passively (S11), or through appeal to more senior staff medical staff (Q10) or to the cancer specialist team. Two participants also described the FN guideline as enhancing team work and their nursing role (P,T, p. 68). Advocacy was more easily achieved with seniority (R13). Nurses with role seniority or long experience attain a higher status and therefore may have a higher level of influence across the medical-nursing boundary (Powell & Davies, 2012).

Nurse specialist roles may carry more status and influence at the medical-nursing boundary (Powell & Davies, 2012). Appeal to oncology nurse specialists by the ED nurses may be an effective way to support and influence the decision-making in the ED, as would a wider range of guidelines and protocols to support management through acute care. The dynamics of this boundary need to be addressed though if the specialist nursing role that lies at the heart of service delivery in the smaller satellite services is to achieve the influence at team, service and policy level that is envisaged (Cranleigh Health, 2011; DHBNZ, 2010; Ministry of Health, 2009). It also suggests that clinicians at the tertiary cancer centres may need to provide a mandate for oncology nurses at the periphery through the instigation of clinical pathways and guidelines.

4.3.3 Beyond the ED team

4.3.3(i) Hospice Interface

Communication and collaboration with services beyond the ED team was described by all participants. All participants without prompting discussed and described a well-established interface with their local Hospice or
Palliative Care Service. In some areas there were formal systems and alerts in place to trigger awareness and prompt ED staff to contact that service, and there was often 24 hour cover available (P,Q,S,T):

Yes we have a 24 hr. helpline with [names Hospice] and that is who we would call through to (R14).

In one DHB a formal alert system was also in use with other chronic condition patients:

Like the renal patients we have a "this patient is a renal patient please contact the renal unit", Palliative Care says this is a palliative care patient can you please let us know the patient is here....but not so for chemo patients (Q11).

She went on to elaborate that if this alert was in place it would prompt contact between the ED and Palliative Care but not the oncology team, even if the patient was still receiving active treatment via the oncology team.

4.3.3(ii) Oncology Interface
In contrast to the well established relationships with the local Palliative or Hospice teams described by all, no participant volunteered any comment about the interaction between the ED staff and their local oncology teams. When specifically prompted by the interviewer to describe that relationship most described little knowledge of the oncology nurses in their area (P,Q,S,T), and no professional contact (P,Q,S).

I've had bugger all to do with them over the last umpteen years, we've talked more to hospice for the patients who are really palliative or perhaps on chemo and sort of under the care of Hospice....we talk more to them than to anybody else (P21).

An ad hoc interface with the oncology team was described by all participants. S said sometimes people ask for oncology to be contacted...a couple of patients have asked us to let them know (S12). One described a 24 hour Hospice helpline but regarding access to an oncology specialist said:
No, I think that would be something that would have to wait until the next day and they would phone a tertiary provider...I don’t know of a case where we have picked up the phone to talk to an oncologist (R15).

A few commented that access to specialist advice did support the decision-making in the ED and supported continuity of care (S,T), and alleviated patient anxiety:

*It helps in a lot of ways to relieve the patient’s fear of “these doctors don’t know what they are dealing with here because they don’t know me” (T20).*

The participant from the DHB which relied on a local nurse-led satellite oncology service was aware of and utilised those staff members. Many participants, however they described this interface, underlined the lack of after-hours availability, as described as one of the constraints under the ED context theme (P,Q,R,T):

*Certainly in hours the oncology nurses are informed and if they can add something they can but after hours of course we have no access to them at all (R16).*

*If it’s during the day and we contact the oncology consultant then it is helpful (T21).*

One participant reflected that the oncology team had never put an alert system in place and had never asked the ED team to notify them when patients presented (Q). This was in spite of alerts being readily used and accepted in that DHB for a number of other complex and chronic conditions. Although this participant (Q) was open to the possibility of more formal communication between teams, another participant (P) did not think such an interface between the Oncology team and the ED team was either desirable or necessary.

To summarise, while there was some communication at clinician level there was little professional interface between the oncology nurses and the ED nurses described. Relationships and communication between their Hospice
team were well established but this was not the case with their local oncology team with whom the interface seemed to be *ad hoc* and dependant on the time of day. It seemed that the more established relationship and readier access to the hospice team might allow that perspective to dominate the clinical decision-making even though the patient was on active treatment with chemotherapy.

4.3.3(iii) Literature Control related to Communication and Collaboration beyond ED

The apparent lack of formal communication and collaboration between the ED team and the oncology team described in this study (P21,Q11,R15) is a long way from the ideals espoused by current government strategy. Improving service delivery across the continuum through effective planning, co-ordination and integration is a significant goal within New Zealand’s Cancer Control Strategy (Minister of Health, 2003). Effective care coordination is seen to be a function of the whole system, not just individuals, and requires communication between providers (Midland Cancer Network, 2008). Collaborative practice across multiple providers is identified in the literature as essential to continuity of care in patients on chemotherapy (Considine, et al., 2009; Courtney, et al., 2007; Livingston, et al., 2011; McKenzie, 2010). Continuity of care, as it is experienced by the patient, may also equate to less future need for health care for those individuals (King et al, 2008).

Internationally there is an increasing recognition of the need for collaboration between acute care and oncology, within critical care (Hull & O'Rourke, 2007), and within surgical care (Dunn, 2007; Ferrell et al, 2003). More specifically, models of care responding to the increased clinical risks in this patient group, recommend the integration of oncology and ED expertise as the key to service development (National Chemotherapy Advisory Group, 2009; National Confidential Enquiry into Patient Outcome and Death (NCEPOD), 2008). The NCEPOD enquiry went so far as to say that emergency care in this population was better delivered by cancer specialists within a specialist centre (National Confidential Enquiry into Patient Outcome and Death (NCEPOD), 2008). Others recommend urgent consultation between the ED team and oncology team (Harding & Simmons,
2012). Unfortunately, given the distance to tertiary cancer specialists in this country, this did not seem to occur, especially after hours (R14). Furthermore there were differences of opinion regarding the necessity of more formal processes expressed in this study (P,Q, p. 81).

The role of the oncology Clinical Nurse Specialist (CNS) at the interface between oncology and the ED was highlighted by Stowe (2011). This was a small study undertaken to assess the impact of an electronic alert that notified the oncology clinical nurse specialist (CNS) to attend the ED when a cancer patient from their caseload presented. This intervention was shown to reduce length of stay and to be cost effective. It also had unintended consequences when it became apparent that the presence of the Oncology CNS in the ED provided essential advice for oncologic emergencies, enhanced collaboration and “protected decisions that have been made, but that are not available to ED staff” (Stowe, 2011 p. 34). By maintaining a greater and more formal presence in the ED, the oncology CNS role may mitigate the negligible interface between oncology nurses and ED nurses found in this study.

Poor communication costs in many ways, including “economic, social, psychological, emotional, and collateral costs to the patient, the patient’s support network, the clinicians, the cancer care system, and to the larger society itself” (Thorne, Bultz, & Baile, 2005, p. 880). Team communication will influence patient/nurse communication; lack of clarity or poor communication of a treatment plan will in turn undermine the quality of the nurse/family interaction (Davis, et al., 2003). Communication on all levels underpins the advanced cancer patients’ experience of continuity of care (Nazareth et al, 2008). Relational continuity and communication continuity, inter-professional as well as interpersonal, are valued by patients and their care-givers (Lohfield, Brazil, & Willison, 2007; Smith, 2010). The benefit of relational continuity for cancer patients attending the ED was noted by one participant in this study (T20).
4.4 Awareness

Awareness was the third major category identified from the data. The sub-themes identified were perceptions and attitudes. These sub-themes were then further classified. Within each sub-theme there was a lot of individual variability within the transcripts. Table 4.4 illustrates the themes and sub-themes of this Category.

Table 4.4 Awareness themes and sub-themes

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<th>Category 3</th>
<th>Themes</th>
<th>Sub-themes</th>
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<tr>
<td>Awareness</td>
<td>Perceptions</td>
<td>Experience</td>
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<td>Bias/Ambiguity</td>
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<td></td>
<td>Attitudes</td>
<td>Non-judgemental</td>
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<td>QOL as a goal of care</td>
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<td>Reflection</td>
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Discussion of the literature in relation to both perceptions and attitudes is integrated and follows the description of the sub-themes of both.

4.4.1 Perceptions

No one position was more prevalent in the discussions, but a number of views were expressed when participants reflected on the particular factors that they felt may influence the decision-making and care of this group of patients in the ED. These perceptions have been grouped into experience (professional and personal) and biases and ambiguity.

4.4.1(i) Experience

One participant described how health professionals’ exposure to and comfort levels with palliative care may influence on-referral patterns within the ED (T). A shared clinician with the local hospice in one DHB seemed to have an impact on the participants’ exposure to palliative care (P,S,T). The EDs in these smaller DHBs also appeared to have very different mixes of medical staff. Differing levels of training and experience were felt by one participant at least to influence on-referral patterns, as she stated:

*A lot of them are GPs anyway so I guess for them it’s easier to go down the palliative route. Those who have only ever*
worked in ED will probably struggle with that a bit more and they would be more likely to refer to medicine (T22).

The same participant, as did one other (P), reflected on changing patterns of presentation to the ED which may have been a result of changing oncology practices over time, saying:

They [the patient] seem to have unrealistic goals and you think ten years ago there is no way that would have been given to you as an option. It is interesting and we don’t understand it... (R17).

Another participant described a personal experience with advanced cancer which she felt influenced her nursing care and response to this patient group: I have also had a friend die of cancer and I have had others so I can look at it from both sides of the fence... (S13). Others described the influence of prior nursing experience in influencing their care of these patients, particularly in their ability to communicate and collaborate with the patient and family:

...probably ICU has given me a bit of a, like an approach of like working with the family (S14).

4.4.1(ii) Bias/Ambiguity

Throughout the interviews there was a tendency for participants to describe scenarios or situate their responses at either end of the disease trajectory. One participant at one point described the availability of and use of specialist haematology advice in relation to the ED presentation of patients with acute leukaemia on chemotherapy, i.e. treatment given with curative intent (Q). Overall though there was a far greater tendency to relate to scenarios at the end of life end of the disease trajectory, regardless of whether the patient presenting was still on active treatment (P,R,S,T). Another of the threads was that of ambiguity. Participants did not define and articulate this as such but it has emerged from the analysis of the transcripts, from conflicting statements made between and by individual participants.
One participant recognised and described a particular viewpoint towards patients under Hospice care that may exist saying:

*There is always that stigma that comes up...oh well, they’re hospice, they are end of life care* (S15).

It was also noted that ED exposure to this patient group was naturally skewed towards those experiencing complications: *it is unfortunate but we only see the people who suffer really badly* (R18). She reflected that this may promote a bias against the value of such treatment:

*I suppose we have a lot of staff who say they would never do that but I say you have got to remember that you only see, I mean, I don’t know what the percentage of people on chemo at any one time in [DHB] and we see 3-4% of those people but we see them when they are suffering so you know, I don’t know that their answer would be the same, I think their answer would be to say why bother, again if it was their life I wonder if it would be the same* (R19).

It is possible that the changes in oncology practices, as discussed in the opening chapter have resulted in changing patterns of presentations to the ED. This was recognised and reflected upon by one participant (R17). Although specialist oncology services have responded and adapted to these changes and challenges, ED staff may be experiencing an increasing dissonance between their perceptions of treatment for advanced cancer, and the expectations of the patient and the oncology team.

There was ambiguity noted between active management of reversible treatment-related side effects (i.e. FN) and an end-of-life comfort-driven goal of care as described in this example:

*We do not want them to die of sepsis so we’re going to do what we can to stop it, even if it’s just going to give them another 12 hours to say good bye....get them up to the ward to get them comfortable up there* (T23).
Similarly the following statement by R also illustrates the ambiguity that may exist when managing acute presentations of patients seen as ‘palliative’:

If they are an acute episode, unless they are palliative then the fact that they have cancer and having active treatment doesn’t influence (R20).

In spite of the dilemmas that may be anticipated to arise in the care of this patient group in the ED (and which this researcher expected to uncover in this project), no participant described personal or professional dilemmas arising in the clinical care of these patients, except the conflict of prioritising the ED case load as previously discussed within the ED context of care (p. 56). However the quandary of over treatment versus under treatment was recognised by one participant (R), who described the ED team’s ethical, reflective practice in this way:

If we were having a debrief or a team meeting when we would ask did we do the right thing but that is all very well to sit here and say that two days later, but at the time they were in acute phase and we did A B C, and that is what ED nurses do anyway, which is not necessarily what is right for the patient but you are never going to be slammed for doing it – that is what I say to my team, a family is never going to say I wished you hadn’t put that tube down, but they may well say I wished you had. So you can’t come back from you didn’t treat (R21).

4.4.2 Attitudes

Individual participants displayed a number of attitudes in relation to their care of advanced cancer patients on chemotherapy. These were identified as a non-judgmental approach, an appreciation of the value of symptom management and quality of life (QOL), and a few made reflective comments about their care of this population group in response to the interview process.
4.4.2(i) Non-judgemental Approach

Many participants described a non-judgemental appreciation of the value of palliative chemotherapy for advanced cancer and verbalised support of the patient’s right to choose such therapies, T saying *it is not our job to judge whether a treatment is effective* (T24), and another:

_This patient is on chemo, someone who knows their condition better than we do has decided that it is going to be of benefit and whether it is curative or palliative benefit doesn’t really matter, somebody has started them on this track, therefore we are there to sort out the immediate problem that they have turned up with and hand them on to those who know them better and will carry on working out whether that is the right decision or not_ (P22).

4.4.2(ii) Appreciation of QOL

Three participants described a recognition of palliative care needs and the positive impact on QOL through appropriate ED intervention, one saying _I think sometimes there is the attitude of why bother but then when they see people walking out a lot more comfortable they see_ (S16). This was particular to one DHB and attributed to the presence of a staff member shared with the local Hospice team that had increased their exposure through assisting with planned interventions for symptom management such as drainage of pleural effusions.

4.4.2(iii) Reflection

A number of participants, prompted by the interview process reflected on the care of these patients in the ED. In particular this reflection was related to the need to improve nursing knowledge and procedural skills, for example:

_We don’t have anything and we don’t ever have any education on it to be honest and that is something we probably need to look at_ (Q12).

_...we really need to beef that up with training next year [portocath accessing] because really what is the point of so_
many people having them if we are not able to use them when they come in and it really frustrates the patient (R22).

Q also acknowledged that the ED might be underestimating the issue saying:

*It’s not really a big issue, but then maybe it should be a big issue, maybe we are a bit blasé (Q13).*

However, another participant firmly stated that care for this group of patients in the ED was no different from anyone else and would not be enhanced closer collaboration with the oncology team (P).

### 4.4.3 Literature Control related to Attitudes and Perceptions theme

There is little found in the literature to enlighten the comments about the impact of ED professionals’ training and experience on clinical decision-making. There is, however, ample evidence that health care professionals continue to equate palliative care with end of life (Fadul, et al., 2009) as was the perception described in this study (S15). This perception is evident even within oncology nurses (Pavlish & Ceronsky, 2009).

There is also increasing ambiguity in the interface between active treatment and palliative care. This was reflected in some statements that highlight the ambiguity in acute care when the patient is on active treatment, yet with palliative intent (R20,T23). This was apparent even though participants expressed a non-judgemental appreciation of the value of such treatments (P22,T24). Ambiguity was also noted in relation to FN (T23). FN is one of the life-threatening complications of chemotherapy (Courtney, et al., 2007). The goal of the FN pathway is to fast track recognition and management with appropriate broad-spectrum antibiotics. It is true that some patients will die of this complication in spite of prompt intervention. However, the expectation would be that the patient would be placed on the pathway and would continue to be intensively managed in spite of the fact that the patient had an advanced cancer, and regardless of the palliative intent of the chemotherapy.
The expectation that the complications and risks of chemotherapy be appropriately managed is highlighted by the following quote from the NCEPOD study:

“Having accepted the risks associated with systemic anti-cancer treatment, patients have every right to expect that they will receive care of the highest standard should they develop complications” (National Confidential Enquiry into Patient Outcome and Death (NCEPOD), 2008, p. 101).

If there is a failure to recognise ‘active’ treatment intervention, does this raise the potential for sub-optimal management of the side effects of active treatment if it is understood to be given with palliative intent?

As discussed in chapter 2.5, the traditional dichotomy has given way the “fuzzy and constantly shifting boundary that chemotherapy and palliation would patrol together...” (Baszanger, 2012, p. 869). The dichotomy was also apparent in how participants used scenarios to illustrate their narrative; Q at the active curative treatment end and all others at the end-of-life end (P,R,S,T). One participant did recognise the difficult balance between under and over treatment and described the team’s reflection on that (R21), but in general, situations described were either/or. In the hospital setting this either/or mentality has been described (Gott, et al., 2011).

The interface between palliative care and the ED has been examined, but more in light of the need to balance the cultural differences between emergency medicine and palliative care (Bailey, et al., 2011; Grudzen, et al., 2012; Grudzen, et al., 2011; Lukin, et al., 2012). This is seen as a necessary way of managing the risks of overtreatment of the terminally ill, but still sits on the end-of-life end of the continuum and does not necessarily address the dilemma of active treatment with palliative intent. Early use of palliative and supportive services not only improves QOL but may improve outcomes (Ahmed, et al., 2004; Temel, et al., 2010); and is advocated internationally (Abernethy & Currow, 2011; Ferris, et al., 2009; National Comprehensive Cancer Network, 2012; National Institute for Clinical Excellence (NICE), 2004). Therefore, the scenario of dual oncology
and palliative care involvement will increase and so potentially will the ambiguity that promotes.

Health care professionals’ attitudes to the value of chemotherapy to treat advanced cancer are mixed within and beyond cancer specialists (Jennens, de Boer, Irving, Ball, & Rosenthal, 2004; Stinchcombe, Detterbeck, Rivera, & Socinski, 2007). Clinicians other than medical oncologists are likely to have an out-dated understanding of its role and higher levels of pessimism (Jennens, et al., 2004). This may lead to a negative bias against its use but that may not matter in the ED when decisions to treat have been made elsewhere. Two participants in this study expressed a non-judgemental attitude towards the value of chemotherapy for advanced cancer (P22,T24). However, these may be personal opinions from ED nurses, who we have noted have little clinical influence in the ED, and not reflective of values held by ED clinicians themselves. It was also suggested that a negative perception of the value of palliative chemotherapy may arise due to the ED teams’ exposure to these patients only when in crisis (R19). Andrew and Whyte (2004) described a similar ambivalence towards palliative chemotherapy described by District Nurses in response to their exposure to patients’ with advanced cancer experiencing toxicity from chemotherapy.

Personal experiences of grief and loss were described by one participant (S13). Personal experience may be drawn upon professionally to enhance empathy and understanding, but lack of relevant personal experience does not preclude such a response (Supiano & Vaughn-Cole, 2011). Commitment to the provision of appropriate supportive nursing care was evident, in spite of the constraints of providing this within the ED. This commitment to appropriate care is also evident in the reflective statements made about the need for more education and training (Q12, R22). Provision of care to cancer patients within the environmental, time and educational constraints of the acute care, non-specialist setting is reflected in the literature (Mohan, et al., 2005).
4.5 Summary

In this chapter the findings of the research have been described and discussed. Overall, clinical care and decision-making in the ED was seen to be contextual. Within the ED context, presentation and urgency necessarily drive the clinical response. More in-depth assessment may be required to place the acute event in the context of the patient’s disease and tailor the clinical response appropriately. Intervention in the context of the patient’s chemotherapy is less apparent except for the management of FN. Decision-making and patterns of consultation may also be influenced by the availability and ease of established relationships, knowledge and experience. Although complexity and escalation of care was described, and ambiguity was apparent in some statements, clinical dilemmas regarding the level of intervention were not evident.

New literature searches were conducted in light of the findings. These, and the relevant research already reviewed in Chapter 2, have been integrated theme by theme in relation to the categories of Context and Communication and in relation to the Awareness category as a whole. This has served in many instances to reinforce the findings in this small study, and also to highlight significant issues raised in the literature that did not arise or were contradicted in this study. In the following chapter these findings will be discussed in relation to the aims of the study.
CHAPTER 5
Conclusions and Recommendations

5.1 Introduction

In this, the final chapter, I will discuss the research findings in relation to the aims of this study. The aim of this study was to describe the experience of a group of ED nurses caring for advanced cancer patients on chemotherapy when they presented with acute conditions to the ED. The methodology used to achieve this will be reflected upon. Recommendations for practice and education that have arisen as a result of this study will be discussed. Finally, suggestions for further research will be discussed as this chapter, and this project, is concluded.

5.2 Discussion

This section will discuss the findings of the research described in Chapter Four specifically in relation to the research objectives. These objectives were to explore the factors influencing nursing intervention in the ED for patients on chemotherapy for advanced cancer, when they presented acutely; and to explore the factors influencing clinical decision-making in the ED for this group of patients. As an exploratory descriptive study this has provided interesting insights into these questions. However, it is a secondary observation of the clinical decision-making undertaken in the ED, through the eyes of the ED nurses participating in the study.

5.2.1 Factors influencing nursing intervention in the ED

ED nurses influenced care at triage, especially with regard to the recognition of FN and initiation of the mandated FN pathway. The role of the ED nurse in the management of FN and the use of FN pathway is in accordance with the literature. ED nurses described going to some lengths to place the acute event in the context of the disease trajectory, but that the chemotherapy itself did not influence care provision, was also a predominant finding. This may have consequences for the optimal management of chemotherapy treatment–related side effects in patients with advanced cancer presenting acutely to the ED.
This also seems to be the distinct difference to the care provided by the oncology team, when assessment and management of events arising in advanced cancer patients on chemotherapy will be heavily influenced by the context of the chemotherapy drugs themselves, and further by the patients’ disease and position on the trajectory. All of which is part of the specialist oncology knowledge base, training and resources, as is the privilege of a longitudinal relationship with the patient/whanau. It may be that both ED and Oncology teams have failed to appreciate the clinical context in which the other team works. It therefore seems crucial that more work is done to address ways in which the oncology team can influence the ED decision-making. In particular how the chemotherapy context can be more influential in the clinical decision-making and interventions provided in the ED.

There was a lot of consistency in the description of the constraints in caring for this complex group of patients in the ED. Lack of resources, low volumes, and the acute, emergency nature of the ED environment, precluded more specialised nursing care. This was aggravated by variable availability of clinical information and access to specialist advice. Many of these issues are in accordance with the literature. The impact of the low volumes described is not so evident in the literature and may reflect the fact that much of the research has been undertaken overseas in larger metropolitan centres that do not replicate the reality of the isolation of our secondary hospitals or the distance to tertiary cancer care. The NCEPOD document may come closest to reflecting models of care and issues arising at the spoke that translate to local situations (National Confidential Enquiry into Patient Outcome and Death (NCEPOD), 2008).

Under the category of communication and collaboration it appears that the ED nurses worked with the patient and family/whanau to establish their goals and expectations. They were aware of some of the barriers that may exist and the potential for divergence in views. Although the impression was of a highly cohesive ED team, it seemed that the decision-making was medically driven. ED nurses undertook to advocate when they perceived the patient/whanau were uncomfortable with the decisions being made. This advocacy was through appeal to ED medical staff or on call clinicians. This
A description of a power differential was found to be in accordance with the literature.

In relation to the final category, that of awareness, there was less saturation of the data so this section may reflect a variety of personal perspectives about what influences care in the ED. The analysis of the data did uncover a number of inconsistencies between and even within participants’ statements. The ambiguity that arises between active and palliative treatment and which has been well described in the literature did seem to be apparent. What were not described though were any clinical dilemmas arising in the ED as a consequence. The assumption that these patients presenting to the ED acutely would present a clinical dilemma was one of the drivers of this research question. This raises the question of whether the dilemma may not even be recognised in the ED, and if it is not, does a clinical dilemma even exist?

This question of whether there is a dilemma or not in relation to the acute care of advanced cancer patients on chemotherapy treatment may be better answered by oncology teams and the patients they provide care for. Having entered into a relationship with these patients and commenced cytotoxic chemotherapy a duty of care arises. This duty drives the care of these patients by the oncology team. That duty may not be apparent to other health professionals due to the ambiguity arising at the active treatment/palliative care interface; or if it is, those health professionals assessing the acute event in the context of their own experience and practice environments may not have the specialist knowledge or resources to fulfil that duty of care. It is also possible that it is too easy to not appreciate a failure to rescue in patients with advanced cancer on chemotherapy who experience poor outcomes. Auditing adverse outcomes following cytotoxic chemotherapy may be a means of ensuring that failure to rescue is acknowledged.
5.2.2 Factors influencing team decision-making in the ED

The data analysis revealed a number of different context-dependant factors with varying levels of influence on the decision-making and care in the ED. Although this was a very small study there was a high degree of data saturation in the participants’ descriptions of the factors influencing the clinical decision-making in the ED. It was apparent that the clinical decision-making was presentation and acuity-driven, and conducted in collaboration with the patient and family/whanau. This was seen to be little different to any other acute presentation to the ED. Once stabilised, care was escalated to in patient or on-call teams. This description is in keeping with the culture and purpose of the ED as described in the literature. The complexity and high rates of admission described were in agreement with the literature. Factors such as the patient’s advanced cancer had some influence, but careful assessment was necessary to put the event in the context of the patient’s disease trajectory. That the patient was on chemotherapy appeared to have the least influence of any of these factors on the clinical response.

The clinical response was determined by the medical team with ED nurses undertaking a procedural and advocacy role. Decision-making beyond the initial response was escalated to in-patient or on-call teams. Specialist oncology advice, while used at times, had limited availability after hours. It seemed that there were remarkable differences in the interface between the ED and Hospice services compared to the ED and oncology team. Well established and collaborative relationships with the local Hospice team may have increased their influence on the decision-making. The more ad hoc interface between the ED and oncology services may have reduced the level of oncologist influence on the ED decision-making. Availability, quality and utilisation of the clinical record may reduce the influence the oncologists may have expected to have.

Patient and family/whanau were also very influential and played a significant role in the decision-making. They made a significant contribution in terms of clarifying their own expectations and goals, but also in the provision of essential information regarding their treatment. The prevalent description of an educated, informed and proactive patient group may be a
testament to the work of the oncology teams in these areas but is at odds with the literature where there are issues described relating more to poor compliance and late presentation. It does not reflect the low SES, high Māori population in these provincial areas that may increase the barriers to effective self-management such as low health literacy and access to healthcare that are noted in the New Zealand literature.

Significant differences were obvious in the relationship between the ED and Oncology/Palliative services and data saturation was achieved on this matter. One could always speculate as to the reason for the different levels of collaboration between ED and Hospice and ED and oncology. It may be driven by the 24 hour availability of the Hospice team, greater volumes of hospice patients in general being seen through the ED, or that Hospice is a locally-generated resource. It may also be a tendency for cancer services to focus on the delivery of chemotherapy but not extend their influence to the entire pathway as has been noted elsewhere (National Chemotherapy Advisory Group, 2009).

The *ad hoc* interface between the ED and oncology services was out of step with the literature and the international recommendations for more integrated care between the two. More needs to be done to understand the barriers to this locally, and to determine whether the apparent low level of oncologist influence on the ED decision-making has any impact on patient outcomes or patient experience of care. Given the trends overseas and the predicted increases in number, complexity and co-morbidities in this patient group in New Zealand this may be prudent.

It may also require the tertiary cancer services and clinicians to support acute care provision by the introduction of clear guidelines and pathways, beyond the FN pathways already in use. This may be necessary to support and mandate the satellite oncology nurses and ED nurses who may struggle to influence the medical decision-making in the ED otherwise. Given the possibility that critical decisions about care may not be made in the ED but escalated to on call teams, these guidelines and pathways need to reach beyond the ED to all generalist acute care areas.
5.3 Methodological Reflection

The qualitative descriptive methodology utilised was an appropriate way to develop an initial understanding of the how clinical decisions are made and how nursing care is provided to advanced cancer patients on chemotherapy presenting to the ED. As well as asking how they would recognise these patients in the ED, the open questions prompted participants to describe how team clinical decision-making, level of intervention, and nursing care was influenced by the patient’s advanced cancer and chemotherapy. While this may have provided an authentic description of how nursing care was influenced, it was a secondary interpretation by the participants’ of what influenced the team’s clinical decision-making.

It was clear in this study that ED medical staff had the greatest influence on the clinical decision-making and interventions and the nurses very little. I suspect it was exactly this power differential that led me to explore the management of this group of patients in the ED through the ED nurses rather than through the ED clinicians. This may also be reflected by the initial opposition to the research proposal raised by the medical staff in one of the DHBs approached for ethics approval.

What this researcher had not anticipated was the difficulty in garnering interest from ED nurses on this topic. Where the researcher had thought to uncover ED nurses grappling with clinical dilemmas in relation to the care of this group of patients, and keen to take up an opportunity to express their concerns, this was not so. This may be illustrative of the low numbers of these patients seen through the ED overall, and their relative insignificance within the ED milieu. It may also reinforce the notion that care is context-dependant and what may be perceived as clinically problematic by the oncology team may not be viewed the same way by health professionals in acute and emergency care.

The study was clear in its intention to describe care of these patients in the DHBs at the spoke at a distance from their regional cancer treatment service. As such it is not intended to reflect the experience of nurses in EDs in the main centres. It was disappointing that participants represented only three of the four DHBs anticipated areas, and that the sample was so small.
However, on some of the main factors influencing care, where the data reached saturation this was noted in the findings. With such a small sample it is possible that these findings are not reflective of all ED nurses in these DHBs. It is also possible that the findings reflect the practices of the single tertiary cancer treatment centre that serves these satellite DHBs. Resonance and relevance of the findings will, as always in qualitative research, be determined by the reader.

5.4 Recommendations for Practice

There is reason for oncology nurses to reflect on their roles, especially those in advanced practice roles. It may be accurate that oncology nurses, this researcher included, focus on the care of these patients within and between oncology services but have not always extended that to other significant clinical points in the pathway that may arise beyond our service. To seek to influence beyond individual patient’s care and promote change at a team, systems and policy level is the hallmark of advanced nursing practice. This has caused this researcher to reflect on her own ability to influence and participate in the decision-making within the oncology team and beyond. The professional influence of this Oncology CNS role within the oncology team may be a feature of specialisation, long-standing relationships with clinicians and the mandate that comes from a longitudinal relationship with the patient and family/whanau. However, it also seems to his researcher that the status conferred by role, seniority and experience only works to a small degree outside the oncology team. This experience is borne out by the power differential evident in this study and highlights the need for a collaborative approach across all disciplines involved in the care of this patient group.

To achieve the level of inter-professional collaboration along the lines of the acute oncology service models described in the literature would require a multi-level approach but would sit well within the expectations of cancer care espoused in government policy in New Zealand. Development of such models of acute oncology care will need to be innovative to overcome the challenge of an economically constrained health care system, low patient volumes, a specialist knowledge base invested in too few staff at the spoke,
and to overcome the effect of rurality. On an individual level it may be valuable for oncology nurses to consider the study done by Stowe (2011) as discussed in Chapter 4.3.3(iii). Although a small study to assess the economic impact of an alert tool, the unexpected finding was that the presence of the oncology CNS in the ED had a positive impact on care, inter-professional collaboration and enhanced the scope of the oncology CNS role. That may be the one thing that as individual oncology nurses we can do now.

5.5 Recommendations for Education

Many participants in this study did raise their own concerns about lack of education to support the provision of specialist nursing care of this group of patients. This was particularly in regard to the acquisition and maintenance of skills pertaining to Port-A-Caths®, but it was also apparent that these ED nurses did not have an awareness of side effects of chemotherapy apart from that of FN. Given the expectations placed on ED nurses and teams by multiple sub-specialties, and that the key focus of the ED is on acute and emergency care it may be appropriate to provide information and resources tightly focussed on the chemotherapy side effects most likely to result in ED presentations and to support that education with simple guidelines. For example, an assessment and treatment algorithm for the management of chemotherapy-induced diarrhoea would place that presentation in the context of the chemotherapy treatment, as well as within the ED context. Not only would the event be managed within the ED context, i.e. generically, with fluid and electrolyte replacement, supportive care, but the offending medication will be discontinued and care specific to CID will be instituted. It is important that such education and guideline development be undertaken in collaboration with the ED team to avoid the imposition of these on ED staff by those outside the ED.

5.6 Recommendations for Further Research

The intention of this study was a beginning attempt to understand factors that influence the acute care of advanced cancer patients on chemotherapy treatment in the ED. As such it is merely an opening gambit. Additional quantitative studies would be required to ascertain if there were significant
differences in outcomes for similar clinical scenarios depending on access to tertiary level specialist cancer care for acute events. This would highlight differences that may exist between emergency care delivered in a tertiary centre with ready access to the specialist oncology team, and emergency care delivered when this specialist advice is at a distance, and whether this was a factor in the disparate cancer outcomes. Short of such a study, an audit of mortality and morbidity related to chemotherapy toxicity in patients with advanced cancer would ensure that poor outcomes, if and wherever they may occur, were recognised rather than let a failure to rescue go unnoticed. What may also be of value and which was lacking in the literature was a qualitative evaluation of the cancer patients’ experiences of, and access to, acute and emergency care while receiving chemotherapy treatments.

The hierarchical nature of health care professionals has been well described and was evident in this study. Considering the finding in this study that the clinical decision-making in the ED was medically driven it would be worthwhile asking the same questions of ED clinicians. This would provide and understanding of the factors that influence their clinical management and decision-making in this group of patients.

This study was initiated on the basis that ED nurses and ED teams were likely to experience clinical dilemmas in relation to the care of advanced cancer patients on chemotherapy when they presented acutely. That this small sample of ED nurses did not does not necessarily mean a dilemma does not exist. It may be that the dilemma has not been recognised, at least in the relatively short time patients are managed in the ED. Further research to explore this topic from the perspective of the oncology team would provide a contrast to the experience and perceptions of the ED nurses and ED team.

Reflecting on the original literature search, and this researcher’s impression that the defined and definable ends of the cancer continuum have been well studied, but that literature relating to the overlap between the two is absent, one is reminded of Elizabeth Baszanger’s description of the “fuzzy and constantly shifting boundary that chemotherapy and palliation would patrol together...” (Baszanger, 2012, p. 869). This shifting boundary may
be a quick sand that can only be probed from the firmer ground on either side; so we retreat to our preferred positions and avoid the ambiguity that it presents. Straddling that boundary is the term ‘palliative’ which may mean end-of-life to some but is increasingly used by others to describe an active disease-modifying but non-curative decision to treat. Much of the ambiguity may be related to the meaning individuals’ attribute to this term. Further research to better understand how acute and emergency health professionals view the term ‘palliative’, and just what influence that has on their clinical decision-making and care provision would add to the understanding of acute and emergency care of this patient group.

5.7 Conclusion

This Chapter brings this project to closure with a discussion of the findings in relation to the original aims of the study, considered within the context of the relevant international and national literature on the subject. As an initial exploratory, descriptive study this has achieved what it set out to do albeit with a very small sample of ED nurses. However it is a starting point, as was indicated at its inception. Having provided a better understanding of the factors that influence care for this patient group in the ED, it does represent an opening gambit in the on-going dialogue between Oncology and ED nurses that seems to be needed. Ultimately this will not be achieved without the dissemination of the findings to both oncology nurses and ED nurses. Opportunities for the publication and presentation of these findings will be sought in the near future.
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Appendices
### Appendix 1

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<tr>
<th>CATEGORY</th>
<th>THEME</th>
<th>SUB-THEME</th>
<th>INTERPRETATION</th>
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<tbody>
<tr>
<td>Context</td>
<td>ED Context</td>
<td>Clinical Intervention</td>
<td>Clinical intervention in the context of the ED is focussed on the presentation itself and the urgency of that. Clinical decision-making is driven by the ED doctors and patient themselves. Intervention beyond the initial stabilisation of the acute problem is generally escalated to the on call or specialist teams that are available. Clinical care is little different to any other presentation to the ED; the cancer diagnosis and being on active treatment, while known, may have little influence on the actual decision-making.</td>
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<tr>
<td></td>
<td>Nursing Intervention</td>
<td>Clinical intervention in the context of the ED is focussed on the presentation itself and the urgency of that. Clinical decision-making is driven by the ED doctors and patient themselves. Intervention beyond the initial stabilisation of the acute problem is generally escalated to the on call or specialist teams that are available. Clinical care is little different to any other presentation to the ED; the cancer diagnosis and being on active treatment, while known, may have little influence on the actual decision-making.</td>
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<td></td>
<td>Nursing Intervention</td>
<td>ED nurses influence patient care at initial triage and assessment. Patients with advanced cancer on chemotherapy represented a complex group of patients who required more holistic assessment. However nursing interventions are apparently no different for this patient group except in relation to the risk of immune-compromise. This was at odds with other statements made that suggested that the patient’s advanced cancer and chemotherapy did influence the clinical care, but may reflect an initial acute (emergency) response followed by a more measured response, often escalated to other teams.</td>
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<td>Challenges</td>
<td>ED Context</td>
<td>Within the context of the ED there are challenges accommodating and prioritising the needs of this population group. ED nurses may experience conflict due to competing priorities. ED nurses have many expectations placed upon them by different sub-specialties. Low volumes of this particular population group preclude more specialised management. Acute care via the Oncology team during working hours may further reduce their exposure to this patient group and increase the tendency for after-hours presentations when they do not have oncology specialist support and advice available. Specialist oncology advice not available 24 hours. Clinical information to support decision-making in the ED may be unavailable when it is really needed or not routinely accessed and even when accessed may not always be helpful to the ED team.</td>
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<td></td>
<td>Patient Context</td>
<td>Characteristics of Patient Group</td>
<td>Recognition of patient on chemotherapy very dependent on the patient informing ED staff at initial presentation. Clinical decision-making is very reliant on the patient being able to collaborate in the decision-making and the patient is a source of information about the oncologists expectations of treatment. Patient group on the whole may be well educated and resourced with information, but their ability to collaborate and support the ED decision-making may be reliant on patients own expectations, health literacy, condition at presentation and ability to articulate themselves. Expectations may have been raised by the oncology staff that may create some conflict in the ED setting.</td>
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### Appendix I

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<th>THEME</th>
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<tr>
<td>Disease Context</td>
<td>Assessing the acute event in the context of the patient’s disease trajectory</td>
<td>ED nurses sought to place the acute event in the context of the patient’s disease trajectory. Establishing what was normal for a patient with a chronic disease enabled them to put the acute event in context. This was important in distinguishing disease-related or other acute events which may be unrelated and/or reversible. There was an appreciation of only seeing the patient at a fixed point in time and that this was a person who had a history and a future, but limited options to treat.</td>
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<td>Context</td>
<td>Awareness of immune-compromise and use of neutropenic pathway</td>
<td>Across all there was a very high awareness of the risk and management of neutropenic sepsis which was invariably recognised by the triage nurse. All areas had a specific neutropenic sepsis pathway which provided a standardised clinical response. Fever was a very objective sign used to trigger this pathway. Most found the pathway enhanced their nursing role but it is worth noting that there may be some negative perceptions of clinical pathways in the ED, especially the imposition of these by those who do not understand how an ED works.</td>
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<td>Chemotherapy Context</td>
<td>Clinical intervention independent of chemotherapy</td>
<td>Clinical intervention in the ED does not appear to be influenced by the fact that the patient is on chemotherapy except for an awareness of immune-compromise. Assessment and management of the acute event is the same as for any other with a similar presentation. Clinical decision-making is often made independently of specialist knowledge and information about chemotherapy related side effects or the overall expectations of the treatment in terms of expected response rates, survival improvements.</td>
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<td></td>
<td>Knowledge of specific chemotherapy-related side effects</td>
<td>There is little in the way of specialist information and resources available in the ED. The patient is a valuable source of information about the specific chemotherapy, either through what they could communicate or what they brought in with them. There was no consensus on whether more information about specific chemotherapy side effects was relevant, with one reflecting that it might be, another adamant that it was not necessary to ED clinical management decisions.</td>
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<td>Communication &amp; Collaboration</td>
<td>With Patient &amp; Family</td>
<td>Collaboration and Communication</td>
<td>ED nurses and teams work with the patient and family/whanau to establish their goals and expectations and to clarify the expectations of oncology care. Nurses used honesty and communication skills to manage differing expectations arising in the ED. The acute event may bring these dynamics to the surface. There is a recognition of dissonance between the patient and the oncologist’s expectations of care and between patient and whanau expectations.</td>
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<td></td>
<td>Within the ED Team</td>
<td>Collegiality within the ED team</td>
<td>Overall the impression was of a highly cohesive team with good interdisciplinary communication. However, most participants had indicated (ED context) that the decision-making was medically led. Participants with more years ED experience seemed very comfortable contributing to the decision-making and advocating for the patient. Advocacy was usually achieved by escalating to more senior medical staff or in-patient on call teams, however different DHBs have different availability of on-call registrars and senior medical staff.</td>
</tr>
<tr>
<td></td>
<td>Beyond the ED Team</td>
<td>Hospice Interface</td>
<td>All participants described very clear and well established relationships with their local hospice teams, including 24hr cover in some areas. When patient is receiving integrated oncology/Hospice care and presents to the ED with an acute event, this is the relationship that seems to dominate, even though the problem may be chemotherapy-related. Therefore there seems to be a skew towards Hospice liaison not Oncology.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Oncology Interface</td>
<td>There was no formal interface between the ED and the Oncology team. Where there was an interface it was ad hoc, more evident at a medical level, not nursing and utilised in working hours only. One DHB with a nurse-led oncology service and particularly complex tertiary relationships seemed to be developing unique solutions to this interface. But not all saw any value in an oncology team/ED interface.</td>
</tr>
</tbody>
</table>
### Appendix 1

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>THEME</th>
<th>SUB-THEME</th>
<th>INTERPRETATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness</td>
<td>Experience</td>
<td>Differing levels of professional experience and training may influence decision-making in the ED, and on referral/consultation patterns. Professional role may influence perceptions and care of these patients. Exposure to those experiencing complications of treatment may promote a bias against the value of such treatments. Changes in oncology treatment practices may be changing patterns of presentation to the ED. There may be increasing dissonance between ED perceptions of goal of Rx and patient/oncologist expectations. Personal experience may influence decision-making and nursing care. Value of personal experience and prior nursing experience to enhance provision of nursing care.</td>
<td></td>
</tr>
<tr>
<td>Perceptions</td>
<td>Ambiguity</td>
<td>There may be a bias against the value of palliative chemotherapy for advanced cancer due to the pattern of exposure to these patients to ED staff. Hospice/palliative care is closely associated with end-of-life care. Scenarios described by some to illustrate the care of advanced cancer patients on chemotherapy were situated at the end-of-life end of the disease trajectory. Some recognition of the transition between active oncology and palliative service and some recognition of integrated care but ambiguity: When patients are seen as Hospice/Palliative. If labelled “palliative” and still receiving active chemotherapy with palliative intent, perceptions and therefore care may be skewed towards palliative, comfort-driven care. Between active management of treatment-related side effects and an end of life, comfort driven goal of care.</td>
<td></td>
</tr>
<tr>
<td>Attitudes</td>
<td>Non-Judgemental</td>
<td>Non-judgemental appreciation of the value of palliative chemotherapy. Value of hope recognised but not necessarily a recognition of the impact of palliative Rx on improving survival for some advanced cancers.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>QOL as a goal of care</td>
<td>Recognition of need for symptom management to improve QOL and ability to impact on QOL through intervention in the ED. This was evident in the ED that shared a staff member with Hospice and had higher exposure to planned interventions for symptom management.</td>
<td></td>
</tr>
<tr>
<td>Reflection</td>
<td>Reflection</td>
<td>Discussion about the care of these patients in the ED provoked a few participants to reflect on that care. Changes in oncology treatment patterns, especially with this group of patients may be changing patterns of presentation to the ED. There may be increasing dissonance between ED staff's perceptions and understanding of goals of active Rx and the patient's expectations.</td>
<td></td>
</tr>
</tbody>
</table>
7th June 2012
Lynne Gray
19 Oswald Street
Mangapapa
Gisborne 4010

Dear Lynne,

I am writing to confirm that the College of Emergency Nurses New Zealand (CENNz) has agreed to pass on to members your request for participants in your research. The committee were very interested in your abstract; there is a notable lack of research into specific patient groups who use emergency departments and we are keen to support such investigations. You would also be welcome to submit an article for our journal at some stage.

Please let me know if we can be of further assistance. In the meantime we await the result of your initial submission.

Yours sincerely

[Signature]

Iona Dichan
Chair
8th June 212

Northern Y Regional Ethics committee

To Whom It May Concern

Kia Hiwa Ra! Kia Hiwa Ra!

Tena Koutou Katoa!

Re: Support of Lynne Gray’s Masters Research.

In my capacity as Kaiwhakahaere Hauora Maori (GM Maori Health Tairawhiti District Health, TDH) I have reviewed Lynne Gray’s Master’s proposal. As a result of this review my understanding is that this is a mainstream proposal however it is expected to have utility for Maori. Lynne has taken into account the guidelines for research involving Maori and the requirements that flow from this. I keenly anticipate that her research and findings will illuminate a pathway forward for cancer treatment responses.

I wish her well in her endeavours and thank you for this opportunity to express my support.

Naka noa na
Appendix IV

Reference Number 29/12

30 July 2012

Lynne Gray
Master of Nursing Student
C-/ Faculty of Health Science
EIT Hawke’s Bay

Dear Lynne

I am pleased to inform you that your research project "Management of Patients with Advanced Cancer on Chemotherapy Treatment with Acute Conditions in an Emergency Department" was reviewed by the Research Ethics & Approvals Committee at their meeting held on 27 July 2012, and formally approved for two years.

The Reviewer(s) note that in your information for Research Participants form, EIT students are specifically cited as being able to pull out of the research at will? Does this mean that non EIT students are not able to withdraw? Please clarify and respond back to the Committee.

You are reminded that should the proposal change in any significant way, then you must inform the Committee.

Please quote the above reference number on all correspondence to the Committee.

Please provide the Committee with a progress report after one year of the project and a brief summary at the conclusion.

The Committee wish you well for the project.

Yours sincerely,

Jeanette Fifield
Secretary – Research Ethics & Approvals Committee

CC: Dr Salome Meyer

Eastern Institute of Technology

Hawke’s Bay Campus: 61-65 Chaucer Street, Napier, New Zealand  –  P: (06) 574 8000  –  F: (06) 574 8013  –  E: info@eit.ac.nz  –  www.eit.ac.nz

Te Puna Campus: 297 Hamiton Road, Gisborne, 4010, New Zealand  –  P: (06) 809 0813  –  F: (06) 809 0855  –  E: info@tepunacampus.ac.nz  –  www.tepunacampus.ac.nz

Regional Learning Centres: Hawke’s Bay; Taumarunui, Thames, Wairoa, Upper Hutt, Rotorua, Napier
Appendix V

Information for Research Participants

<table>
<thead>
<tr>
<th>Date:</th>
<th>24th August 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Project Title:</td>
<td>Advanced cancer, chemotherapy and the Emergency Department</td>
</tr>
<tr>
<td>To:</td>
<td>ED Nurses in [redacted]</td>
</tr>
<tr>
<td>Researcher(s):</td>
<td>Dr Salome Meyer, Adrianna Grogan, Lynne Gray RN,</td>
</tr>
<tr>
<td>Affiliation:</td>
<td>Eastern Institute of Technology</td>
</tr>
</tbody>
</table>

Description of the research:
An exploration of how Emergency Department (ED) Nurses manage acute presentations of people on chemotherapy for advanced cancer. The objectives are to identify factors that influence clinical decision-making and nursing care.

What will participating in the research involve?:
A 30-60 minute audiotaped telephone interview at a time and place convenient to you. Discussion will be guided by open questions but will otherwise be driven by what you want to share of your experiences related to the topic.

What are the benefits and possible risks to you in participating in this research?
You may be uncomfortable if you have experienced difficult situations in the ED with these patients who may have had adverse outcomes. You may also benefit from exploring any problems you have experienced and contributing to a better understanding of the issue.

Your rights:
- You do not have to participate in this research if you do not wish to.
- If you are a student at EIT and decide to take part, you can withdraw your information from the research within 2 weeks and this will not affect treatment or assessment in any courses at EIT.
- Once you have completed the research you have a 2 week period within which you can withdraw any information collected from you.
- You are welcome to have a support person present (this may be a member of your family/whanau or other person of your choice)
- You may request a summary of the completed research

Confidentiality:
All information that identifies you or the DHB in which you work will be omitted once the audiotape is transcribed and the audiotape will be deleted. The transcription of your discussion will be maintained electronically in a secure place away from your signed consent and only shared with the interviewer, the thesis supervisor and associate supervisor.
Transcription will be held securely for 10 years. Data from all participants will be used in the analysis and write up so individuals and individual DHBs will not be identifiable.

If you wish to participate in this research, or if you wish to know more about it, please contact

<table>
<thead>
<tr>
<th>Contact Person:</th>
<th>Lynne Gray RN</th>
</tr>
</thead>
<tbody>
<tr>
<td>EIT School/Section:</td>
<td>School of Nursing</td>
</tr>
<tr>
<td>Work phone #</td>
<td>06 8685054</td>
</tr>
<tr>
<td>Mobile phone #</td>
<td>027 9353922</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Supervisor Name(s):</th>
<th>Dr Salomé Meyer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work phone #</td>
<td>974 5450</td>
</tr>
<tr>
<td>Email address</td>
<td><a href="mailto:smeyer@eit.ac.nz">smeyer@eit.ac.nz</a></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Head of School/Manager:</th>
<th>Rachel Vernon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work phone #</td>
<td></td>
</tr>
<tr>
<td>Email address</td>
<td><a href="mailto:rvernon@eit.ac.nz">rvernon@eit.ac.nz</a></td>
</tr>
</tbody>
</table>

For any queries regarding ethical concerns, please contact:

Chair, Research Approvals Committee, EIT. Ph. 974 8000

This study has been approved by the EIT ethics committee on 27th July 2012, Reference # 29/12.
Appendix VI

CONSENT FORM

Project Title: Management of patients with advanced on chemotherapeutic treatment in the Emergency Department.

Researcher(s): Lynne Gray

I have read and I understand the Information for Research Participants sheet dated 24/08/2012 for volunteers taking part in this study. I have had the opportunity to discuss this study and am satisfied with the answers I have been given.

I understand I am able to withdraw all of my information until ----/----/---- (2 weeks after interview)

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the testing at any time and this will in no way affect my academic progress/employment.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I have had time to consider whether to take part, and know who to contact if I have any questions about the study.

I agree to take part in this research Yes No

I consent to my interview/activity being videotaped/audiotaped

I wish to receive a summary of the results

Signed: __________________________

Name: __________________________
Signature of Research Participant’s Support Person (if applicable)

_________________________________________________

Date: ______________________

Witness: _________________________________________

I/We as researcher(s) undertake to maintain the confidentiality of information gather during the course of this research.

Signed________________________________________________

Dated____________________

This study has been approved by the EIT Research Ethics and Approval Committee on 27th July 2012, Reference # 29/12.
2 July 2012

Lynne Gray  
19 Donald Street  
Mangapapa  
OISBORNE

Dear Lynne,

RE: District Health Board Research Application - Reference 12/07/112

Thank you for your application to conduct research within the District Health Board. I am pleased to advise that your application has been successful. Subject to:

1. Obtaining Eastern Institute of Technology (EIT) Research Ethics and Approvals Committee (REAC) approval for this study (please forward a copy of this to this office once received).

Please note that the locality form is now out of date from 1 July 2012, however, this letter along with your application should provide you with sufficient locality approval.

Please find enclosed a signed copy of your application. At the conclusion of your research, will require a final report on the outcomes of this research.

Should you have any queries during your research, please do not hesitate to contact me during normal working hours (details below). Best wishes for your research.

Regards,

On behalf of the
Research Committee
Appendix VIII

Lynna Gray
Oncology Nurse Specialist
Tairawhiti District Health
PO Box 7001
GISBORNE

Dear Lynna

The Clinical Board of the District Health Board considered your request to conduct research into: “Management of patients with advanced cancer on chemotherapeutic treatment with acute conditions in an Emergency Department” at the hospital.

The Clinical Board has approved your request.

We wish you all the best with your research project.

Yours sincerely

Acting Chair
Clinical Board,
Appendix IX

30 November 2012

Lynne Gray
Oncology Clinical Nurse Specialist
Tairawhiti District Health Board
Email: lynnewilkie@clear.net.nz

Dear Lynne

Clinical Board – Locality approval research paper

Further to your email of 5 November, I advise that at the 24 October Clinical Board meeting your research request was considered and approved. The minutes approving your request is as follows:

7.1 Request for locality approval “management of patients with advanced cancer on chemotherapy with acute conditions in an Emergency Department”. The board noted the research proposal from Lynne Gray, Master of Nursing student, Faculty of Health Science, Eastern Institute of Technology. Having sighted the ethical approval from EIT the board approved that Lynne could take part in the research.

Good luck with your project.

Yours sincerely

Chief Executive

K/2012/letter/3/12/25/Gray, Locality approval for research application, 29-11-2012
Appendix X

Locality Assessment by Locality Organisation

Refer to pages 12–15 of Guidelines for Completion of the National Application Form for Ethical Approval of a Research Project (NAFG-2003-v1).

Locality organisation sign off

Ethics committees review whether investigators have ensured their studies would meet established ethical standards if conducted at appropriate localities. Each locality organisation is asked to use the locality assessment form to check that the investigator has also made the appropriate local study arrangements.

Ethics approval for study conduct at each site is conditional on favourable locality assessment at that locality.

Please note that the locality organisation may have additional requirements to be met before a study may commence at that locality.

Part One: General

To be completed by the principal investigator for this locality.

| Full project title: | Management of Patients with Advanced Cancer on Chemotherapeutic Treatment with Acute Conditions in an Emergency Department |
| Short project title: | Advanced Cancer: Chemotherapy and the Emergency Department |
| Locality to be assessed: | District Health Board |
| Brief outline of study: | To explore how Emergency Department (ED) Nurses manage acute presentations of people on chemotherapy for advanced cancer. The objectives are to identify factors that influence care, identify barriers and enablers and how these impact on clinical care provision. |
| Principal investigator (for this locality): | Lynne Gray |
| Contact details: | Home: 15 Oswald Street, Mangapapa, Otorohanga 086635254 lynnegray@clarcag.rrz Work: Taumarunui District Health, PO Box 7201 08 8620500 8150 Lynne.Gray@dh.org.nz |
| Other local investigators (list all at this site) | |
| Contact details | |
Part Two: Locality issues

To be completed by the principal investigator for the locality and signed by the authorised locality representative. (See the Guidelines (NAFG 2009 v1) (pages 13-15) for more information and examples.) Identify any local issues and specify how these issues will be addressed.

1. Suitability of local researcher
   For example, are all roles for the investigator(s) at the local site appropriate?
   Has any conflict of interest might have between her or his local roles in research and in patient care been adequately resolved?
   - Yes ☐
   - No ☐

2. Suitability of the local research environment
   a) Are all the resources (other than funding that is conditional on ethical approval) and or facilities that the study requires appropriate and available?
   - Yes ☐
   - No ☐

   b) Is this site accessible for mobility-impaired people where necessary?
   - Yes ☐
   - No ☐

3. Have issues such as cultural issues specific to this locality or to people being recruited at this locality been addressed?
   - Yes ☐
   - No ☐

4. Have the local investigator contact details and other important contact details been provided to the locality organisation for checking?
   - Yes ☐
   - No ☐

Part Three: Declaration by locality organisation

I am authorised to complete locality approval on behalf of this locality organisation. I understand that I may withdraw locality approval if any significant local concerns arise. I agree to advise the principal investigator and them the relevant ethics committee should this occur.

(Questions 1-4 at Part Two above must be completed prior to signing.)

I confirm the organisation has sufficient indemnity insurance to compensate participants for harm that does not qualify for compensation under the Injury Prevention, Rehabilitation and Compensation Act 2001.

Signature: ___________________________ Date: ___________________________

Name: ___________________________ Position: ___________________________

Contact details: ___________________________

Hospital & Specialist Services
District Health Board