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**Finding what works and what doesn't
work: Caring for women with a
fungating tumour of the breast**

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Erratum

This study is also limited by problems related to sampling and the inability to achieve data saturation. Both of these factors impacted on the construction and development of the causal model. As such, confidence in the causal model derived from the data is not assured and the findings of the study should be viewed accordingly. However, the causal model can still be of some use to clinicians and hopefully will provide the stimulus for further study in this area.

Abstract

A fungating tumour of the breast causes distress to those living with the illness and creates many challenges to the nurses who care for them. Control of malodour, exudate, haemorrhage and cosmetic acceptability creates complex wound care problems. Managing to live and maintain a sense of normality must take account of the palliative and chronic nature of this illness.

This study utilises the grounded theory research method to discover the main concerns of nurses who care for this group of clients and how they continually resolve them. Three women who have this condition have provided information that adds and lends support to how the nurses provide care. This thesis argues that **finding what works and what doesn't work** is the core process that resolves the main concern of striving to maintain a sense of normality in life activities. Problem-solving, wound care and wider psychosocial problems initiate the process of **finding what works and what doesn't work**. Through making sense of the situation by gaining an understanding of the women's situations, being non-judgemental and building trusting relationships, the ability to **find what works and what doesn't work** is more likely to be achieved. This must take account of the physical, cultural and professional considerations that impact on the nurse's ability to provide appropriate care. The consequence of **finding what works and what doesn't work** is that the nurses' practice has the capacity to be transformed. This study provides insight into the creativity and complexity that characterises expert community nursing practice in caring for this particularly challenging group of clients.

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Chapter One

Introduction

The interest for this research arose out of practising as an Oncology District Nurse. In the course of practising in this speciality it has not been uncommon to encounter women with a fungating tumour of the breast. It is difficult to comprehend how these women go about their daily lives with such an horrific wound. There is a lack of research to guide health practitioners in aspects of care other than managing a gross wound. Clearly, nursing this particular group of oncology clients requires knowledge and skill. Literature describing the roles of nurses and uncovering expert practice in a community setting is scarce. This researcher is concerned that the knowledge and skill of community nursing is not comprehensively documented.

Breast cancer is a subject that is receiving increasing attention in New Zealand both nationally and within the health system. The most recent statistics from the Cancer Society report that in New Zealand 1500 women receive a breast cancer diagnosis and 600 women die of breast cancer each year (Cancer update in practice, 1996). Breast cancer is the leading cause of death for non-Maori women and for Maori women it is the second leading cause of death following lung cancer. Eighty four percent of all deaths resulting from breast cancer occur in women over the age of 50 (Cancer update in practice, 1996, p. 1). There are numerous risk factors associated with breast cancer and some are not well supported by research. The Cancer Society indicates that being female, becoming older (meaning 50 years and over) and having a family history of breast cancer, are the strongest risk factors. It is thought that diet plays a role in the risk of developing breast cancer. Although unproven, diets high in fat are thought to be detrimental and consumption of fresh fruit and vegetables as well as fibre is thought to be helpful. Breast-feeding is also thought to reduce the incidence of breast cancer in pre-menopausal women (Cancer update in practice, 1996).

The diagnosis and treatment of breast cancer is a subject that has received extensive research. Despite the wealth of information available there are still uncertainties. These uncertainties create decision-making difficulties for both health professionals and women about diagnostic procedures and treatment options. Because of these

decision-making difficulties a multidisciplinary group led by John Collins (Professor of Surgery Faculty of Medicine and Health Science Auckland) and John Simpson (General and Breast Surgeon Wellington) have produced the Guidelines for the Surgical Management of Breast Cancer (1997). These guidelines include criteria for diagnosis and recommendations for the treatment of breast cancer and have been endorsed by the Council of the Royal Australasian College of Surgeons. They are designed to guide rather than dictate by collecting the best available evidence about breast cancer management and making it readily available to health professionals and the general public.

Facione and Giancarlo (1998) suggest that early detection for breast cancer has improved the staging level at diagnosis. However, there remain a significant number of women who still present with an advanced breast cancer. These advanced breast cancers are discovered by women themselves. Thirty percent of these women have had symptoms for at least three months (Facione & Giancarlo, 1998, p. 430). In some low socio-economic groups sixty percent of women have had symptoms for at least three months with many women having had symptoms for six months or longer (Facione & Giancarlo, 1998, p. 431). Attitudes that prevent patients seeking help include the belief that earlier diagnosis would not change survival outcome, delaying diagnosis is not perceived as a risk, and poor access to health services. Fear and depression are psychological factors that also delay health-seeking behaviour (Facione & Giancarlo, 1998).

The issues outlined above are particularly relevant to patients with fungating breast tumours because they have the most advanced form of breast cancer. The definition of a fungating tumour is expanded upon in the literature review. For the purpose of an introductory definition a fungating tumour occurs when the tumour erodes through the skin to form either a nodular mass or a crater of ulceration (Grocott, 2000).

The most common site for a fungating tumour is the breast. No statistics in New Zealand are available relating to the proportion of women with breast cancer who have a fungating tumour. An unpublished Master's Thesis by Lawes (1998) examines the epistemology of breast cancer in Pacific women in New Zealand. Data analysis on the statistics for the ethnic groups reveals that more Pacific Island women present

with advanced disease than other ethnic groups although the incidence for breast cancer is lower. As Lawes (1998, p. iii - iv) states,

Pacific and Maori women appear to have lower incidence of breast cancer than Other women, and Pacific women present with the most advanced disease at diagnosis. International evidence suggests that these patterns are contributed to by socio-economic status, delay in diagnosis, other social factors such as malnutrition, and possibly biological factors.

The only statistical information obtained on women with a fungating tumour of the breast is provided by Fairbairn (1993). Fairbairn (1993) cites one study that documented 104 replies from radiotherapy centres, hospices and community nurse centres. This provided information to calculate that 2,417 fungating lesions were seen in one year, sixty two percent of these fungating lesions were of the breast (Fairbairn, 1993, p. 206). The outcome of this study was that fungating wounds occur in enough numbers to represent a significant problem.

The next most obvious question pertains to the reason women delay in presenting to health professionals until a fungating lesion has developed. The reasons are many and varied. Pudner (1998) suggests that there is failure to seek advice or help due to a fear of cancer or embarrassment caused by the location of the tumour. Other reasons, according to Fairbairn (1993) include other priorities such as family needs, fear the unknown or of hospitals, ignorance, stigma from feeling unclean or as a punishment for past misdemeanours. However, a fungating tumour can also occur when breast cancer treatments are no longer effective or there is no further treatment available to halt the cancer.

A delay in presenting is especially significant because where there is a diagnosis of a fungating tumour of the breast the cancer is advanced with metastatic spread likely. Therefore the aims of treatment become palliative rather than curative. Mullins (1986) defines palliative treatment as therapy aimed at relieving or reducing the intensity of symptoms of disease without necessarily producing a curative outcome.

The problems of care and treatment of women with a fungating tumour of the breast are complex and must take account not only of the physical implications of this condition but also include the psychological, social, sexual and spiritual dimensions

of a person. Love (1995) identifies psychosocial support as an area that medicine has not addressed. The growth in support groups especially for breast cancer has arisen out of the fact that there is seldom any psychosocial support provided by the medical profession. Little attention has been paid to this important aspect of care although this is changing (Maunsell, Brisson & Deschenes, 1995). In terms of sexuality Robinson (1998, p. 45) explains that less than ten percent of clients will raise the subject of sexuality themselves although it is reported that eighty five percent of people experience sexual dysfunction following treatment for cancer. Exploring issues related to sexuality includes our feelings about our body, our worthiness of love and our physical ability to participate in sexual relationships. Health professionals have a mandate to assess and intervene appropriately the concerns clients express in regard to sexuality (Robinson, 1998). Nurses in the community setting have the opportunity to explore these concerns and are therefore in a position to promote quality of life for these women and their families.

This introductory chapter provides an overview examining the nature of fungating tumours of the breast and the implications of living with these wounds. Following this, the interest that stimulated this research topic is discussed. Explanation of these aspects leads into justifications for this research and the aims of this thesis. Prior to the conclusion of this chapter a format for the following chapters will be outlined.

1.1 Overview

The definition of a fungating tumour has already been provided and as it suggests, a cancer that has invaded through the epithelium conjures images of something quite horrific. The size of the wound can vary from a small area, like that of a two dollar coin, to one that can cover most of the chest wall circling right around to the back. This type of wound is subject to recurrent localised infection, capillary bleeding and has large quantities of exudate and malodour. Dressing care is therefore central to wound management. Cook (1998) utilises a single case study and Grocott (1992) writes from experience to describe the objectives for wound care for fungating tumours. These authors suggest that the aims of nursing wound care should include control of pain, reduction of complications such as infection or haemorrhage, control of exudate, control of odour, minimal disruption to the client's life with dressing

changes, dressing changes without causing trauma, restoration of body symmetry and cosmetic acceptability. These objectives of wound care influence the patient's quality of life and, clearly, the psychological impact of these wounds is significant.

The psychological impact of a fungating tumour wound refers to the thoughts and emotions associated with having cancer of the breast. Having breast cancer according to Wilkinson and Kitzinger (1994) is likely to lead to thoughts about one's own mortality and/or being frightened by treatment options. The potential to feel abandoned by lack of social support is common. Fairbairn (1994) discusses the psychological needs of women with a fungating tumour, in a general way, and suggests that their psychological needs would be as great as women with operable breast cancer if not more. The way in which these women feel and cope with their condition will be affected by their fears and misconceptions about breast cancer, the shame associated with a delay in presenting for medical help that can be made worse by the attitudes of staff, denial mechanisms, revolt experienced by having a gross wound, and the disappointment and bitterness where fungation is the result of failed treatment (Fairbairn, 1994). In-depth discussion of the care nurses provide, related to wound care and the psychological implications of a fungating tumour is elaborated upon in the literature review chapter.

As mentioned previously the diagnosis of a fungating tumour of the breast results in treatment that concentrates on palliative intervention. Fairbairn (1993) provides an overview of fungating breast tumours. In this article she states, "The presentation of a fungating lesion determines a stage 3 presentation which is considered incurable but not untreatable, although locally advanced disease does not always indicate disseminated disease" (pp. 209-210). Discussion of palliative treatments for women with fungating tumours of the breast is provided in the literature review. These palliative treatments include surgery, radiotherapy, chemotherapy and hormonal therapy.

1.2 Interest that led to this research

Women with a fungating breast tumour not only have to cope with the implications of having cancer, but they also have to cope with a graphic reminder and a wound that is very difficult to manage. This graphic reminder is so physically obvious and so

closely tied to female sexuality and body image because of its location. Although literature suggests that women over the age of 50 are the predominantly effected group, in practice women as young as 27 have been diagnosed with a fungating tumour of the breast. Fungating tumours distort the shape of the breast leading to difficulties in restoring body symmetry. The disfigurement and the problems of exudate and malodour have led to many questions that have been difficult to answer.

The most immediate problem for a novice practitioner in this field is finding the most appropriate wound dressing to apply to manage these difficult wounds. An initial literature search on the subject of fungating tumours revealed an abundance of writing on wound care specific to these wounds, (Carville, 1994; Clark, 1992; Collinson, 1993; Cook, 1998; Cosgrove, 1997; Davis, 1995; Fairbairn, 1994; Fitzgerald & Simms, 1987; Grocott, 1992, 1997; Hallet, 1995; Hastings, 1993; Moody & Grocott, 1993; Shutler, Jones & Thomas, 1997; Woodhouse, 1992), to name but a few. Within this literature a variety of wound products are advocated. Sophisticated products such as alginates, a non-adherent absorbable primary dressing product, through to practical initiatives such as the use of incontinence products to contain exudate have all been suggested. The rationale for why particular products are advocated is based on experience with such products and knowledge of dressing product characteristics to fulfil objectives in promoting quality of life. Most of these recommendations are not research based. Fairbairn (1994, p. 272) states:

The last few years have seen a slight increase in the number of articles written about fungating wounds, but most are not based on clinical research into this area of wound care... As Thomas points out, the guidelines on wound care for fungating lesions are not based on controlled clinical trials but on a survey of what is commonly used and the "personal views of the author on the likely value of certain dressings or treatments in the management of the different wound types based upon a knowledge of the properties and performance characteristics of the materials concerned".

Moody and Grocott (1993) also support this view suggesting that care is provided without being based in research but rather by experiential and exploratory means. Nevertheless, the literature did provide a starting point to examine wound care in relation to caring for women with this condition.

More questions have arisen in caring for these women because nursing care is not limited to managing wounds. Gross wounds that are extensive in size and exudate are

frequently malodorous and prone to bleeding become the catalysts to other issues such as self esteem, maintaining relationships and a sense of normality in daily living. Although the initial intention was to explore the concerns of the women themselves this was not possible. Therefore this research explores the concerns of nurses who care for this group of clients supported by data from some women.

The following questions need to be asked in order to explore the role of a community nurse caring for this particular group of clients. What kinds of care do nurses provide? What knowledge underpins their practice and how does this influence how they deliver care to these women and their families? In fulfilling a primary health-care provider role, what are their main concerns? How are their concerns resolved and what strategies do they use? Therefore, questions that relate to nursing and how care is delivered have arisen and answering them is the aim of this research.

To ask these questions and to attempt to find answers, a research method that enables the core concerns of the participants to emerge has been selected. The research method that will fulfil this goal is grounded theory. Grounded theory also provides us with information about the strategies that participants utilise to resolve core concerns and integrate experience (Glaser, 1998). In this way, the participant's patterns of behaviour are brought out into the open and made explicit. This provides all involved with the care of women with a fungating tumour of the breast, and the women themselves, with a greater understanding of what motivates and directs actions that are taken.

Also relevant to these questions is the context of health care. A medical diagnosis incorporates underlying pathology, presence of symptoms and employs technology to investigate and treat the problem. Nurses have a role in balancing the medical implications of a diagnosis with a wider holistic view of the person. If this is the case, what does this look like and how does this occur? The premises of grounded theory ensure that these core concerns and the behaviours that result are made explicit.

1.3 Justification for this research

This research was undertaken in an endeavour to understand the core concerns of women with a fungating breast tumour and nurses who care for these women. This is

why grounded theory was deemed suitable for this research project. Glaser (1998, p. 36) states,

Grounded theory is uniquely suited to this task of discovering the basic core category (which is usually, but not necessarily, a basic social process). Stated another way, the core category shows the continual multivariate processing of what is going on to relieve the participants' main concern.

Thus the strategies utilised by participants, that continually resolve what concerns them, are also uncovered.

There is no prior research on this particular subject and so there is a range of possibilities for what might be reported. Owing to the exploratory nature of this research, and the focus on social processes, grounded theory was selected as the most suitable research method. The processes of theoretical sampling, constant comparative analysis and theoretical coding provide a framework that yields rich descriptive data that can be analysed to develop a theory, which integrates experience (Glaser, 1998). Grounded theory also facilitates the use of literature and Glaser recommends that an extensive review of the literature conducted in the writing up phase can consolidate and provide depth to the theory that results. However, in undertaking this research some prior knowledge of the subject of fungating tumours was inevitable because of the researcher's clinical practice. Medical and nursing literature relating to fungating tumours provides context and background information to this study and is suitable to be included as a literature review.

The grounded theory method and its underlying assumptions are linked to a philosophy of science. This philosophy as discussed by Hutchinson (1993) is that of symbolic interactionism. Bowers (1988) describes symbolic interactionism as a theoretical focus upon the individual's behaviour rather than the social system and examines the social-psychological theory of social action. Briefly, symbolic interactionism is concerned with the self (as socially constructed), the world (the social world as interpreted and experienced), and social action (a series of processes that occur among individuals in the context of their social world).

In undertaking this research, it was not known if all the questions this researcher has asked would be answered. Although this researcher has been persistent in trying to recruit participants with fungating tumours of the breast there have been almost no

women with this experience available to participate. In light of this, this research has focussed on the nurses' concerns and core processes.

1.4 Aims of this research

The primary aim of this research is to explore the main concerns of women with fungating tumours of the breast. Due to the limitation of the few women with this condition, nurses were included as a group who have concerns with regard to the care they provide. Therefore a secondary aim exploring the nurses' concerns was considered appropriate. Related to exploring the main concerns, is to uncover how the participants continually resolve their main concerns.

It is significant that little is known about this subject and the intent of this research is to add to the body of knowledge around the subject of advanced cancer. As an outcome of increasing knowledge, it is hoped that nurses will have access to research that relates to their practice. A better understanding of the nurses' concerns in caring for these women and the concerns of women with a fungating tumour of the breast, will give a much broader and more in-depth perspective to integrate into daily practice to improve the quality and effectiveness of care.

1.5 Format for following chapters

This thesis contains five chapters. This first chapter titled Introduction has provided a broad explanation of this thesis. Discussed initially was the broader subject of breast cancer. The statistics and risk factors associated with breast cancer were outlined. This provided context to the subject of fungating breast tumours. An explanation of the definition and epidemiology of fungating breast tumours was provided. Following this, some possible reasons why fungating breast tumours may occur and the palliative nature of this situation was provided. Included in the overview was a brief discussion on the physical implications relating to the wound, the objectives of wound care and the psychological impact that results. Palliative interventions were also outlined. How interest in this particular topic for a research project arose has also been explored. Questions that emerged from this researcher's clinical experience in caring for this group of clients and the lack of research to support practice have been

put forward. These questions lead into justifications for this research and the development of aims for a thesis project.

Chapter Two provides an in-depth look at literature around the subject of this thesis. The medical and nursing literature that reflects the disciplinary body of knowledge about the subject of fungating tumours is presented. This includes literature about the diagnosis and prognosis of a fungating tumour, and symptom management issues. Reviewing symptom management issues involves palliative treatment, wound management and the broader psychological, emotional and social aspects of care.

The third chapter outlines the research method utilised in this thesis. Grounded theory in the context of a qualitative research approach is defined. The underlying assumptions of this method are also discussed. Grounded theory as a research process is expanded upon and includes explanation of the constant comparative method of data analysis, theoretical sampling and theoretical coding. Also explored in this chapter are the processes of completing this research including the gaining ethical approval, the access and recruitment of participants and how rigor has been established.

Chapter Four presents the results of data analysis. This includes identification of the categories and their relationship to the core category. Examples from participant's data are used to explain aspects of the data analysis as well as leaving an audit trail to establish rigor.

Lastly, Chapter Five is a discussion of the findings in relation to the literature. The core category of **finding what works and what doesn't work** is explored and related to this chronic illness. Also presented are the implications and limitations of this study and the directions for further research.

Chapter Two

Literature Review

This literature review chapter provides an opportunity to explore the literature related to fungating tumours of the breast and the nursing care that is provided. Both the medical and nursing literature will be discussed to provide an overview of diagnostic and prognostic indicators and symptom management issues. Review of symptom management issues includes palliative treatments, wound care implications and the psychological, emotional and social elements of care.

Although the grounded theory method, as described by Glaser (1998), does not advocate a formal literature review as such, it is included in this study because background information related to the subject provides a context for the study. An opportunity to explore the current knowledge of fungating tumours is taken and it introduces the topic and provides a critique about what is known thus far.

To begin it must be noted that most of the nursing articles are not research-based and focus on wound care issues. Evidence for the majority of nursing articles utilises single case studies and only two articles by Grocott (1997; 2000) are scientifically researched. Indeed the dearth of research-based literature is identified by Clark (1992), Cosgrove (1997), Grocott (1993, 2000), Hastings (1993), Ivetic and Lyne (1990), Moody and Grocott (1993) and Shutler, Jones and Thomas (1997). It is interesting to note that Ivetic and Lyne reported this problem in 1990 and Grocott in her article published ten years later still reports the same situation. Nevertheless, in conducting this literature review principles and practices especially related to wound care, are similar among authors on the subject and are the same whether the fungating malignant tumour is specifically of the breast or anywhere else on the body. Therefore weight of consensus of opinion provides some validity to what is written. The medical literature is not designed to be a comprehensive review. Instead it is used to provide background information on the subject of advanced breast cancer and the mainstay of treatments for this condition.

2.1 Diagnosis and prognosis

The definition of a fungating breast tumour is an appropriate place to begin. Articles that specifically address the subject of fungating breast tumours within the medical literature are difficult to find. This is due to the fact that the medical definition of locally advanced breast cancer includes those that have fungating wounds. Locally advanced breast disease can be characterised by infiltration of the cancer into the skin and chest wall and/or matted axillary lymph nodes with or without fungating ulcerating lesions as a consequence (Dauphin et al, 1997; Esteva & Hortobagyi, 1999; Rodger, Leonard & Dixon, 1994). Esteva and Hortobagyi (1999) use the TNM (T = represents the tumour, N = regional lymph node involvement and M = distant metastases) classification system to relate locally advanced breast cancer and the staging process. To have a diagnosis of locally advanced breast disease the tumour must be larger than five-cm (T3), and/or involve the skin (T4), with any node involvement (N). Any tumour category with N2 (matted axillary node) or internal mammary lymph node (N3) is also diagnosed as locally advanced breast cancer. Inflammatory breast cancer due to its aggressive nature and high level of metastatic features is also classified within this diagnostic group. Nursing literature expands upon this definition to explain that fungating tumours grow rapidly and haphazardly. Cancerous invasion can involve the blood and lymph vessels. These lesions have the potential to necrose due to a loss of vascular supply. The end result may either be a crater of ulceration or a nodule with the appearance of a fungus. (Carville, 1994; Clark, 1992; Cook, 1998; Cosgrove, 1997; Fairbairn, 1993; Fitzgerald & Sims, 1987; Grocott, 1993, 2000; Hallet, 1995; Hastings, 1993; Ivetic & Lyne, 1990; Moody & Grocott, 1993; Price, 1996; Shutler, Jones & Thomas, 1997; Woodhouse, 1992) Ivetic and Lyne (1990) identify that while there is consensus about the definition of fungating lesions, there is contention as to whether the term fungating or ulcerating is used to describe them. Some authors use the terms interchangeably while others use them according to the staging of the cancer. For the purposes of this literature review the terms are used interchangeably.

The most common site of a fungating tumour is the breast and can be either the sign of primary cancer, or a secondary manifestation of cancer (Ivetic & Lyne, 1990). The statistics of the number of women diagnosed with advanced breast cancer where

fungation is a manifestation are difficult to elicit. The numbers of women who present with locally advanced disease is estimated at five to fifteen percent although for non-industrialised countries this can be as high as forty - sixty percent (Esteva & Hortobagyi, 1999, p. 457). The statistics also depend on clinical definitions indicated by Rodger, Leonard and Dixon (1994), to describe anywhere between 1 in 4 or 1 in 12 women that present with locally advanced breast cancer (p. 1431).

If it is accepted that approximately ten percent of women present with locally advanced breast disease what then is their prognosis? Rodger, Leonard and Dixon (1994) report the median survival as 2 – 2.5 years. Despite the use of medical therapies such as radiotherapy and/or chemotherapy relapse is common - effecting over half of these women (Norton, 1996; Rodger, Leonard & Dixon, 1994). Therefore, this situation means that medical therapies are palliative in nature, where quality of life is the aim, and symptom management of disease is the outcome.

The nursing literature reflects the medical literature when describing the aims of treatment being palliative as opposed to curative (Clark, 1992; Cook, 1998; Fairbairn, 1993; Grocott, 1992, 1997, 2000; Hastings, 1993; Haughton & Young, 1995; Moody & Grocott, 1993; Woodhouse, 1992). Some nursing authors suggest that it is only when treatment options are exhausted or have become too toxic that care becomes palliative (Fitzgerald & Sims, 1987; Grocott, 1993; Hallet, 1995; Ivetic & Lyne, 1990; Shutler, Jones & Thomas, 1997). Despite this difference of when the person's condition becomes palliative, the objectives of care in terms of management of symptoms including wound care remain the same. Fitzgerald and Sims (1987, p. 16) describe this when they state:

If the cancer is responding to treatment by chemotherapy, radiotherapy, hormonal manipulation or immunotherapy, then the nurse can promote healing by good wound management. If the disease is not responding, then good wound management and psychological support can do much to enhance these patients' quality of life.

Symptom management for women with fungating tumours of the breast revolves around alleviating the symptoms related to advanced disease, and/or the side effects of palliative treatment regimens, wound care measures, and addressing psychological, emotional and social needs.

2.2 Symptom management

Symptom management for the purposes of this literature review is restricted to that found within the literature on fungating tumours. It is not the scope of this thesis to examine palliative symptom management in its entirety. Palliative treatments are determined, according to Hastings (1993), upon the staging, size, location of the tumour, and the general health of the patient. Justification for why palliative symptom management is needed is provided by Hastings (1993). "The lesion itself is only a small part of the problem for patients with a malignancy, but the distressing nature of its symptoms can lead it to become the focus for their lives for many patients" (Hastings, 1993, p. 70). Hormonal therapy, radiotherapy and chemotherapy are the primary methods used to achieve management of symptoms for fungating tumours. Surgery can also be considered. Symptom management is therefore also concerned with the alleviation of side effects of these mainstay treatments as well as considering symptoms such as pain and nausea/vomiting.

One of the most effective yet least traumatic treatments for fungating tumours of the breast is hormonal therapy (Clark, 1992; Fairbairn, 1993; Hallet, 1995; Hastings, 1993; Ivetic & Lyne, 1990). Crown (1998, p. 12) describes response rates of up to sixty percent in women with hormone receptor positive metastatic breast disease. The most common hormonal therapy used is tamoxifen.

It is suggested by Rodger, Leonard and Dixon (1994, p. 1431) that the preferred treatment for locally advanced disease is radiotherapy, which results in thirty percent of women having no local disease upon death. Radiotherapy has side effects and these include fatigue and skin inflammation/desquamation. Response rates can be increased to as high as eighty percent by the addition of hormonal treatments or chemotherapy and this is generally well tolerated even by the frail elderly (Rodger, Leonard & Dixon, 1994, p. 1431).

The role of chemotherapy is an area of debate in the medical literature. This is due to the delicate balance between the benefits of chemotherapy, such as extending survival and palliating symptoms, and the disadvantage of impairing quality of life due to the side effects of chemotherapy (Crown, 1998).

Crown (1998), in a comprehensive review of medical research literature, identifies patients with advanced breast cancer that are hormone receptor negative or where there is metastatic disease present, as the group that have the most to gain from chemotherapy. This is because hormonal therapy has limited effectiveness. Chemotherapy is given in drug combinations and the first line regime is cyclophosphamide, methotrexate and 5-fluorouracil (CMF). Crown (1998) argues that CMF is generally well tolerated and provides effective palliation of symptoms although the response is partial and it is expected to be from six to twelve months before relapse occurs. Doxorubicin 60 - 75 mg/m², according to Crown (1998), then became the gold standard as a single agent therapy for first line treatment of metastatic breast disease. This treatment regime has produced a forty - fifty percent response rate in this group of patients (Crown, 1998, p. 13).

Crown (1998) then suggests that research into the development of new drugs in the treatment of breast cancer has led to the discovery of taxanes and these are now the focus of medical research. Paclitaxel (taxol) and more recently docetaxel (taxotere) have been trialed resulting in docetaxel becoming a standard treatment at 100 mg/m². This dose has shown disease response at all metastatic sites. Median duration of response to docetaxel was 8.3 months and the median survival 16.4 months (Crown, 1998, p. 13). Docetaxel has also proven to be effective second and third line treatment especially for those patients that have anthracycline resistant disease (Crown, 1998).

Surgery is less likely to be an option but when it is indicated can range from the removal of the breast (mastectomy) through to a 'toilet' procedure (to achieve debridement of necrotic tissue) in those patients where it is not contraindicated by frailty (Fairbairn, 1993; Fitzgerald & Sims, 1987; Hastings, 1993; Haughton & Young, 1995; Ivetic & Lyne, 1990; Roger, Leonard & Dixon, 1994). Collinson (1993) and Carville (1994) question the need for surgical debridement for two reasons. Collinson (1993) argues that the availability of wound products that debride more gently contraindicate surgery. Carville (1994) explains that eschar can protect underlying structures and removing the eschar can increase the risk of bleeding.

Symptom management also includes alleviating pain. Although Hallet (1995) and Hastings (1993) acknowledge that many fungating lesions are painless, when there is pain there can be a variety of causes. These include the size and location of the lesion,

pressure on other organs, nerve involvement, past pain experiences and psychological distress. The first step according to Carville (1994) is to identify the cause of the pain after which appropriate interventions can be implemented from changing the type of dressing through to systemic analgesia. Systemic pain control is managed mostly with paracetamol and a slow-release form of morphine (Cook, 1998; Cosgrove, 1997; Woodhouse, 1992). Hallet (1995) also indicates the use of medications from the tricyclic and steroid groups to assist in the alleviation of pain. Obviously medications have side effects and nurses should also be concerned with managing these. Through a single case study outlined by Cosgrove (1997) the importance of regularly reviewing pain relief is noted. Pain levels may increase as disease progresses, or may decrease as a result of treatments. Practitioners need to be aware of this so that interventions can be adjusted appropriately.

Nausea and vomiting are other symptoms that need to be managed. These symptoms are most commonly related to treatments such as chemotherapy although Price (1996), supported by a single case study, identifies that malodour from fungating malignant wounds can cause nausea and vomiting. Nausea and vomiting can lead to an inability to maintain nutritional status thereby causing weight loss, weakness and lethargy. Therefore reducing nausea and vomiting through treating the cause and using antiemetics is indicated. Hallet (1995) and Cosgrove (1997) recommend diets high in protein, carbohydrates, fats, vitamins and minerals to rebuild weight and energy levels.

2.3 Wound management

The provision of wound care can be considered a symptom management endeavour. However, it is discussed separately in this literature review in order to portray each aspect. The wound management literature is extensive and therefore only literature relevant to the management of fungating tumours is discussed. This includes wound care related to malodour, exudate, haemorrhage and cosmetic acceptability. Before reviewing these aspects the aims of wound management are described.

The aim of wound care is to address the challenges fungating wounds create. Moody and Grocott (1993) explain that these wounds are dynamic - that is they frequently

change in terms of size and shape, as well as levels of exudate, malodour, infection, haemorrhage and pain. This makes finding suitable dressings difficult. The underlying disease may be aggressive with a resulting short life expectancy or localised causing disfigurement yet a long life expectancy. The impact of the wound can be significant to the client and/or the family. Fitzgerald and Sims (1987) make it concise when they say “The aim of wound management is to control odour, discharge and haemorrhage; to promote wound healing where possible and to maintain the dignity of the patient” (p. 16). All of the authors reviewed reflect components of this aim whether stated in the objective for palliative symptom management or in terms of wound management. With the aim clarified, malodour is the first of the symptoms to be discussed.

Malodour is described by Carville (1994), Fairbairn (1994) and Haughton and Young (1995), as the most distressing symptom of fungating wounds. Bacterial colonisation is suggested as a cause of malodour and examples of bacteria, commonly found in these wounds, include proteus, klebsiella and pseudomonas (Clark, 1992; Collinson, 1993; Cook, 1998; Ivetic & Lyne, 1990). The cause of malodour, according to Cook (1998) and Haughton and Young (1995), is said to be due to the complex interaction of aerobic and anaerobic bacteria that produces diamines - for example, putrescine and cadaverine. Reduction of bacterial load is logical in eliminating malodour. Although Grocott (2000) supports all the above causes of malodour she suggests that the exact causes of malodour have not yet been established.

The assessment of malodour is subjective and a guideline such as that suggested by Haughton and Young (1995) is helpful in measuring the degree of odour and any progress being made. A scale, with indicators about strong, moderate, slight and no odour, is outlined by these authors. While this is not a highly accurate empirical measurement tool the alternative option is to make no assessment. There are also inherent problems with subjective measurement scales. This includes who should make the assessment, as it can be argued that the patient is more sensitive than the nurse to this aspect, and that different nurses making assessments will vary ratings on scales because of subjectivity (Haughton & Young, 1995). There are no real solutions to this difficulty.

Following an assessment of malodour the next step is to carry out interventions aimed at eliminating it. As indicated above treatment of malodour includes the reduction of microbial load by the use of antibiotic therapies. In terms of reducing microbial load, antibiotic therapy is indicated where there is an identifiable infection present, demonstrated by the culture of a wound swab and the presence of signs and symptoms of infection. The antibiotic needs to be specific to the organisms identified. Metronidazole is the antibiotic most frequently used, as it is effective in treating both aerobic and anaerobic bacteria (Carville, 1994; Clark, 1992; Cosgrove, 1997; Fitzgerald & Sims, 1987; Hallet, 1995; Haughton & Young, 1995). Antibiotics can be given systemically or as a topical application and there is debate as to whether the systemic or topical route is preferred. Problems with systemic therapies relate to low tissue concentrations of antibiotic due to poor vascular supply and the potential effects of long-term use of metronidazole such as peripheral neuropathy (Clark 1992; Collinson, 1993; Cook, 1998; Hastings, 1993; Price, 1996). Alternatively topical metronidazole is reported as effective for treating malodour, although Cook (1998) identifies that the research studies on the use of topical metronidazole have been uncontrolled studies with sample sizes too small, that is less than 50 participants. Therefore the use of topical metronidazole and its effectiveness remain anecdotal.

Shutler, Jones and Thomas (1997) and Ivetic and Lyne (1990) describe the historical use of antiseptics, such as eusol and hydrogen peroxide, in treating malodour by inhibiting bacterial proliferation. Because these agents are de-activated by body fluid, blood and pus and compromise wound healing by causing damage or toxicity to wound tissue, they are contraindicated. This opinion is also supported by Carville (1994), Collinson (1993) and Fitzgerald and Sims (1987).

Palliating malodour also involves the use of wound care products. Charcoal dressings are the most common odour absorbing dressing and are recommended by Carville (1994), Clark (1992), Hallet (1995), Hastings (1993) and Haughton and Young (1995). Price (1996) explains that the silver in the charcoal dressing inhibits bacterial growth and therefore decreases odour. Contention exists because charcoal dressings do not treat the cause of the odour but rather they only contain it. Thus as Collinson (1993) suggests charcoal dressings should be used as a short-term solution to complement alternate methods of odour control.

Less orthodox methods of odour control such as adding sugar to the wound bed or applying yoghurt or buttermilk to the wound have created controversy. Shutler, Jones and Thomas (1997) and Ivetic and Lyne (1990) provide a rationale for the need to be cautious when considering using these products. Yoghurt and buttermilk, icing sugar and even baking soda aimed at reducing malodour are not supported by research, as there is only anecdotal evidence to recommend their use. Indeed Haughton and Young (1995) argue that yoghurt and buttermilk are no longer recommended due to the possibility that infection will be introduced by the lactobacillus present in these products.

As indicated previously removal of necrotic tissue, termed debridement, can assist the treatment of malodour. Debridement can be achieved in a variety of ways and surgery has already been discussed. As mentioned previously vigorous debridement is not indicated in a patient who is frail or imminently terminal. The simplest method is autolytic debridement where wound exudate under a hydrogel, hydrocolloid or alginate dressing creates an environment for the slough and necrotic tissue to loosen from the wound (Clark, 1992; Collinson, 1993; Fairbairn, 1994; Hastings, 1993; Haughton & Young, 1995; Shutler, Jones & Thomas, 1997). Enzymatic debridement can be achieved by the injection of varidase under eschar once to twice daily (Hastings, 1993; Haughton & Young, 1995).

Environmental interventions are perhaps the simplest ways of managing odour although they will not treat the malodour. Examples of environmental interventions include changing soiled clothing and bed linen, appropriate disposal of wound dressings, opening windows, deodorisers and essential oils/aromatherapy (Carville, 1994; Cook, 1998; Haughton & Young, 1995; Price, 1996). The use of perfumes or aromatherapy is cautioned as they only mask the smell and can leave the client/family with psychological associations of the perfume/aromatherapy to the loved one (Collinson, 1993; Hastings, 1993; Haughton & Young, 1995).

The management of exudate is probably the next biggest challenge of wound care. Fungating malignant wounds can produce exudate in litre volumes making even the most absorbent dressing product struggle. Alginates are recommended by various authors and specifically by Fairbairn (1994) and Hallet (1995). These products absorb several times their own weight in exudate. A major advantage with alginates is

that they do not adhere to the wound surface due to the formation of a gel substance when exudate combines with them. Hydrocellular foam dressings, wound drainage or ostomy bags or a butterfly needle inserted into the dressing so exudate can be aspirated out are other alternatives (Collinson, 1993; Carville, 1994; Hallet, 1995). However, it is unlikely these dressing initiatives will be enough to contain the levels of exudate mentioned above and secondary dressings are needed. The use of incontinence products is an effective and cost-effective secondary dressing (Fitzgerald & Sims, 1987).

The selection of primary and secondary dressings for the control of exudate requires consideration of the role of these products and cost implications. Cook (1998) provides a case study example to reflect these concerns. Two dressing regimens were trialed and costed out to evaluate their performance. The first dressing cost \$256.00/day and needed to be changed four-hourly. The other dressing cost \$53.00 with the primary dressing left intact for 24 hours and the secondary dressing changed four-hourly. Although written from an Australian perspective cost comparisons would be similar in the New Zealand context. Cook (1998) concludes that modern wound dressings are appropriate for healing wounds because of the decreased frequency of dressing changes and their ability to enhance healing. However, in wounds that will not heal because of underlying disease and the inability to reduce frequency of dressing changes due to malodour and exudate, the costs of these products are prohibitive.

In the 90s, the reality is that health care has to be delivered within a framework of budgetary limitations but without compromising optimal outcomes. This can challenge our thinking and encourage us to look for solutions beyond conventional wound management practices. (Cook, 1998, p. 109)

Clark (1992) argues that whatever dressing is chosen it must contain exudate in order to reduce the psychological effects of social isolation by restoring patient confidence.

Only two research articles were found related to dressing performance in controlling exudate. Grocott (1997) utilises the Teler system to clinically evaluate the performance of current dressing materials. The Teler system was used to interpret observed data examining symptom management, performance of the dressing and the impact of the wound on daily life. In-depth interviews and participant observation

provided qualitative data and quantitative measures according to the Teler system were collected. The method employed in this research was a multiple case study design and data was presented from one case with the sixteen other participants' data showing recurring themes. Non-probability sampling was used because population derived data was not available so randomisation was not possible. Statistical generalisations were not possible because the participant population was not homogenous in terms of the types of fungating wound and the participants' conditions were not stable enough. However, some conclusions were made. The Teler system, an ordinal scale, was used to measure the number of dressing changes needed, the amount of exudate leakage and the ability of the dressing to fit to the wound. After the introduction of hydrocellular foam dressing one participant reported improvement in all three indicators. Three participants, including the case study, found some improvement in containment of exudate and reduction in the frequency of dressing changes. For the remainder of the participants no improvement was noted in any of the Teler indicators. In the discussion Grocott (1997) explains that the ineffectiveness of the dressing reflects the irregularly shaped wounds and the extensive nature of these wounds found on rounded parts of the body. Therefore it is concluded that in similarly uncontrolled fungating tumours the same results will occur. The inability to achieve dressing fit to the wound results in exudate leakage that in turn impacts significantly on patients' lives.

Grocott (2000) builds upon the work of 1993 in another study examining dressing performance in controlling exudate to increase quality of life in individual experiences. Forty-five cases constituted the sample size. The method utilised in this study is a theory-driven evaluation with three phases, quasi-experimental and emergent collaborative designs and an emergent theory-driven evaluation. Seven dressing regimens were trialed to make before and after comparisons on the control of exudate. The outcome of this study suggests that the ability for wound dressings to manage exudate is pivotal in order to address the problems that fungating wounds create.

Those problems included exudate leakage, the need to change dressings before they were planned and inadequate dressing-fit resulting in the soiling of clothes. The critical argument is that the theory of moist wound healing alone does not account for

the processes involved in chronic malignant wounds. A theory of wound care that includes chronic wounds needs to address exudate management. Wound care also needs to address the problems of dressing-fit and adherence to the body. The design of dressings in an ideal, universal, laboratory type of situation needs to be superseded by employing a systems approach, which reflects actual circumstances. The weight of evidence to support these conclusions includes valid measures derived from Teler data, observations, participant and clinician reports and photographs. Limitations to this study exist around the validity of the laboratory test data and unless *in vitro* fit and fixation can be replicated on clients this will continue to be a problem (Grocott, 2000). Nevertheless this research provides a very adequate beginning in explaining the mechanisms involved in managing fungating wounds, particularly exudate.

Another common problem related to fungating wounds is the potential for haemorrhage. The cause of haemorrhage is due to tumour erosion of capillaries and/or major blood vessels (Carville, 1994; Hallet, 1995). Haemorrhage in fungating wounds can be life threatening and certainly frightening to the patient and the family. Therefore fragile tissue with surface capillaries evident need to be treated carefully with non-adherent dressings and loose clothing to reduce friction (Carville, 1994; Fitzgerald & Sims, 1987; Hallet, 1995; Hastings, 1993). Haemostatic agents assist in the control of bleeding. Primarily they are available in wound care products such as calcium alginates. Their action is caused by exchange of calcium ions and sodium ions to stimulate platelet activation (Carville, 1994; Collinson, 1993) Carville (1994) also reports that topical solutions, such as adrenaline or ornipressin, can be applied to halt bleeding. Writing from experience Carville (1994) has found that stomahesive powder is also haemostatic in its action and therefore very effective for reducing the bleeding in fungating tumours. Silver nitrate commonly used as a silver nitrate stick, or silver sulphadiazine cauterises the capillaries although it can cause discomfort initially (Carville, 1994; Clark, 1992; Fairbairn, 1994; Fitzgerald & Sims, 1987; Hallet, 1995; Shutler, Jones & Thomas, 1997). Clark (1992) cautions the use of silver sulphadiazine when radiotherapy is being given as it disperses radiotherapy rays.

Finally the cosmetic function of a dressing is discussed. Attention to cosmetic acceptability is important and perhaps one of the more difficult aspects of wound management to achieve. This is because fungating tumours cause disfigurement and

the bulky dressings required for exudate management make addressing issues of body symmetry problematic. Cosmetic acceptability of dressings is included as an objective of wound care by Fitzgerald and Sims (1987), Hallet (1995) and Hastings (1993). Fairbairn (1994) suggests the use of bras and/or vests to hold dressings in place as well as attempting cosmetic symmetry. The use of a tubular bandage or the innovative adaptation of incontinent knickers reduces the need for tapes and adhesives to secure dressings in place (Carville, 1994; Cosgrove, 1997; Grocott, 1992; Woodhouse, 1992).

2.4 The holistic dimension

To provide comprehensive care to women with a fungating tumour there needs to be consideration of their psychological, emotional and social needs. These needs are inextricably linked to the meaning of breasts. Love (1995) explains that breasts have deeply embedded cultural meanings; they are the external badge of womanhood and are symbols of nurturance and sexuality. Because of these meanings anything that affects the breast, particularly cancer and consequent alterations to size, shape or function, is therefore going to challenge those cultural understandings and create psychological and emotional distress. The inclusion of these elements of a person in the provision of wound care to this group of patients reflects the nursing practice of holistic care. Holistic care is an approach that acknowledges the perception of people as whole beings filled with complexity. The influences of illness add further complexity to how their lives are lived (Carville, 1994; Fairbairn, 1994; Ivetic & Lyne, 1990; Moody & Grocott, 1993).

The characteristics of this population of patients have not been explored in any significant way. Ivetic and Lyne (1990) suggest information such as age, sex, occupational status and social class could enhance sociological and medical literature thereby enabling a greater understanding of fungating tumours, whom it effects and why some delay presenting earlier. By gaining an understanding of this population and the issues associated with them nurses can then contribute to improving quality of life (Ivetic & Lyne, 1990). Nurses may also improve quality of life when they explore the patient's situation holistically.

Holistic care, according to Hallet (1995), refers to the assessment of nutrition and hydration, possible vitamin and mineral deficiencies, age and mobility, determining what aspects of the fungating tumour cause the most distress and what treatments including wound care will be most acceptable to the patient. In addition to this, Collinson (1993) suggests it is important to determine what the patient and/or her family find most distressing, as this can be quite different from what nurses perceive as the priority problem. Holistic care perceived in this way assists meeting the primary objective of care which Hallet (1995) outlines as improvement of quality of life.

Impact upon quality of life is in part due to the distress associated with these wounds (Grocott, 1997). Grocott (1993) describes the psychological distress that can result from physical symptoms such as malodour and exudate that in turn cause a loss of confidence in normal socialising. This can lead to progressive isolation and the development of a sense of helplessness. Collinson (1993), Clark (1992) and Fitzgerald and Sims (1987) also identify this aspect.

Two articles in particular explain the psychological distress caused by malodour. Depression, disgust, social stigma, embarrassment and withdrawal are reactions to malodour (Price, 1996; Haughton & Young, 1995). Price (1996), basing her discussion on the writing of Clark (1992), makes the link between malodour and the resulting psychological effects of helplessness, worthlessness and social isolation. The conclusion is that odour creates a social stigma, which interferes with social as well as intimate relationships. Odour can also be the most distressing aspect for family and can be left as the primary memory when the patient has died (Carville, 1994). Cook (1998) also reflects the above views by reporting that malodour is detrimental to quality of life caused by the alteration of relationships, self esteem and the ability to socialise with others. Fairbairn (1994) cites odour as the most distressing symptom of fungating wounds as it creates feelings of isolation and un-cleanliness. Again there is limited researched evidence to support these views. However, consensus of opinion provides substance of argument for odour to be considered psychologically distressing. Thus malodour is reported as being responsible for psychological implications such as depression, embarrassment, disgust, worthlessness, un-cleanliness, altered relationships and social isolation.

Interestingly Fairbairn (1994) utilises the research on the psychological distress following mastectomy to support her claims about psychological distress caused by a fungating tumour. Fairbairn (1994) claims that women experience anxiety, depression and sexual difficulties long after the mastectomy procedure. Although there are no studies to compare the similarities between mastectomy survivors and women with fungating tumours of the breast Fairbairn suggests the effects would be at least as great. Fairbairn (1994) then describes some of the emotional experiences women with a fungating tumour of the breast may have. Delayed presentation to health professionals is a frequent explanation for how these wounds result and this delay can cause guilt and shame. This can be compounded by the attitudes of health professionals. Denial mechanisms may also be responsible for causing the fungating wound and can also create unrealistic expectations of treatments. Where a fungating tumour is the result of failed treatment feelings of devastation and bitterness related to the sense that the treatment has been in vain can be experienced. The revolt of the wound, according to Fairbairn (1994), can produce a feeling of vileness or repulsion. Grief processes may also be evident because a fungating tumour is not diagnosed as curable. This can then produce a constant visual reminder of a frightening disease – namely cancer (Carville, 1994; Fitzgerald & Sims, 1987; Price, 1996).

In order to provide care to these women in light of the many and varied emotional responses, some approaches to the delivery of care are offered. Sensitivity by the nurse is suggested as necessary in the provision of care and the development of a relationship characterised by partnership (Carville, 1994; Fairbairn, 1994). This then leads to recognising what the client/family determines a priority according to their values and beliefs (Davis, 1995; Price, 1996). Cognisance of the potential for family to experience increasing levels of care giving is required so that appropriate referrals for support can be made and burnout can be prevented (Carville, 1994; Grocott, 1993; Hallet, 1995; Moody & Grocott, 1993). As a consequence of exploring the situation, Hastings (1993) would suggest the nurse and client are then able to set realistic goals. This thinking means the nurse can more readily address quality of life issues and structure care to accommodate these elements including the client taking some control over her situation. “If the patient and family are given the opportunity to make choices throughout this management, a relationship will develop based on ownership and control that is essential in improving quality of life” (Hallet, 1995: 85).

Fitzgerald and Sims (1987), as well as Clark (1992), Fairbairn (1993) and Woodhouse (1992), all suggest that the best place for care is in the community due to the chronic nature of these cancers. Chronic illness creates a situation where care is delivered over long periods of time and as previously indicated this can be over years. It is not the scope of this literature review to explore chronic illness in its entirety. However some comment as to the impact of chronic illness on providing care needs to be made. Chinn (1996) explains that although chronic illness is a reality for many people, a medically focussed health system is still unprepared to examine and address the impact of this type of illness. It is then proposed that a shift in focus from curing to caring by being involved with the person is a more useful approach. Health professionals in this model can stay involved to support and care for the person (Chinn, 1996). Living with chronic illness also acknowledges that the person can shift from a focus on illness to a focus on health (Paterson, 2001). This provides the opportunity for persons living with chronic illness to actively participate in life activities and create new ways of being in the world. As Lindsey (1996) states, "Focusing predominantly on the illness experience leads to a problem orientation and to a deficit perspective. A large part of a person's whole experience is missing and therefore denied" (p. 465). Providing care with this perspective of chronic illness is important for community nurses so that they practice with a holistic focus and provide caring interventions when illness is in the foreground and support interventions that give independence when illness is in the background.

2.5 Conclusion

Through reviewing the literature it is apparent that caring for women with a fungating tumour of the breast is filled with complexity. The diagnostic and prognostic indicators clarify a palliative approach to care and the treatment options must focus on the alleviation of symptoms without impairing quality of life. Wound management is an important aspect of symptom management and needs to address issues related to malodour, exudate, haemorrhage and cosmetic acceptability. In order to make these interventions appropriate to individual situations a holistic focus is required. A holistic approach is cognisant of the emotional, social and psychological aspects that impact on the woman's life. Consideration of all these factors assists in providing

care that meets the needs of clients in a situation characterised by working with the client to manage her chronic illness.

Chapter Three

Method

Grounded theory was the research method selected for this study and is presented in this chapter. Included in this discussion of method is the rationale for the use of grounded theory, its origins, the premises and the way that grounded theory has been applied to this research. Prior to concluding this chapter the validity and reliability of this method and the ethical considerations will also be presented.

3.1 Rationale for the grounded theory method

The intent of this research is to uncover the concerns of women with a fungating tumour of the breast and the nurses who care for them. Evident within the literature is that knowledge relating to this subject is relatively unexplored except for the principles of wound care, which is based on experiential knowledge. Therefore this research is exploratory in nature and is suited to a qualitative approach. As Glaser (1992) suggests qualitative methods are most useful for uncovering the actions, experiences, and perspectives of people in situations. Although data can be derived qualitatively or quantitatively in grounded theory this research draws primarily on qualitative interviews with participants. Because of this the grounded theory method provides a framework that yields rich descriptive data that can be analysed to develop a substantive theory which integrates experience (Glaser, 1998).

In terms of developing theory Glaser (1998) suggests grounded theory must provide answers or explanations that fit, work, are relevant and are readily modifiable to situations that are constantly changing. Indeed the population of women with fungating tumours of the breast and nurses themselves are not static. Instead they exist in a situated context that is likely to experience constant change. Therefore this study proposes answers that meet Glaser's (1998) criteria and can provide some understanding of social and/or psychological phenomena which Chenitz and Swanson (1986) suggest is the main purpose of grounded theory. To explain how these answers have been arrived at the origins and premises of the grounded theory method are now

explored. This provides the context to explain how these have structured this research and the influences that have occurred.

3.2 Origins of grounded theory

The grounded theory method and its underlying assumptions are linked to a philosophy of science. Pragmatism, according to McCallin (1999), shaped grounded theory and symbolic interactionism has informed the method. Charmaz (1990) states, “Symbolic interactionists assume that as thinking, acting, creative individuals, human beings respond to the actions of others after interpreting these others’ intent and action. A symbolic interactionist perspective leads one to look at self and meaning as processes” (p.1161). Informed by the symbolic interactionist perspective grounded theory is one method that attempts to access this knowledge.

Barney Glaser and Anselm Strauss founded grounded theory in 1967 and describe it in their book titled The Discovery of Grounded Theory: Strategies for Qualitative Research. Glaser and Strauss (1967) have a background in sociology and developed this method in order to develop theory that aims to understand social interaction. Grounded theory aims to uncover the behaviours of people and how these resolve their main concerns. This in turn provides clinicians with practical outcomes of research and a standpoint from which to view behaviour.

Although grounded theory was developed within the discipline of sociology it is gaining popularity in other disciplines such as business management, education and health. Glaser (1998) suggests that the reason grounded theory is popular across disciplines is because it is a method that is highly useful for exploring the relevant problems in a substantive area. As nursing is a practice discipline grounded theory outcomes have had much appeal. They provide nursing with answers that fit and work to problems of substance.

Prior to discussing the premises of grounded theory brief mention should be made as of the differing views between Glaser and Strauss concerning the way data can be analysed. Strauss and Corbin (1992) have proposed a paradigm model to assist data analysis. This paradigm model encourages the researcher to arrange data according to set coding categories including the causal model. Glaser (1998) has also produced

recent guidelines on the operationalisation of grounded theory and in these he continues to emphasise the importance of emergence, although acknowledges that the six C theoretical coding family has become very popular among researchers. This research project utilises the causal model for data analysis while attending to the principles of emergence and fit to the causal model. According to Glaser (1998),

If a grounded theory has been generated with sufficient rigor, if it provides satisfactory explanation, if it can be used by others who like the outcomes, such as providing a conceptual perspective that works, if it spawns further research, then it has earned its way into the division of labor of social research and into the identity of the researcher. (p. 45-46)

3.3 The premises of grounded theory

Grounded theory is primarily an inductive research method. Inductive research according to Glaser (1998) requires the researcher to gather data in the substantive area while suspending one's own knowledge to analyse what is going on. The data is analysed into conceptualisations and hypotheses about possible relationships between concepts (Charmaz, 1990 and Glaser, 1992). Deductive reasoning is used in the process of theoretical sampling whereby decisions are made as to where to collect data next so conceptualisations are corrected and expanded upon (Glaser, 1998).

The grounded theory method is structured around finding basic social processes that become a core variable (Hutchinson, 1993). Basic social processes (B.S.Ps) or basic social structural processes (B.S.S.Ps) are evident as they occur over time (repeatedly in the data) and despite varying conditions (across all participants). The B.S.P or core category must account for most of the behaviour that occurs in the substantive area. Other categories and their properties should be related to the core category and are defined at various conceptual levels such as sub-core categories and categories. These sub-core categories produce theoretical completeness (Glaser, 1998). Therefore the B.S.P or core category is the variable that integrates the theory demonstrating how the other categories connect to provide a theory that has theoretical completeness as opposed to just dense description.

In order to produce a grounded theory Glaser and Strauss (1967) recommend a systematic approach whereby data is collected, coded and analysed simultaneously.

The processes of constant comparative analysis, theoretical coding and theoretical sampling ensures the grounded theory has rigor throughout the coding, memoing, sorting and writing up of the study. As Charmaz (1990) states, “In contrast [to other qualitative approaches], grounded theorists use their emerging theoretical categories to shape the *data collection* while in the field as well as to structure the analytic processes of coding, memo-making, integrating and writing the developing theory” (p. 1162). Thus all the processes create ‘groundedness’ of the theory. The processes of constant comparative analysis, theoretical coding and theoretical sampling are now discussed.

Constant comparative analysis is a defining feature of grounded theory according to Glaser and Strauss (1967). It enables the researcher to identify facts that are repeated by evidence within the data in order to show underlying patterns of behaviour (Glaser, 1998). Each incident within the data is coded into as many categories as possible and they are compared with other incidents to generate theoretical properties of the categories (Glaser and Strauss, 1967). Theoretical properties clarify the full range and types of continua, dimensions, conditions, consequences, and their relationships with other categories. Hypotheses about the general relationships of categories to one another can be postulated to show where there are gaps in the data and how categories relate to one another. This is the analyst’s cue to stop coding and record a memo on these ideas (Glaser and Strauss, 1967). Recording a memo at this time captures the idea and helps resolve conflicts about the data. Memos also make clear which incidents relate to what theoretical ideas preventing the overuse of one incident to illustrate different points (Glaser, 1998). According to Wilson (1985) memos assist the development of theory because memoing requires conceptual thinking, summarises the properties of categories, offers ways to integrate categories, and relates this analysis with other theories. Examples of this are provided further on in this chapter.

Categories and their properties become integrated because of the constant comparisons and the need to make some theoretical sense of the data. Hutchinson (1993) suggests that to achieve the objective of theoretical coding the researcher should ask questions of the data that look for both the interactions and the structures. This enables links between the two, where they are present, to be made. Axial coding,

according to Strauss and Corbin (1990), is a strategy that can be used to make connections between categories. Its focus is on specifying a category such as the conditions that give rise to it, the context in which it is embedded, the action/interactional strategies that assist in managing it and the consequences of those strategies. Making these connections has then enabled data to be put back together following open coding and the causal model provided a framework to integrate the various categories culminating in the core category. The causal model identifies the causal conditions, context, and intervening conditions, action/interactional strategies and consequences and these are represented in the data analysis chapter (Strauss & Corbin, 1990). However, this model has been utilised acknowledging that theoretical codes must pattern out with the data so that the theory is grounded (Glaser, 1998).

As indicated above the constant comparisons and hypotheses that show gaps in the data, provoke the researcher to sample elsewhere and this is termed theoretical sampling. Theoretical sampling is the strategy outlined by Glaser and Strauss (1967) and is a large focus in Glaser's (1978) book. Glaser and Strauss (1967) define theoretical sampling as:

Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges. (p. 45)

The analyst may have some general idea of the structure and processes involved in the situation being studied. These will guide initial theoretical sampling. Once initiated, Glaser and Strauss explain that theoretical sampling is continuous and is influenced by personal concerns and time constraints.

Saturation is achieved when no new concepts emerge and is the criteria used to indicate the point at which the researcher can stop theoretical sampling and complete the research (Glaser and Strauss, 1967). However time constraints have restricted the level of data saturation in this project. The implication of this is to suggest that this research provides an adequate beginning to exploring the concerns of these participants and future research will build on these outcomes.

Now that the premises of grounded theory have been explained it is appropriate to focus on the grounded theory method in relation to this research project.

3.4 This research and the grounded theory method

Discussion about the research method requires explanation about how grounded theory influences the general ways of conducting research. The research question, literature review, access to the field, the participant group and how they were recruited, data collection, data analysis and writing up are all important considerations to research and are the subject of the following discussion.

3.4.1 The research question

As stated previously this research was undertaken in an endeavour to understand the core concerns of women with fungating tumours of the breast and the nurses that care for them. This forms the basis to the research question because in grounded theory a narrow pre-conceived hypothesis is not indicated. Charmaz (1990) explains that by asking broad questions the study will not need to be discarded or re-developed if the data shows the question to be irrelevant. Glaser (1998) suggests that the goal of grounded theory is to gain the perspective of the participants, their main concern and how they continually resolve this, which cannot be known prior to investigation. A professional issue or concern may not be the concern of the participants and therefore data collected may not answer the professional question. Glaser (1998) states:

Thus the reader should remember that grounded theory is for studying, after its emergence, a core category and how it continually resolves a main concern underlying the drive of substantive action. It is not for study of a preconceived theoretical code or empirical unit however popular or 'buzzed' they may be. (p. 86)

3.4.2 Review of the literature

Following the research question, generally in research, a literature review is conducted. A formal literature review is not indicated in a grounded theory research design because of the potential for literature to contaminate the researcher with preconceptions arising from interpretations, found in other authors' works (Glaser and Strauss, 1967; Glaser, 1992, 1998). However, Charmaz (1990) explains that the literature review is only delayed and not absent from the research. Although this researcher had explored the literature on the subject of fungating tumours for clinical

practice purposes this only resulted in providing background context to the study. Glaser (1998) reassures researchers that preconceptions, even if they arise out of the literature, will not pattern out with data if they are incorrect. Once categories were formulated and the process of putting data back together again was being completed this researcher returned to the literature. Literature applied in this way is considered another slice of data for the purpose of building and saturating categories. Thus as Glaser (1998) claims literature will be accorded its rightful place as a slice of data.

3.4.3 Access to the field

Prior to conducting this research approval was sought from the relevant Health Funding Authority (H.F.A) Ethics Committee. The Massey University Human Ethics Committee has a joint agreement with the H.F.A Ethics Committee and clarification was sought regarding the mutual acceptance of this project by both organisations. Approval from relevant Hospital Managers was also included in this application. This project could be commenced upon acceptance of the Ethics Committee. Over the duration of this project the geographical area was extended due to difficulty recruiting participants and ethics approval for this was also obtained.

Relevant to conducting research in New Zealand and obtaining ethical approval for this project is the need for consultation with Maori. This is because Maori are identified as a group likely to be participants as indicated in the introduction. Research involving Maori requires specific guidelines to be followed to protect Maori from inappropriate involvement in research. These guidelines are elaborated upon in a document produced by the Health Research Council of New Zealand HRCNZ (1998). Consultation is central to research on Maori health issues so that misunderstandings and differences of opinions are avoided.

Consultation is a vital step in the development of a research project that involves Maori as participants or is on a topic of particular relevance to Maori health. The consultation process can lead to the development of research partnerships, focusing of research topics, identification of the most useful research design methods, the resolution of contentious issues and the maximisation of the various potential benefits of the intended research project. (HRCNZ, 1998, p. 5)

Enlisting consultative support has proved a lengthy process. The following are the outcomes of consultation. It was discussed and found in consultative interviews that the guidelines for research involving Maori parallel Pacific cultures. A representative from both Maori and Pacific Island cultures has agreed to provide an advisory role in this research. Grounded theory was identified as being an appropriate research method for researching Maori and Pacific Island cultures. It was also agreed that the participants themselves are appropriate to check interpretations of their data and analyse for correct meaning. By the participants checking the interpretations and analysis they can ensure that cultural aspects related to their experience of health are accounted for. Recommendations about the dissemination of results were also made. However, only one Maori woman participated and she did not request any of the above recommendations be followed. Following cultural consultation participants were then recruited.

To access participants a variety of methods could be employed ranging from placing an advertisement in a newspaper to utilising an intermediary. This research project initially sought recruitment of participants via an intermediary. An intermediary was deemed most appropriate so that potential participants could have their confidentiality within the medical system maintained. However, intermediaries can act as gatekeepers. There is a similarity between intermediaries and Seidman's (1998) definition of formal gatekeepers as they both control access to the participants. Although, no author explicitly states it, it is advisable to have more than one intermediary. Intermediaries or formal gatekeepers do not have a vested interest in the research and therefore when they become too busy or you are not visible to them then recruiting frequently stops (Hutchinson, 1993). After initially deciding to use one intermediary and finding that this provided limited access to an already small population, the district nurses themselves were also asked to recruit participants. This also provided the opportunity to recruit the nurses as well.

Nurses who have direct contact with potential participants were asked only to introduce the project to the women. Because of the relationship between the nurses and the women and the possibility that the women could feel obligated to participate the nurses were only required to establish interest from the women, thereby avoiding the possibility of coercion. This process also helped to prevent misinformation about

this study inadvertently being given by intermediaries. As Seidman (1998) states, “Third parties may be necessary for gaining access to potential participants but should be used as little as possible to make actual contact with them” (p. 40).

When the geographical area for recruitment of participants was extended precautions were taken because this researcher practised clinically in the area. To protect participants from coercion an explanation was given at the introductory interview that their participation would be protected as per the ethical guidelines and that any women participants would not have this researcher as their nurse as well.

3.4.4 The participant group

Ideally, this researcher had the intent of exploring the concerns of women with a fungating tumour of the breast and was confident that there would be enough women participants to enable this outcome. However, it has transpired that women participants have been too few for this. To ensure that this research could produce useful information on the subject of this type of advanced breast cancer the researcher has also included nurses who care for these women as another subject for exploration. Therefore two participant groups are described.

In terms of the women participants three women with this condition were recruited. Three other women were approached to participate and for their own reasons, primarily because of ill health, decided against participating. It is acknowledged that this group of participants is tiny and conclusions are extremely limited. Nevertheless the ethical requirements of conducting research mean that this group of participants cannot be excluded. Therefore as limited as their data is, it is included in the analysis.

Thus a second group of participants was sought and consisted of nurses who provide care to these women. This group was considered important to the research because nurses are the primary providers of care. District nurses, as well as nurses in support roles who had had experience in caring for women with fungating tumours of the breast were interviewed. Because these nurses fulfil varying roles this has provided scope to theoretically sample different kinds of nursing care to assist in developing theoretical completeness. The nurse participant group consisted of three General District Nurses, two Oncology District Nurses and two Cancer Society Nurses.

Purposive sampling was undertaken so that in-depth relevant data could be collected. When a participant expressed interest in joining the study a phone call was made to set a time for discussion of the study. All participants except one at this time asked for an explanation over the phone and the information sheets to be sent out. The information sheets for both groups of participants are included as Appendix A and B. In responding to their wishes interviews were begun on our first meeting. However this researcher took the time to explain the study and ensure the participants were ready to consent and participate. All participants consented and the formal consent form, Appendix C, was signed before beginning the interview. All participants were reassured that they could withdraw from the study at any stage should they wish to.

3.4.5 Data collection

Once a person decided to participate an interview was arranged. The setting for the interview was flexible to ensure participants felt comfortable and most interviews were conducted in the person's home. A few nurses were interviewed in offices at their work location and this was at their request. First interviews with the total ten participants usually lasted approximately 45 to 60 minutes each. Secondary interviews, with six of the nurse participants, lasted approximately one hour and a half. Interviews with two nurse participants to check and discuss the causal model contributed another hour of data. Therefore about twenty hours of interview data, in total, was collected.

Data was collected primarily through semi-structured interviews. These interviews invited participants to share their experience by beginning the interview with an open-ended question. The question to the women was:

Could you start by telling me about your experience living with cancer that has broken through the skin?

To the nurses the following opening question was asked:

Could you begin by telling me about your experience in caring for women that have a fungating tumour of the breast?

Prompts such as *can you expand on that* or *tell me a little bit more about ...* guide the participants in telling their story. The interview guide is included in Appendix D.

Interviews were taped with the participant's permission so data could be transcribed for analysis. A transcriber who signed a confidentiality agreement (included as Appendix E) was utilised because of the time constraints involved in completing this research. If participants wished to retain their tapes then this would have been facilitated. The issue of anonymity relating to taped data is addressed in the section on ethical considerations.

Semi-structured interviews, that frequently last one to two hours each and are followed up with more interviews, require skill on the part of the interviewer. Seidman (1998) provides some guidance as to the techniques that assist in interviewing and these have been considered prior to conducting the interviews. Awareness of the need to be listening rather than talking, clarifying what is meant, tolerating silence and careful questioning have been employed in the interview situation so that quality data could be obtained. For example, in this study this researcher has asked questions for clarification such as:

"You mentioned the phrase therapeutic relationship. What does that mean to you?" (Interview 1 with Sandra, p.2)

"How does that impact on the care that you provide when faced with those constraints?" (Interview 2 with Susan, p.8)

The relationship between the researcher and participant has been carefully attended to so that rapport could be established in order to yield rich descriptive data. In terms of reciprocity, this researcher has offered the same type of reciprocity as that stated by Seidman (1998). "The reciprocity I can offer in an interview is that which flows from my interest in participants' experience, my attending to what they say, and my honoring their words when I present their experience to a larger public." (p. 92)

3.4.6 Data analysis

Following transcription of the interviews and checking the transcription with the tapes, coding line by line according to the principles of the constant comparative

method occurred. Coding data to generate categories produces two types of codes. Substantive or in vivo codes are generated from the comparisons found in the data and have both imageric and analytical power (Glaser, 1998). Hutchinson (1993) would term this a level I code that captures the action occurring in a setting. In the following quote the action of “assessing problems” was identified:

“Well, I think the big issue in the fungating tumours is the odour that comes from them. I think the women have a lot of problems with that and the fact that it’s stuck under their nose. And that, that they quite often feel unclean because of these tumours. And they’re not very nice to look at, and, if they’ve got husbands and partners and that, there’s that sort of issue that comes into it.”
(Judith, Interview 1:3)

Categories and theoretical codes, the second kind of coding, emerge when the researcher relates substantive codes together in the process of integrating the theory (Glaser, 1998). In this study “assessing”, “intervening” and “evaluating problems” as well as “looking at the whole” have been coded into the category of “problem solving”. When this occurs a process of axial coding can begin. Axial coding, or as Hutchinson (1993) would phrase level II or III codes, limits the coding of data and theoretical sampling to those variables that relate to the core variable in significant ways. Thus the analyst searches for the conditions and consequences etc that relate to the core variable. For example, “problem solving” was identified as the causal condition and this was explored with participants in order to understand how “problem solving” contributes to a process of “finding what works” and “what happens when problem solving does not work”. This level of coding is essential in producing research that is not simply pure description. If all the data cannot be coded then the theory does not fit completely. An incomplete fit means that the categories and/or the theory must be modified (Glaser, 1978). Memos also demonstrate this transition. In this study initially the core variable was thought to be ‘Looking at the Whole’. This did not pattern out with all of the data and so this researcher wrote a memo to explore this, included as Appendix F, and returned to the data until the core category of **finding what works and what doesn’t work** emerged.

Integrating data produces the grounded theory and in this research it was anticipated to be substantive theory. Substantive theory is theory developed for an empirical area

of investigation as opposed to formal theory, which develops conceptual aspects across different empirical areas (Glaser, 1998). The core category that accounts for the most variation in behaviour and integrates categories and their properties was **finding what works and what doesn't work**. Looking through the data, codes and memos the main story line demonstrated that nurses participated in a process of finding strategies that worked and discarding those that did not in order to enable the women to obtain a sense of living normally. This is elaborated upon in the data analysis and discussion chapters. Glaser (1998) suggests that diagrams can be used to represent the integrating framework and provide a visual display of synthesised categories. Therefore a diagram precedes the data analysis chapter in order to provide a quick reference point for integration of the categories.

Following the identification of the core category the theory can then be delimited around this core variable. Delimiting is a term used by Glaser (1998) to refer to the process of narrowing down or funnelling down information into a manageable amount. Underlying uniformities in the original set of categories and their properties mean that a theory can be formulated by abstracting them to a higher level. This then reduces the number of categories. In this study "assessing problems" was initially coded as "identifying a problem" and "defining the severity of the problem". By abstracting this to "assessing problems" the number of categories was reduced and by relating "assessing", "intervening" and "evaluating problems" the sub-core category of "problem solving" could be developed. "Looking at the whole" was also delimited into this category because it was found to be relevant to "problem solving". The outcome of delimiting is to produce a theory that has parsimony (comprehensive without being cumbersome) and scope (applicable to a wide range of situations) (Glaser & Strauss, 1967; Hutchinson, 1993). These categories are therefore conceptually dense and fit extremely well to the data.

3.4.7 Writing up

The insights gained throughout the research are then written up formally. During the writing up phase of this project this researcher has been guided by what Glaser (1998) refers to as relating concept to concept and thinking theory and writing substance. However, there is frequently too much data to be incorporated into the finished

product. In this study memos have assisted in focussing on those categories that are conceptually dense and fit with the core category of **finding what works and what doesn't work** and this is what has been presented.

At the conclusion of writing up the appeal for future research is made. Explanations are given as to the limits of the current study. The primary directives for future research relate to the areas of theoretical sampling that were beyond the resources of the current project. Finally appeals for future research can also include the implications of the current grounded theory research. These limitations and appeals for future research are made in the discussion chapter.

3.5 Validity and reliability

Ensuring that a research project is rigorous is an important aspect in the construction of the study. Quantitative and qualitative research endeavours must use different measures of rigor, as they do not produce the same outcomes of research. Clearly measures of validity and reliability originating from quantitative designs will be found to be inadequate if applied to qualitative research projects (Krefting, 1991). Krefting (1991) presents a model of ascertaining trustworthiness for qualitative and quantitative research and this is used here to explore issues of rigor. This model has been selected because as Krefting (1991) explains it has been widely accepted by qualitative researchers, especially nurses, due to its well-developed conceptual framework. Trustworthiness is established by accounting for the four factors of truth-value, applicability, consistency and neutrality and these are now explored.

3.5.1 Truth Value

Truth-value is defined by Krefting (1991) as the confidence with the truth of research findings based on the research method, the participants and the context upon which the study was undertaken. In terms of the grounded theory method Glaser and Strauss (1967) frequently refer to the need for categories and their properties as well as for the theory itself to fit and work. According to Chenitz and Swanson (1986) fit in grounded theory means that the categories that are generated must be indicated by the data. Work describes the usefulness or relevance of the theory to explain, interpret,

and predict phenomena under study. The diagram representing data analysis was taken back to two of the nurse participants for their feedback. Sandra states that:

“It makes sense because it articulates what we do. It applies to many nursing situations because it’s simple and it’s very clear.”

Michelle stated:

“It reflects my practice – it fits.”

This provides evidence as to the truth-value of this substantive theory.

3.5.2 Applicability

The applicability of the study to other settings or with other groups of participants refers to the ability to generalise findings (Krefting, 1991). However Sandelowski (1993) suggests that generalisability is problematic for qualitative research due to the situated realities of people who are dynamic and changeable. Krefting (1991) discusses transferability as a measure of applicability and explains that research projects need to demonstrate that their findings fit with other contexts. The grounded theory strategy of theoretical sampling goes some way to establishing transferability because sampling different groups of participants produces a theory transferable to those groups. In this research **finding what works and what doesn’t work** is relevant to community nurses who work with this group of clients. Future research could explore the relevance of this theory to community nursing of other client groups; for example, broader oncology diagnostic groups or complex medical conditions. Other areas of community nursing such as ostomy or gerontology are another area this substantive theory could relate to.

3.5.3 Consistency

Krefting (1991) suggests that applying consistency measures that aim to give the same outcomes is inherently difficult because of variability between researchers as well as the diversity of participants. Dependability instead of consistency according to Krefting (1991) is applied whereby the variances among data and studies are

explained and made visible. As Sandelowski (1993) explains no two researchers will interpret data or produce the same result because there are inevitable differences in opinions as to philosophical viewpoints and theoretical interpretations. Sandelowski (1993) states, "Trustworthiness becomes a matter of persuasion whereby the scientist is viewed as having made those practices visible and, therefore, auditable; it is less a matter of claiming to be right about a phenomenon than of having practiced good science" (p. 2). Examples have been provided throughout this chapter to demonstrate the amount of data available for coding, how categories have been generated particularly by the use of the constant comparative method and the process for deciding what has been written up and what has been delimited. Throughout the data analysis chapter explanations have been given to show how categories and their properties relate to the core variable providing an audit trail for decision making.

3.5.4 Neutrality

Neutrality is an approach applied to the data and not the investigator according to Krefting (1991). Approaching the data with neutrality or objectivity is an attempt to reduce bias on the part of the researcher in the study. Every effort has been made by this researcher to approach data without pre-conceptions and colleagues have also been recruited to check the data analysis for fit and work. We are also reassured, by Glaser (1998), that the process of modifiability corrects biases. A bias simply becomes another property of a category and is controlled by the honesty of the researcher. A bias will not pattern out in the data analysis. It will not demonstrate fit and work in the generation of categories.

In summary, issues of validity and reliability put into terms suitable for qualitative research have been discussed. Explanations of how this researcher has established the truth value, applicability, consistency and neutrality of this project contributes rigor and trustworthiness to it. Glaser (1992) highlights that fit, work, relevance, and modifiability are four criteria of a well-constructed grounded theory. This research has produced a theory that is supported by categories and their properties that fit work and 'grab' the reader. Future research may modify this substantive theory. Nevertheless a beginning has been made to understanding the practice of community

nursing in regard to caring for patients with a fungating tumour of the breast. Some insight has also been gained as to the experience the women themselves have.

3. 6 Ethical considerations

A discussion of ethical considerations involves describing the processes utilised to provide informed consent and that account for special considerations.

3.6.1 Informed consent

Human subjects have the right of self-determination as discussed by Seaman (1987). Self-determination means voluntary participation and full disclosure of information. Voluntary participation ensures subjects are not coerced into the research project. The informed consent process ensures that participants have full knowledge as well as understanding about the research being undertaken. To ensure informed voluntary consent is applied to this research project an information sheet was given to participants. As mentioned previously the information sheets for this study are included as Appendices. Outlined in the information sheet was the purpose of the research, the expected time required to participate, possible negative effects that may be experienced by participating as well as interventions available to participants should they experience these, and how the data would be utilised. The signed consent form (Appendix C) confirms that participants have had a full explanation of this study and as per H.F.A Ethics recommendations they would be stored in a locked cabinet.

The participant's right to privacy was addressed by arranging meetings at the convenience of both the participant and researcher. Participants were interviewed on their own to protect their privacy unless the participant herself wished to have a family/whanau member or a cultural advocate present.

Confidentiality and anonymity are essential in research of this type to protect the participants and their data from being identified. To ensure anonymity pseudonyms were used in any written material. Geographical areas were not identified in the written documentation of this research. The transcribers have signed a confidentiality agreement, included as Appendix E, so participants were protected. Participants would be shown, if they wished, interview transcriptions so any detail that would

threaten anonymity or that a participant wished to withdraw could be removed. Interview tapes were destroyed after completion of the project so that any names or identifying data could not be accessed through this means. If participants wished to keep their taped interviews then this would be facilitated acknowledging that they take responsibility for any identifying data on the tapes.

3.6.2 Special considerations

Previously mentioned, in the background information, is that the women participants for this project may very well be from a different cultural group from myself as I am a European New Zealander and cognisance of cultural differences and appropriateness is important. It was made explicit in the information sheet given to participants that any discomfort created by cultural difference was not intended and if the participant wished to withdraw because of this aspect then this was acceptable. Because I do not speak any language other than English the Ethics Committee recommended that family members acceptable to the participant and who can interpret could be utilised. This has not proved to be necessary because all women participants were able to speak English. As mentioned previously cultural consultation occurred to ensure cultural safety within the research setting. All participants were also assured that any discussion they did not feel comfortable with would be stopped.

Women with fungating tumours of the breast, in the main, have a terminal illness which raises the possibility of participants dying before the project is completed. As the time frame for completion of this research is included in the information sheet, and is up to two years, a discussion was held with the participants in regard to what will happen to the data in the event of their death before final completion. This meant explaining that their data will be included as long as they have agreed to this.

Participants also needed to be aware of how outcomes of research would be presented and disseminated. Obviously by conducting this research as a thesis topic results of research would be presented in a formal bound thesis document. A copy of this will be available in the Massey University Library and a copy will also be kept by this researcher. As part of the thesis project the School of Health Sciences requires an article for publication regarding an aspect of the research. This article will probably

pertain to outcomes of this research project. In meeting the requirements of research involving Maori it was highlighted previously that dissemination of results also go to departments in the relevant District Health Board and the General Practitioners. It is also reasonable to expect that presentation of findings will be of interest to nursing groups and be part of future nursing conferences. Whether or not all of these methods of dissemination of information are employed, the protection of participants through methods outlined within this ethics section will be attended to. This researcher is also open to suggestions from participants as to appropriate ways to disseminate the research, as they are contributors and therefore have some ownership of the data.

3.7 Conclusion

To summarise, this chapter has described and discussed the grounded theory method of conducting research. This has involved explanations about the reasons why grounded theory was utilised, its origins and premises and the way grounded theory has influenced the process of completing this research. Prior to concluding the discussion about research method the validity and reliability and ethical considerations have also been addressed. Attempts have been made throughout this chapter to make the research process explicit so as to contribute to rigor.

Chapter Four

Data Analysis

Chapter four presents the categories that emerged from the data analysis. As stated in the method chapter the causal model developed by Strauss and Corbin (1990) provides the framework for the discussion of categories. Prior to discussing each category the main concern of the participants will be outlined. This provides context to the core process of **finding what works and what doesn't work** which the participants utilise to resolve this main concern. A diagrammatic model depicting how the core process and the categories relate to one another is also provided before an in-depth discussion of each occurs. The categories that emerged in this study include: problem solving as the causal condition, making sense of the situation as context, considerations to care as the intervening condition, building a trusting relationship as the action/interactional strategy and transforming practice as the consequence. The nurse participants provide the majority of data analysed and data from the three women is included to support the analysis where it is relevant. Literature has also been interwoven as another slice of data to support the analysis.

4.1 Main concerns of the participants

In the course of interviewing all participants were asked what they considered to be their main concern. All of the participants in this study describe how they strive to construct a sense of normality. The nurses explain that their care is aimed at facilitating their client's ability to participate in normal life activities. The quote selected reflects a summary of what other nurses have stated throughout their interviews.

“Main concern, um, I guess their maintaining as much of their normality as they can to a, so, I guess that physically and getting the optimum treatment to enable them to stay as well as they can as long as they can and that would include things like getting the right dressings and things so that they are comfortable and minimising things like smells. And then I guess, that would encompass, I guess, some sort of hope trying to get them to come to terms with where they're at and what's happening for them. And enabling them to maintain some sort of social contact.” (Susan, Interview 1:5)

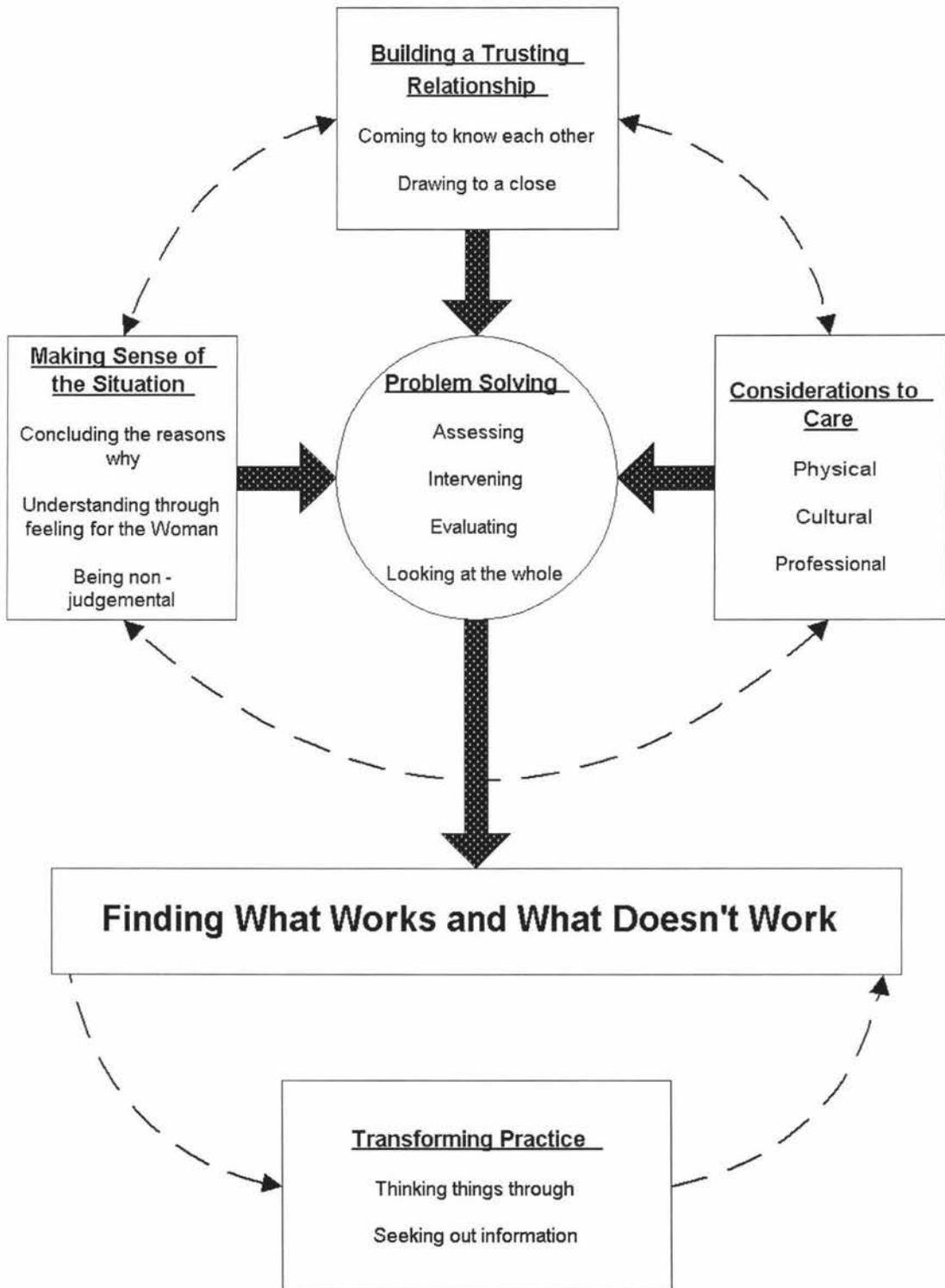
It is through **finding what works and what doesn't work**, that nurses attempt to facilitate normal participation in life activities for their clients.

The three woman participants all describe how they strive to have a sense of normality. This means structuring their life around continuing to participate in normal life activities.

"To keep as well as I possibly can...Do all the things I would normally do. I would do my own shopping. The things I'm happy doing. You know." (Joan, Interview 1:8)

In light of the main concern, maintaining a sense of normality, the categories that contribute to the process of **finding what works and what doesn't work** are now presented. A diagrammatic model of the categories in relationship to the causal model precedes this analysis.

4.2 Diagram Of The Causal Model



4.3 Problem-solving

Problem-solving is a causal condition because the participants utilise this process to manage the difficulties associated with a fungating tumour of the breast. Strauss and Corbin (1990) define a causal condition as the events, incidences or happenings that lead to the main phenomena. Problem-solving is a process of finding a solution to something that is difficult to deal with and is practised until something that works is found (Gordon, 1986). **What doesn't work** simply becomes information that leads into **finding what works**. Indicators are the codes that formulate the category and indicators of problem-solving include assessing the problem, intervening, evaluating the intervention and looking at the whole. Looking at the whole refers to the way in which problem-solving is viewed in a holistic manner. Elements of this holistic focus occur throughout the problem-solving process as well as being a general approach nurses utilise in practice. Each of the indicators is now explored.

4.3.1 Assessing the problem

All of the nurses refer to the many problems that they assess when visiting a woman with a fungating tumour. These assessments identify problems, such as physical, psychological and social that they encounter looking after this group of women. Accurate assessments are the pre-requisite to **finding what works and what doesn't work** because how else will the correct intervention be found if the exact nature of the problem is not determined?

In terms of assessing physical problems all of the nurses identify the size and nature of the fungating wound as the primary problem. These assessments are full of description to clarify the exact nature of the problem. Wound problems include malodour, exudate, haemorrhage, cosmetic appearance and the difficulty of finding dressing products that will manage these problems. Gill provides a description of a situation that demonstrates this type of physical assessment.

“She whipped off her dressing gown and she had, um, fungating lesions, (pause) multiple lesions that were from the size of a five cent piece up to three to four centimetre diameter. She had quite a large bust (pause) fungating right across both breasts - Nipple completely gone in one breast. Um, the lesions extended up across the top of her, um, chest wall and into the axilla on both sides. Her arms were solid, absolutely solid; she still had finger movement at

that stage. So the aim of that was to get a, um, and they had high exudate. The smell at that stage wasn't bad because she could still daily shower. Wasn't a huge amount of blood (pause) there was just high exudate." (Gill, Interview 1:3)

Malodour deserves specific mention because it is discussed by all of the nurses and three nurses identify odour as one of the most distressing symptoms of a fungating lesion because the wound is located 'right under the nose'.

"Well, I think the big issue in the fungating tumours is the odour that comes from them. I think the women have a lot of problems with that and the fact that it's stuck under their nose." (Judith, Interview 1:3)

Broader symptom management issues, such as pain and nausea, anaemia and lymphoedema, are also described by the nurses in this study. In the following quote what becomes evident is that highly complex assessment and problem-solving skills are needed by nurses to care for this particular group of clients.

"I'm talking about the odours – that's one of the things. And, um, the dressing changes 'cause they leak and you've got to contain the exudate that's coming out the best way you can possibly manage to do it. And apply, keeping the dressings comfortable. 'Cause, and then, of course, you've got general things like pain relief and management of nausea if they have that, and so on. Just general, overall whatever you do for all these people with cancer. But then they've got this problem, relationships are often difficult depending on their husbands and their families." (Mary, Interview 1:5)

Assessing problems also refers to the psychological aspect of the woman's situation. Again all of the nurses make assessments about this aspect and identify that the main psychological problem is un-acceptance by the women of the seriousness of their illness. This is made more complicated by the fact that these women are frequently very private, resulting in a lack of feedback by the women.

"It was a difficult one. I guess, partially because she didn't want to know about what was going on. She didn't want to know about the disease process – she wanted to pretend it wasn't happening. So initially she wouldn't even look

at it. Um, and we didn't get any, it was very difficult to get any feedback about what was comfortable in the way of dressings. How much pain she had how much leakage, how much smell, how much anything she had. Because she just didn't want to know about it." (Susan, Interview 1:3)

Michelle has found in her practice that these women can display a psychological detachment from their bodies.

"To me it seemed they were quite detached from it – they regarded it as just a wound, it wasn't actually their breast and I was treating a wound and dressing it." (Michelle, Interview 1:2)

Having a psychological detachment seems to imply that the women do not want to think about the implications of the wound and the possibility that they have cancer. Facione and Giancarlo (1998) studied narratives of women with self-discovered breast symptoms and found a similar detachment process that supports this view. "In these narratives the reader has the sense that in the course of not giving the symptom importance, it is blocked from conscious awareness, and thus rendered unreal" (Facione & Giancarlo, 1998, p. 434).

Social relationships can be effected by problems related to effectively managing the wound and require assessment. There is the potential to be socially isolated if malodour, exudate, haemorrhage and cosmetic appearance are not controlled as the person will find it difficult to participate in normal life activities.

"And I guess odour is probably one of the most distressing things to a woman when it's right under their nose. And I think that interferes so much with their personal relationships, their sexual relationships and everything." (Helen, Interview 1:2)

The nurses assess the potential effect on social relationships because it will effect **finding what works and what doesn't work.**

"So you've got to look at the physical, the emotional, and the spiritual and psychological...About who they are, how old they are. Their cultural identity,

um, you know. If they're living in a relationship. If they've got children. How old their children are – how they relate to being a parent with a disfiguring tumour. How their friends relate – how the rest of the family relate. And also how they relate in the community that they live in. Are they isolated because they've got a fungating tumour? They don't feel they can go out because it smells. Um, so there's all of that too – because they're not a small – they're part of a wider community, a whole, a whole thing.” (Sandra, Interview 2:5)

People who have an ostomy are another group that can experience similar potential for social isolation (Deeny & McCrea, 1991). In this grounded theory study Deeny and McCrea (1991) identified that for a person with an ostomy resuming social roles is important. When there is a lack of confidence in the ostomy appliance there are constant worries about having an accident in public. This parallels the potential embarrassment for women with a fungating tumour of the breast if there is a lack of confidence in the dressing. Social isolation can be the result.

The nurses also assess what family and wider social supports exist and how helpful they are to the women in striving to maintain normality. Sometimes the family relationships are not helpful to the situation and the nurses assess this in order to see whether or not they can positively influence this. Frequently the spouse is recognised as the source of support and provides information about what is happening as well as being involved in care.

“She had a husband and as I said it was her second husband. He was very supportive and as I said helped her with her dressings. He was great. Um, my 34 year old girl was not married so there was no, as I said her Aunt looked after her so that was her. And the other lady was well, I don't know where her husband was but she lived with her daughter. So I naturally think about the relationships...” (Judith, Interview 1:11.)

This researcher has been interested in the lack of discussion by nurse participants about the subjects of sexuality and spirituality. This is especially relevant to this group of clients because the fungating cancer is of the breast, with palliation of symptoms the main aim of treatment. Nurse participants have been questioned about this. In terms of sexuality the following response explains that a trusting relationship built over time is required to explore these concerns.

"I think as nurses we think about sexuality as meaning intercourse, but it means so many different things to different people and sometimes I think we have to assess what it means. It's an area that we need to look at but it's very difficult to say to a person how is your sexuality or what is your sexuality. For that first visit and those first few visits, those aren't the issue." (Gill, Interview 2:6)

In the same study by Deeny and McCrea (1991) ostomy clients also described difficulties with sexuality as one of their socio-cultural needs. The relationship between the client and the nurse was a deciding factor as to whether these needs could be discussed. This lends support to the importance of a trusting relationship for assessing personal concerns that form the basis to problem solving and **finding what works and what doesn't work**.

The same type of response occurs for discussions about spirituality. Helen indicates that it is the nurse's comfort in discussing spirituality that will determine whether this occurs or not. This comfort may well be dependent on it being the right time to discuss such subjects.

"Sometimes it is a difficult one to discuss, however, I am very open and prepared to walk any path with that patient, so I think in many cases the problem there is not of the person talking about spirituality, it is the nurse approaching it ...I think in the very terminal phase I am better at it than at the beginning." (Helen, Interview 2:9)

The complexity of many problems existing at once is acknowledged by the nurse participants. However the nurses indicate that they address the physical problems first in accordance with what the women find the most distressing problem and then turn to the other issues.

"Sometimes there are [multiple problems existing at once]...I'll initially identify the problem and then prioritise them. Depending on what the patient sees as the biggest problem and then practically will try and solve those problems...Usually I, um, address the physical problems first. Um, the wound, how we're going to manage that. And then once that's sorted out then we can look at the other issues they have." (Michelle, Interview 2:2)

In terms of how problems are assessed the nurses offer three strategies; feeling your way, seeing it and the client telling you. Feeling your way is an approach particularly useful for clients who are private and not forthcoming in sharing information. Through a process of feeling your way, the nurses can then **find what works** to address their needs.

“I guess you get a feel for it. You get a feel for what’s a normal sort of reaction and what’s not ...and I guess after you’ve had 2 or 3 visits you can usually pick out whether their need was for just general support – their emotional support, their information.” (Susan, Interview 1:8)

The process of feeling your way relies on picking up cues from the non-verbal body language and what is not said. Nurses manage this situation by either waiting for the time the women will share their problems or by confronting the women with the suspicions that they have.

“Because, they might say things like, um, I can cope with it or it’s ok. It’s really what they say to you really. Things that they’ll say to you that makes you think that you’ve got more pain than what you’re going to tell me...They’ve got a frown and they’re tense – but they’re not going to tell you that...Sometimes I’ll ask in-depth – um, head on, confront them with that – ‘you’re having more pain than what you’re telling me, aren’t you?’ And sometimes they’ll say yes – they are. But they didn’t want – they thought it was – they could cope with it. You know that sort of thing.” (Mary, Interview 2:2)

Seeing the problem is a method of assessment that makes obvious what the problem is and is self-explanatory.

“You could see. You know you didn’t have to be Einstein to work it out. You could see the deterioration there.” (Gill, Interview 1:9)

The third strategy is that the client and/or family tell you what the problem is. The nurses explain that this is a straightforward approach to sharing problems.

“And it used to take her an hour and a half to two hours in the morning by the time she had a shower and got the dressings done, got dressed and so it was not fun. And then at the end all the dressings needed to be changed again. And she was getting tired a lot of the time as well. So it was very frustrating. He [her husband] said to me that some days she’d just sit in front of the mirror trying to get these dressings on with him helping, crying with the frustration. Not nice.” (Judith, Interview 1:5)

Following the assessment of problems the nurses endeavour to offer interventions aimed at resolving the problem and **finding what works and what doesn’t work**.

4.3.2 Intervening

The provision of wound care is the most discussed aspect of intervention. Wound care initiatives are implemented in order to address the wound problems previously assessed. Malodour, exudate, haemorrhage and cosmetic appearance are all managed and the following quote captures some of the wound care interventions available.

“So we devised a system that, she got, um, the continent knickers (pause) cut the crutch out of them so that she could wear them as a boob tube. We used, um, a large Abrisan or was it an Abena continence pads and they hold up to about 2.4 litres. We used big melolin squares inside that, and they were starting to smell at that stage so we just used lots of tubes of flagyl gel. Um, and there was no tape on skin or anything like that.” (Gill, Interview 1:4)

Wound care interventions are not static because these wounds are dynamic and subject to constant change. A process of **finding what works and what doesn’t work** means that the nurses constantly explore treatment options each time the problem changes until an effective intervention is found.

“We went through a process of using things like Kaltostat till we got to a point where that actually didn’t always work, and then we used adrenaline straight onto the bleeder and that was not all that successful, and finally we used transexamic acid orally for her and that worked really well.” (Sandra, Interview 1:11)

A common theme to the provision of nursing care is that it needs to be based upon a stance of open-mindedness. Open-mindedness ensures that a solution that works for the particular situation is found.

“I certainly don’t think I’m terribly innovative. But, yeh, I think it’s also a willingness to try new things, explore new options. Being open-minded I think is important. Um, being prepared to learn often from different situations...They’re often exploring, and particularly if you’ve got someone from another culture or whatever. I would say to them well, what do you do in – what would your culture do? So to me it’s more an open-mindedness and communication thing.” (Susan, Interview 2:14&15)

All of the nurses refer to the need to find creative or innovative solutions to wound problems. Nurses use phrases such as looking outside the square, exploring, unlocking options or lateral thinking to reflect this type of approach.

“You have to be innovative. You have to look for something that’s actually going to do the job. And it’s got to be something that’s going to work. Something that’s got to be cost effective. It’s got to be something that’s going to meet your aims.” (Gill, Interview 1:12)

However, “Innovation doesn’t simply appear because we will it to do so. It emerges out of our understanding of the way we know and learn – our epistemology” (Sherman & Schultz, 1998, p. 28). Looking for something that will work requires the nurses draw upon their experience and knowledge base.

Intervening is also about addressing the wider situation. It involves supporting the woman, enlisting the support of family, enabling self-care practices, providing information, advocating and referring to the multidisciplinary team. Supporting the woman means ‘being there and letting go’ as needed so that the women can have some sense of normality yet not feel abandoned when there is a problem.

“And because I am a great advocate for independence and living life for as long as you can, I’m saying I hold hands for a while and I release hands and I come back, so I’m there as a support person just ready to hold your hand and walk you through the next phase when you need a little bit extra.” (Helen, Interview 2:23)

In terms of supporting the women two of the women participants identified family as an essential source of support. Sarah and Joan discuss the support they have received from their families and Sarah is quoted here.

“Well, my husband works offshore and every operation I’ve had he’s been offshore except for this last one. And he was a bit, even cut up with that. But he was there when I opened my eyes in the ICU and there at the hospital... I’m going to lose my breast and everything like that. And he said it’s not going to make any difference to him.” (Sarah, Interview 1:8)

Having assessed family relationships and how supportive they are to the women it is logical that the nurses then utilise family support whenever it is appropriate. Nurses enlist the support of family primarily to provide support to the woman herself. Extension of this support role includes enlisting family to help with wound care and/or caring for her when her condition deteriorates.

“Because I was thinking caregivers are really important, particularly with these women who need extra support...and sometimes they are beneficial to both the nurse and the patient because they may be able to help with dressings if that’s required...And just that emotional support of getting them to a point where they know they have someone else there.” (Michelle, Interview 1:12)

Five of the nurses who provide physical care to these women encourage self-care practices as an intervention strategy. The intention of encouraging self-care is to promote independence and empowerment. Gibson (1991) states “Health care professionals cannot empower people; people can only empower themselves. However, nurses can help them develop, secure and use resources that will promote or foster a sense of control and self-efficacy” (p. 357). Nurses in this study provide interventions when necessary and encourage self-care at appropriate other times.

“Like she may have, she may need to shower at night or twice a day. It’s impossible for me to get there at a particular time. I might say ‘well, you know, how about I, I teach you how to do all these things’. So to me that’s encouraging. Encourage them to ring the oncology department if she’s got an

appointment she can't make it to...Just empowering, giving her control.”
(Michelle, Interview 2:27)

Empowering through enabling self-care is a nursing intervention that works for Joan. She explains that she likes to manage her own dressings most of the time and finds it helpful to have the nurse check the wound at regular intervals.

“Because I just feel that I would do all that I can during the week [in terms of wound care]. But if someone comes just once a week - just to double check. So if anything's not pleasing, they're not pleased with something, they can immediately right that. That to me is a big plus. That's wonderful.” (Joan, Interview 1:5)

An outcome of encouraging self-care is to provide the women with a sense of control over the situation. This sense of control not only relates to physical problems but also includes a perception of control over the situation as a whole. In terms of giving a sense of control to the women the nurses then acknowledge that they must stand by that and support women's decisions whether they agree with them or not.

“And I thought that was important for her. That she was in control right up to the end. She had the hands on the reins. And even though she was making the decision I didn't agree with – and in my heart of hearts I really wanted to talk to her about dying – um, and about her death. The fact that she didn't deal with it still made that ok for her. And that her not dealing with it was my issue and not hers.” (Gill, Interview 1:9)

Providing information according to the needs of the woman raises the role nurses have in regard to advocacy. The client herself may not necessarily know all of what is available to her. Therefore the nurse has a responsibility to ensure what is available is made known as well as how this can be accessed. Almost all of the nurses directly discuss their advocacy role.

“The nurse also has a responsibility as an advocate for that patient to make sure they get the very best care. The patient doesn't know what's out there, what's available (pause) what products or counselling, etc, etc is available, so they are disadvantaged. Whereas the nurse does have that information.”
(Sandra, Interview 1:4)

Jennifer describes how she has found the advocacy role of her Community Nurse an important help to her.

“I didn’t actually have expectations of the community nurse. It was offered to me and I accepted it mainly because it was a passive reaction really. But what has happened is that I have come to understand that by what they’ve done – is that they are my advocates. Number one they’re my advocates. For example she has phoned the hospital on my behalf to ask for information which I didn’t quite know how to ask for.” (Jennifer, Interview 1:3)

The multidisciplinary team is an essential component of care and all the nurses in this study acknowledge and value their contribution. Involving the multidisciplinary team is vital for **finding what works and what doesn’t work** because specialist advice and input can be sought for difficult problems. The nurses acknowledge that they cannot practice in isolation therefore the multidisciplinary team provides support that assists nurses to manage these highly complex situations.

“I actually work in a multidisciplinary team. We have a small team. So the occupational therapist and the physiotherapist and the field officer work in our office. And the social worker comes regularly. So that we have this, um, team, on tap that we can refer to for our problems. So if we’ve got – if it’s a problem with sitting, or seating or pressure areas you can immediately go to the occupational therapist and get her to sort it out. She’ll go and see the patient and deal with it.” (Mary, Interview 2:18)

Once interventions have been carried out by the nurse, and/or the multidisciplinary team, an evaluation of the intervention follows.

4.3.3 Evaluating the problem

Evaluations are made by the nurses to complete the process of problem-solving. If the intervention fixes the problem then the nurses have found **what works**. If the intervention **doesn’t work** then the nurse goes back to the drawing board. In terms of fixing the problem most of the evaluations are in regard to wound care interventions.

"I mean you get a bit of bleeding which you control with a – in our patient's particular case we used Kaltostat these days. And that managed to control the bit of bleeding there was. There wasn't a lot. It was mostly when you took the dressings off when she was to shower and you just popped a bit of Kaltostat on and that seemed to fix it." (Mary, Interview 1:3)

Part of fixing the problem is that it makes a difference to the client's quality of life. Making a difference is an attempt to restore some of the normal life activities that may have been affected by the illness, particularly the fungating wound.

"If we can knock back on the odour then it can make a huge difference to their quality of life and how they feel about themselves, their self esteem and whether they want visitors, want to sleep with their husbands. You know." (Helen, Interview 1:9)

A part of **finding what works** to fix the problem is the client's response to the intervention. As indicated previously nurses prioritise problems in accordance with the client. Naturally then, the client being pleased with the outcome is an important consideration when making evaluations.

"...And we organised her a gutter walking frame with a board across it and had it down low that she could actually walk around her house. So we got that and we trialed that and she met me at the door one day and she said I've been out and I've smelt a rose. The first time she'd actually been able to independently walk out and that the pleasure of the, on her face, I have smelt a rose was just so great." (Gill, Interview 1:5)

In terms of evaluating care two nurses refer to situations of **what doesn't work** and the need to examine this aspect. This is an indication that the nurse needs to change the plan of care in order to **find what works**.

"If they're not working, um, then I would evaluate. And by not working I would see that they're not maintaining the odour, they're not maintaining the exudate and, um, they're causing discomfort to the patient and they're not practical. The dressing's not practical. So, um, then I will re-evaluate...its pointless doing something if it's not working." (Michelle, Interview 2:8)

Throughout this process of problem-solving in order to **find what works and what doesn't work** there is a sense of holistic care and looking at the whole of the situation.

4.3.4 Looking at the whole

'Looking at the whole' is a phrase that captures how the nurses in this study take a holistic focus of the person as well as considering the wider environment and how it influences the care they provide.

"To me it means looking at the whole person rather than just the breast. For example, looking at the whole thing, the spiritual, mental, physical, emotional side of someone, and for me that is done in my assessment as well, thinking who else do I need to get involved; how are they coping; are they working; who are you living with; how are the dynamics with you and your partner. So looking at the person as a whole rather than just this is what's wrong with you...So I guess you are looking at the person and seeing that everything is in balance...If not, then you need to get the other team members involved if it's appropriate." (Michelle, Interview 1:11)

'Looking at the whole' includes, but is not limited to, the concept holistic health. Bird (2000) and Hallet (1995) refer to holistic care of fungating tumours in the community and reduce this to a discussion of the four dimensions of a person; that is the physical, psychosocial, cultural and sexual. Wilson (1998) suggests that holistic health perceived in this way renders health and illness the domain of the individual. In this study the nurses value looking at the whole as a way they practice in a community setting. It acknowledges the situated environment in which people live with an illness and the problems they might have.

"But in the community you're going into their homes, you're seeing how they live, and you're getting a much better understanding of who they are just by their environment and the people you meet there. And they tend to tell you more – you can talk about their garden or their embroidery that they're doing or their grandchildren who are there or in photos. So you can relate and get all that information coming to you and it is much easier to get a handle on who they are seeing them in their own environment. (Sandra, Interview 1:17)

A consequence of taking such an approach is that the nurses see the bigger picture and provide supporting interventions in line with this bigger picture. Supporting in terms of looking at the whole means that **finding what works and what doesn't work** is not necessarily about making interventions directly but is sometimes supporting the strategies already being used by the women.

"The holistic approach as far as I am concerned is not just going and doing. And for her I did nothing in those first two visits, other than just say yes... Yep. And just looking at the big picture and not just taking (pause) we could have gone in and done wound. Right just lets focus on wound. But there's a whole lot of other things that were related to that. Because she said to me what do you think about me taking vitamins? What do you think about me going to the Spiritualist Church? What do you think (pause) do you (pause) what do you think? And I said do you get satisfaction and comfort from all of those things? And I said I'm not here to tell you otherwise. I said the solution for every problem is not found in the prescription pad or the nurses suitcase."
(Gill, Interview 1:8)

Clearly the holistic approach and the broader term looking at the whole reflects a general approach the nurses in this study take to problem-solving. Arguably if nurses do not take an approach of looking at the whole then gaps in their care will be evident and this will thwart the process of **finding what works and what doesn't work**.

To conclude, problem-solving is a process nurses utilise to care for this group of women. It involves making assessments about the nature of the problem as well as acknowledging that multiple problems add complexity to problem-solving. Assessments are made by feeling your way, seeing the problem or having the client tell you there is a problem. This provides the basis for making interventions aimed at remedying the problem and includes wound care initiatives aimed at treating the symptoms of a fungating tumour. The need for open-mindedness so wound care can be innovative assists the ability to **find what works and what doesn't work**. Following these interventions evaluations are made and this provides the nurses with the ability to ascertain what works because it fixes the problem, it makes a difference and the client is pleased. Throughout the process of problem-solving the concept of holistic care is evident because the nurses focus on all aspects of being a woman

living with an illness and not simply on the disease process. Looking at the whole is also a general approach that encompasses holistic health care and looking at the bigger picture.

4.4 Making sense of the situation

Making sense of the situation is a category that refers to the way nurses explore ideas about why fungating tumours occur and how these women might feel because of the horrific wounds that can result. This information provides context so that problem-solving is effective and a trusting relationship can be built. Context, according to Strauss and Corbin (1990) refers to the set of conditions within which interactions take place and therefore making sense of the situation is considered context in the causal model. In order to make sense of the situation the nurses provide explanations of the possible reasons why the situation has occurred and how they gain an understanding of the woman's situation through feeling for the woman and empathising with her. Being non-judgemental is also essential to the process of understanding and making sense of the situation. These are the indicators of making sense of the situation.

4.4.1 Concluding the reasons why

Nurses draw conclusions and attempt to reason why fungating tumours occur in the first instance, why self-treatment is practised and the wider contextual factors such as ignorance and fear that led to the occurrence of this situation. Reasons why fungating tumours occur are postulated, by the nurses in this study, to be because the women present too late or that the woman believes the cause of the wound is something other than cancer. Fungating tumours that are the result of failed treatment are only mentioned by one of the nurse participants in this study. The nurses then 'deduce' that they occur because of factors in the woman's life and the main reason identified by five of the nurses is neglect or ignorance. Other factors cited include fear, embarrassment, culture, other priorities at the time, socio-economic, being of an older generation and being poorly educated. 'Deduce' has been used because the nurses do not know for a fact, supported by reference to research; instead they think these factors have caused the situation.

"I think they're from the lower socio-economic group and probably, um I think they're probably ignorant of a lot of the reason why they haven't presented earlier. So I think, yeh, that's probably the pattern. Because, as I say, most of the women tend to get in there early. I mean, some of them, on lower socio-economic European women, some of them may not be fungating, but that definitely present late with poor prognosis because they've presented late. So, yeh, there probably is. Um, I should say finance aspect, yeh. Uneducated (pause) not aware of what, you know, what they should be doing, what is out there to help them. And, and, and perhaps not into the preventative part of care." (Judith, Interview 1:3)

However, the literature does reflect many of these same causes. Fairbairn (1994) indicated that delayed presentation to health professionals, psychological mechanisms such as denial of the problem and failure of medical treatments for breast cancer are the common causes of a fungating tumour. This author writes from the United Kingdom perspective demonstrating that there are similarities about factors influencing presentation to health professionals between these two countries. However, increasing awareness about breast cancer and public health promotion strategies aimed at early detection might reduce the incidence of fungating breast tumours caused by delayed presentation. Interestingly the three women interviewed in this study developed their fungating wound despite extensive medical treatment for breast cancer. There is a likelihood that this will become a more common form of presentation.

Fear is another strong reason the nurses use to deduce why the women do not present earlier. Reasons are formulated by the nurses in this study to suggest that women might have been frightened about the diagnosis of cancer itself and/or the treatments for cancer such as chemotherapy, as well as the cancer being of the breast which raises issues about body image and sexuality.

"I guess it's, one of the biggest things is this fear of cancer...they knew somebody who had a horrendous experience and died a painful lingering death and they don't want it to happen to them...Think sometimes the media doesn't do cancer any favours...I know that some women say that can often be a reason why I don't want a mammogram because I don't want to know...perhaps a fear of surgery, perhaps a fear of losing some of their womanhood, or the altered body image. Perhaps a fear of death." (Susan, Interview 1:10)

Presenting late with a fungating wound raises the implication that the women have been managing the situation themselves and nurses in this study make conclusions about why self-treatment is sought. Many of the nurses describe situations where the women opt to apply cultural remedies such as poultices or complementary wound therapies in order to treat the cancer. Indeed Mary, one of the nurses, points out that self-treatment utilising a poultice of comfrey leaves was common and one of the only available treatments in the past. In today's context cultural remedies and/or complementary medicine can be a preferred choice. Most of the nurses in this study acknowledge this and suggest the woman is **finding what works** for her.

"I can't exactly remember the number, but most of them had been applying their own dressings to these wounds before any treatment was done. So they were using remedies and dressings from their cultural medicine and just applying the pads." (Michelle, Interview 1:1)

All three of the women participants interviewed describe the way they use complementary therapies to either treat the cancer or manage the wound. Jennifer uses antioxidants and dietary changes. Joan also has altered her diet and uses honey on her wound. Sarah has used a variety of complementary therapies and believes that they have assisted her recovery from cancer because they strengthened her immune system and made the tumour more prominent so it could then be removed. Each of these women is searching for solutions that work for them.

"But I've stuck to maybe half a dozen kinds, one of them is cell food which is oxygenated – concentrated, oxygenated minerals, immunoacids and a few other things. It's proven right at the beginning it made such a difference when I was taking cell foods. It actually pushed the tumours out – pushed the lumps out and you could identify the tumours. And those three were the only ones that came out of my chest. There were other little lumps there – nothing happened. They were scar tissue. So it kind of identified which ones were the tumours." (Sarah, Interview 1:22)

Coming to conclusions about why the women present with a fungating breast tumour leads the nurses into developing an understanding of the situation and the process of making some sense out of it.

4.4.2 Understanding through feeling for the woman

One way or another, all of the nurses in this study make known their feelings about the diagnosis of a fungating tumour and the way they feel for the women and their families. ‘Appalling’, ‘horrible’ and ‘devastating’ are words that are used to describe the situation. It can be argued that this is the first step in developing an understanding because it induces a sense of feeling for the situation.

“Obviously a horrific situation where you see a ghastly wound like that obviously impacts on you, not just your professional approach, but it obviously impacts on how you feel and perhaps in some way that empathy is triggered from those early phases...” (Helen, Interview 2:29)

Feeling for the women and their family is an expression of human compassion. It assists the nurse to make a connection with the woman and the nurses are then more able to put themselves in the client’s shoes. Being able to see where the woman is coming from helps nurses elicit their concerns in order to **find what works and what doesn’t work**.

“If you can’t see where someone else is coming from – you can’t be of an awful lot of therapeutic use to them. Um, I guess if you put yourself in someone else’s position you can get much more of a clearer where they’re at, and perhaps you can offer them some more useful, um ...And sort of being able to identify with someone that (pause) but it’s not feeling actual sympathy (pause) being able to put yourself in somebody else’s shoes... But I guess as nurse’s, and I guess with experience too, the more experience you have, I guess in some ways the easier it is. I think you tend to be able to get a feel of, of what it, someone is feeling or experiencing. How accurate that is we won’t know I guess. Um, but you often get (pause) if you can pick up the feedback in the non-verbal communication, you can often get the feel, or a sense of where someone’s at, and hopefully what’s really, um, bothering them or, um. I guess it helps you identify better.” (Susan, Interview 2:1)

In trying to articulate what empathy is, participants were asked to explain their views. Having a feeling for the woman and her situation is the precursor to empathy. This was identified in a quote above when Helen suggested empathy is borne out of feeling for the woman and the horrific wound. Michelle also reflects this view.

*"Empathy means to me being able to feel what they are going through."
(Michelle, Interview 1:2)*

Understanding also seems to go hand in hand with empathy or feeling for the situation.

"I think you find – it's hard to understand, I guess. And we're usually desperately trying to understand and to have some sort of empathy with the person that we're caring for." (Susan, Interview 1:5)

Benner and Wrubel (1989) discuss the need for nurses, particularly in an oncology setting, to be able to understand the client's situation. Gaining an 'insiders' perspective of the illness means that disease and suffering is made accessible to nurses so that they can comfort the person and assist her to find ways of coping with her illness.

Understanding, in order to make sense of the situation, can have the effect of personal growth. Learning more about the self, assists being able to understand another.

"I think it's understanding, because we're never going to have it because we're not them. We're just really getting to know ourselves better by using that process and asking and trying to understand – we're trying to understand it better for ourselves." (Helen, Interview 2:27)

Gaining an understanding of the situation that in turn develops a sense of the self and makes sense of why these women are in this position parallels what Gallagher (1999) describes as coping with the dark side of Public Health Nursing. Public Health Nurses "find a purpose for remaining involved in what are often chaotic and depressing scenarios" (Gallagher, 1999, p. 22).

Through the nurses' approach of feeling for the women and having empathy for the situation an understanding is gained. However, the nurses describe that it is only by having a non-judgemental stance that this can be accurately achieved.

4.4.3 Being non-judgemental

Comparing the woman's situation with your own values and beliefs is another way the nurse tries to make sense of the situation. Making these comparisons begins the process of being non-judgemental because it separates out how values and beliefs influence decision-making and how those decisions might not be the same as one's own. Caring for clients involves acknowledging cultural understandings of illness (Benner & Wrubel, 1989). Awareness of how cultural understandings of illness influence decisions leads to accepting that difference is something not to be judged. Clearly, **what works** for one person may not work for another and someone else might make a different decision given the same situation. The nurses explore this as they compare themselves and what decisions they might make to those of the women.

“And she still wanted her womanly shape and I think that's a big issue for women. That they still feel (pause) that these terrible things on their chest wall are still their breasts. For a lot of women that is an issue. I think that's probably why a lot of women don't go and have their breasts off. Which again is quite different to what I think. I think if I found a mass I would be in there (pause) if they want to take the breast off, that's fine. Because my breasts are not me (pause) they're a part of me but they're not my big image, so. But for a lot of women they are. And their womanly shape.” (Gill, Interview 1:15)

Distinguishing between the client's values, beliefs and decisions and one's own prevents the influence of preconceptions and judgmental attitudes to care. Being non-judgemental assists the process of **finding what works and what doesn't work** because nurses gain an understanding of the situation and are able to offer care accordingly.

“Because from my perspective and from my background, it is difficult to understand why they got to that position. So you have to make some sense out of it otherwise you can't be of any assistance to them because you would constantly be judging them, and you can't judge them.” (Sandra, Interview 1:7)

Being judgmental can negatively influence the trusting relationship. It will impair on the ability to connect with the client and can result in perceiving the woman as simply a wound. Without the trusting relationship brought about by making sense of the

situation nursing care is likely to be a one-sided business with reduced capacity for the nurse to **find what works**.

“If you go in there judgmental and business-like, you’re never going to connect, you’re just not going to make it. Because unless you have that relationship foundation established, you might as well be another nurse cruising through your life. And I think that’s part of the issue for nurses who don’t see the patient and often lack the continuity, then they’re just going to see that patient as a wound and that patient will never open up.” (Gill, Interview 2:28)

Having an understanding of the situation learned from being non-judgemental also enhances the nurse’s ability to offer problem-solving strategies. Being non-judgemental means having an approach where you can gain an understanding of the client’s perspective and what problems she is experiencing. Pushing ideas on a client, based upon pre-conceptions, will not help the situation. Thus in order to **find what works** the nurse must understand the situation. Lack of understanding is likely to lead to **what doesn’t work** because the client’s lived situation has not been fully accounted for.

“Well, if you can understand where the patient’s coming from then you can help them much better. Because if you try to just push, put your ideas onto them without understanding why, why they’ve, why the situation’s different to them – and it’s not going to help. You have to try and understand what the problem actually is. You have to find out what the problem is – actually what the problem is - to the patient. Not what the problem is to the nurse but what the problem is to the patient so we can deal with it.” (Mary, Interview 2:19)

In summary, the nurses in the study make sense of the situation in order to provide context to problem-solving and building a trusting relationship. Making sense of the situation begins with nurses attempting to reason why women present with fungating tumours and why they have pursued self-treatment. Developing a feeling for the women and their families assists nurses to understand and have empathy for the situation. Being non-judgemental is essential so that pre-conceptions do not compromise the ability to understand and make sense of individual’s decisions and needs. Information gained from making sense of the situation provides contextual

knowledge for building a trusting relationship and **finding what works and what doesn't work** as problems are addressed.

4.5 Considerations to care

Considerations to care, is an intervening condition within the causal model. Intervening conditions according to Strauss and Corbin (1990) are those factors that impact on the action/interactional strategies, which in this study refers to the ability to build a trusting relationship. The nurses identify factors that influence their ability to provide care to this group of women and these include physical and cultural considerations as well as professional considerations. It would appear that this list of considerations to care is not extensive. However it encapsulates the considerations that these nurses find relevant to caring for this group of clients. This category has been phrased as considerations to care and not limitations to practice because the nurses find creative strategies to overcome them. Each of these is now addressed.

4.5.1 Physical considerations

Physical aspects of delivering care are those factors that are difficult to change and reflect the actual environment in which care is delivered. One of the nurse participants works in a rural area and this meant that geographical distance restricted the number of visits she could make. Never the less, ways to accommodate this physical consideration were found and the husband was included in managing the dressings between nursing visits. As a result of overcoming this consideration of care the nurse practices the process of **finding what works**.

“Because he had – because she lived so far away we couldn't visit every day. She lived, um, half an hour's journey to her house and it would – the job would take, took an hour and a half so that was two hours out of our day. We couldn't manage that. So her husband was very good and he, um, used to do the dressings, at home.” (Mary, Interview 1:2)

Geographical isolation was not identified by any of the other nurse participants. However, four of the nurses did suggest time constraints could be an issue when the woman needed a longer amount of time than what was planned in that visit. This impacts on building a trusting relationship because the nurses identify that spending

time with the woman is important in building trust. Grocott (2000) explains that in the United Kingdom nurses can experience difficulties providing enough time for visits because workloads are generally measured according to the number of visits and not necessarily taking account of the complexity of care. The nurses in this study indicated that they did not experience such strict criteria in the allocation of workloads and they all suggested that there are ways around this consideration. In the main the nurses **find what works** is to set aside another time where the visit could be spent addressing the issues. Sandra suggested that, generally, if longer amounts of time were needed this could be accommodated by managing the workload.

“...I think when you work in the community time constraints are something you can deal with. You know how much time you need to spend with your patients, so I don't think time constraints in the community setting should necessarily hinder the problem because if you think you need to spend more time with a patient, maybe you have to look at how you manage your time.”
(Sandra, Interview 1:9)

Another physical consideration concerns the cost of wound care products that are used to manage these difficult wounds. Again differences between New Zealand and other countries such as the United Kingdom demonstrate the contextual realities of nursing. Young (1996) explains that in the United Kingdom clients can only obtain certain wound care products on prescription and outside this the cost is transferred to the client. In the New Zealand setting wound care products are provided by the health system and the client incurs no direct cost. However, there is an ever-increasing awareness by nurses about the cost of products and services that they provide and it therefore becomes a consideration for the nurses in this study.

“It's up to them to make a choice but it's a matter of offering the best product and cost comes into it – a cost effective product that does the job and meets the needs.” (Helen, Interview 2:12)

Awareness of cost implications of wound care products does not prevent the particular product being used, rather, if the cost can be justified by clear and logical rationale, it is introduced into the plan of care.

“Well, cost is one of the big factors. And in this particular case it was probably the major factor. At first we used, um, forgotten what it was called now. It was called; carboflex I think it was called. It had carbon in it and it had, um, I think a kind of Kaltostat base to it. And that was really excellent because it kept any bleeding, any bleeding down and it kept the odour down and it was easy to apply. But they were \$100.00 a box and they only lasted ten days. Yeh, but our boss actually approved of that product. But then it was too big for that product and you had to decide what the next thing to do is.” (Mary, Interview 1:3)

Apart from cost, the lack of dressing products that are specifically designed for these wounds is another consideration the nurses have to practice with. Wound care products have not been developed for fungating wounds where the levels of exudate, malodour and haemorrhage far exceed the capability of conventional wound dressings.

“Dressing products can be a limitation, particularly with the odour. The products that we use help with the odour to an extent, but there is nothing that has been made specifically or designed particularly for this type of wound and I wouldn’t want to have a nappy on my breast but it’s the best thing for controlling the amount of discharge that these wounds have.” (Michelle, Interview 1:6)

Despite this problem the nurses demonstrate initiative in adapting wound products to meet their needs. Wound care **doesn’t work** when wound care products cannot provide the client with the ability to participate in normal daily activities. Nurses therefore adapt wound care products to meet their client’s aims and objectives. Because nurses consider the impact of dressings on the client’s lives they can facilitate the process of working together as part of building a trusting relationship.

“You have to look for something that’s actually going to do the job. And it’s got to be something that’s going to work. Something that’s got to be cost effective. It’s got to be something that’s going to meet your aims and objectives. And we found with the process that we set up with the continence knickers and the shaped continence products met all those objectives. It was soft, it contained the high levels of exudate, it still kept her womanly shape...It was comfortable. It was something she could manage. So it was simplistic and it contained the smell. Did everything we wanted it to do.” (Gill, Interview 1:12)

4.5.2 Cultural considerations

One of the main considerations in delivering care to this group of clients identified by the nurses in this study relates to cultural differences. As identified earlier, in the New Zealand context it is more likely that women with fungating breast lesions will be of Maori and Pacific Island origin. All of the nurses in this study are European and three nurses identify cultural difference as a consideration in the way they deliver care. Cultural differences are acknowledged and alternative options are sought such as involving other appropriate people in care. When nurses have the opportunity to nurse people from other cultures there is a sense of this being a privilege.

“I actually talked to my Maori lady about whether she wanted to talk to somebody else but no, she didn't. Not even another Maori person. More culturally appropriate perhaps than myself, being European, white person. Um, yeh, I thought perhaps because I'm the breast cancer support person and there are a few Maori ladies that have had breast cancer and chemotherapy and I thought she might like to talk to. But she didn't want to talk to anybody. I think I actually felt quite privileged that she actually talked to me about it.” (Judith, Interview 1:12)

However, the impact of different cultural beliefs and understandings about illness between the nurse and the client also need to be considered when providing care. Both Michelle and Sandra identify this aspect and suggest it is difficult to discuss aspects of care or build a trusting relationship because of cultural differences. Ideally the nurses want to be able to refer to health providers from the same culture.

“I think it's really difficult for white, middle-class nurses to have or develop a therapeutic relationship with Polynesian women. You can do your best, but I think for those women it probably would be more therapeutic to have their own people to talk to them.” (Sandra, Interview 1:6)

The difficulties created by cultural difference relate to understandings of health and illness and communication. It is cultural heritage that shapes the ideas, attitudes and reactions of a person especially in a time of illness (Durie, 1994; Ngata & Pomare,

1992). Communication, both verbal and non-verbal, according to Metge and Kinloch (1978) are intricately related to cultural values and are internalised to the extent that they are seen as natural. When relating to people from a different culture these values and beliefs are a taken-for-granted assumption whereby differences are not acknowledged or understood. Metge and Kinloch (1978) describe this as talking past each other where each party misreads each other's words, makes inappropriate responses and makes judgements about each other based on misunderstanding. However, in practice **finding what works and what doesn't work** means working with what resources and knowledge the nurses have.

“Well with the Maori people – if you can, um ...find the key worker – the key person in the family sometimes it'll help. To solve – to get round the problem. So you can manage – then you can do the caring. Do whatever care you need.” (Mary, Interview 2:21)

4.5.3 Professional considerations

Professional considerations refer to the transfer of client information to the community and the influence of the nurse herself to care. Difficulties accessing medical information contribute to a perception of a fragmented health system where health professionals feel they are working on their own and are therefore unable to provide the best service to their clients. In this way it reflects **what doesn't work**.

“I guess one of our major limitations is access to information within the hospital system. Not being part of it, we're not – unless you get a supportive staff nurse or a supportive consultant – we don't get the information. Clinical information and that can be difficult within your practice. We don't necessarily even get what things – like what medications people are on, and that can be an awful lot of time wasted and, um, you feel like you're asking the people the same thing all the time. So, if we ever got all on a computerised system or something so the information could be shared better I think it would help open continuity...And I guess sometimes, um, you feel like it would, that perhaps you're not providing a comprehensive service. You're only sort of looking at one aspect and I guess everybody's doing that, aren't they, to a degree.” (Susan, Interview 2:7&8)

However, Helen suggests that there have been improvements in the sharing of medical information. It provides a practice context where nurses feel more informed and prepared for meeting clients and caring for them. While these nurses appear to contradict each other it should be noted that they both work in different areas and with different organisations.

“But I think we’ve made huge inroads to where nurses can access information from these days, and even all the medical documentation is through the computers now – like surgery notes and laboratory results. Over the last five years we have evolved incredibly and the knowledge base I have now going in is so much more complex. I actually have the information whereas before I was trying to piece the information together before my first visit. If the discharge summaries are done I have got everything they’re going to give me and have a comprehensive understanding of what’s ahead of me before I meet them.” (Helen, Interview 2:30)

Possessing information and visiting as a health professional raises awareness of the power nurses have. There is a common perception that power is not such an issue for community nurses because they are visiting in the client’s home. As Nichols (1998) states, “Caring for a person at home reverses the power base for those accustomed to institutional work. The clinician is a guest in another’s home” (p. 4). However, three nurses in this study acknowledge the power they have as nurses, ways that power can be abused and the need to be careful that power does not negatively influence the client.

“Power is something you have to be really careful with, because as much as you don’t think you have it, you do have it, simply because of your position and you have to use it very, very wisely.” (Sandra, Interview 1:4)

Having power or the perception of power introduces the risk that it will be abused. The abuse of power by nurses is identified as the nurse taking over from the client. Taking over means over-visiting, changing care without consultation with the client or not providing information. This results in dis-empowering the client. This is not compatible with the way nurses build a trusting relationship such as talking through concerns and planning care.

“Um, power may be abused when nurses aren't willing to give that power up to the patient. Taking over. Changing things without consultation with the patient. Um, not discussing any potential problems that someone may have. Just presuming...” (Michelle, Interview 2:30)

Michelle then goes on to suggest that the way she positively uses her power is to empower her clients. Acknowledging that power rests with clients is relevant to other health visitors such as Public Health Nurses and is an attribute of expert practice (Gallagher, 1999). Kubsch (1996) explains that experts use power to positively influence others through using their knowledge and skills. The transfer of power into a vehicle for empowerment is important to the women in this study. Two of the women discuss how they have been empowered by nurses.

Jennifer describes how the medical world has a dis-empowering effect. Differences between the community and tertiary institutions are noticed by Jennifer.

“‘Cause I think that's um, quite a historical experience for women ...that they feel dis-empowered in the medical world. That they have, um, the authority of doctors and specialists that leaves them, um, without sufficient knowledge or whatever to help determine their own treatment. Their own future. And because the community nurse seems to be of the community rather than from that hierarchy, I think she, that reinforces that advocacy role...Admittedly I do see that doctors are getting better at seeing you as a person, rather than an object to be treated. But it seems to me that the community nurses have taken on this role of dealing with the person.” (Jennifer, Interview 1:6)

Sarah relates an experience where she took control over her situation. Sarah was having problems with poor venous access and the pain associated with inserting intravenous cannulae was causing distress. Through a hospital admission she learned about emla cream used to numb the area where the needle would be inserted and used this information at clinic appointments to her benefit.

“So I made sure my appointments were early so that if I had to sit there all day I jolly well would sit there all day. They're not going to shove me out in three or two hours or whatever it was. And I asked for the numbing cream and they'd say 'oh, you don't need the numbing cream – it'll be all over in a second'. Eh, I said, my body, my pain and I want it. I want that cream. I'd get quite narky, and they'd have to put that emla cream on.” (Sarah, Interview 1:19)

Perhaps what can be drawn from this discussion of professional considerations is that community nurses are aware and have thought about the power that they have and in doing so ensure that their care is empowering in order to support the strategy of building a trusting relationship.

In conclusion considerations to care is an intervening condition that impacts on the strategy of building a trusting relationship. The nurses consider the impact of physical, cultural and professional constraints to practice and think of creative ways to overcome them. Sometimes considerations to care present a challenge to the nurse that is difficult to overcome. If these considerations to care are not addressed they simply become limitations to practice. In situations where it is difficult to change the circumstances such as geographical distance or cultural difference the nurses utilise what resources they can. Finding creative ways around these reflects the nurse's ability to **find what works and what doesn't work**.

4.6 Building a trusting relationship

Building a trusting relationship has emerged as the actional/interactional strategy, in the casual model outlined by Strauss and Corbin (1990), utilised by the nurses as they **find what works and what doesn't work**. Actional/interactional strategies manage, carry out or respond to phenomena under specific conditions (Strauss & Corbin, 1990). A relationship based on trust provides the foundation to care and **finding what works and what doesn't work** is achieved by the process of coming to know each other. This care is provided until the relationship draws to a close. All of the nurse participants refer to the need to develop a trusting relationship. Data from the women participants lends support to what is suggested by the nurses. Indicators of building a trusting relationship are coming to know each other and drawing to a close.

4.6.1 Coming to know each other

Coming to know each other describes the way that nurses and their clients build a trusting relationship in order to **find what works and what doesn't work**. For this to be successful a sense of trust must be established between the nurse and client. Five

out of seven of the nurse participants suggest that the relationship between them and women with fungating breast tumours begins by building trust. Building trust is essential to developing a relationship with these women because then concerns are more likely to be shared. As stated previously these women are frequently very private and un-accepting of their illness. It is only when concerns are shared that nurses have the opportunity come to know each other so they can **find what works and what doesn't work** in terms of strategies needed for clients to participate in normal life activities.

"I guess start by building up a trust relationship is probably the most important thing. Um, and once you have built up some sort of rapport some sort of trust relationship, you can usually, then they will start talking to you about what their main concerns are, um, maybe what's stopping them from doing things that they enjoy or would like to have done." (Susan, Interview 1:6)

One of the woman participants in this study was asked what she felt was important in the relationship between her and the nurse. Her response indicated that trust would ensure she was cared for.

"Well, I think, um, you have to have trust in the person that's coming to help you. And I think if you have trust, if you trust them ... I'll be alright because they'll look after me." (Joan, Interview 1:5)

Factors that assist the building of trust include developing rapport, spending time, continuity and presenting as a professional. Developing rapport with the women is identified by nearly all of the nurse participants and Michelle suggests that nurses also need to develop rapport with the family.

"Yes, [involving family in care] to get that co-operation and have that rapport so that you are trusted when you came into the house as well." (Michelle, Interview 1:10)

Developing rapport is described as 'clicking together'. Fosbinder (1994) explains " 'Clicking', an immediate rapport between patient and nurse, facilitated the process of getting to know you" (p. 1088). Clicking together is influenced by the ability for the

woman to be open and have her expectations met. Put another way, nurses in this study have suggested that if a client is very private, not wanting to share concerns, or feels let down by health professionals then rapport is very difficult to develop. Mary, in a follow-up interview, suggested that developing rapport could be assisted by talking about mutual interests. Occasionally sharing something of yourself is helpful. Fosbinder (1994) also reported this in her qualitative ethnographic study on client perceptions of nursing care. However, most of the nurses indicated that sometimes rapport does not develop because of personalities. This reflects a situation of **what doesn't work** and is considered by the nurses as the time when they might hand the woman over to a colleague.

"I mean there will be patients that you instantly click with. But you know other patients it will take a long time to develop that trust... I think it's a personality thing in a lot of instances. I think it's as simple as that. I mean, you get on with some people and you don't get on with other people...I mean I guess there are some relationships or some times where you, it just doesn't develop. Maybe then you have to hand it on to a colleague." (Sandra, Interview 2:2&3)

Coming to know each other involves spending time together. All of the nurses in this study describe the way that they spend time with the women in order to build trust so they can explore concerns. Spending time makes it easier for the women to open up and expose themselves.

"And it's very hard to go in for someone to reveal themselves totally on the first visit if you haven't actually had time to build up a relationship." (Helen, Interview 1:5)

Spending time can also involve a process of separating physical nursing cares from time spent exploring concerns and problems. Two of the nurses in this study **find what works** is to 'do the wound care' and then make time to 'sit down and talk'. It is also evident that talking about things can be achieved while nursing tasks are being completed. This will be discussed later. However, what is significant here is that

separating talking from doing is important when the nurse needs to spend time with the woman.

“If you’re standing over a patient doing a wound, that’s where their focus is going to be. I think sometimes you may get a pick up of something that they’re not quite saying to you, and once the dressing is done then you can sit on the edge of the bed so you’re not in that high/low situation and say, you mentioned such and such to me - what do you mean? Or do you want to talk a bit more about that?” (Gill, Interview 2:20)

Complementary to this concept of spending time is continuity. Continuity is referred to as the same nurse visiting most of the time or a small set of nurses organised to visit. The relationship between the client and nurse is enhanced by continuity.

“However, in many of these situations I try to work my workload so I don’t introduce them to too many nurses. If I am the primary nurse I try to work very carefully. I don’t own that patient, but I think it’s better for them over a month not to have four different nurses going in. No relationship is ever developed on that.” (Helen, Interview 2:16)

Jennifer, a woman participant, reiterates the importance of continuity. When asked about continuity she describes the drawbacks of not having continuity and indicates that continuity from the Community Nurse has resulted in ‘knowing’ one another.

“Because that is one of the drawbacks of the public hospital system, that you almost never see the same doctor. So you have to go through the same background every time and you feel that that person doesn’t know you. Whereas, what you, ah, begin to appreciate from the District Nurses is that they do. They’re older and – is that they come to know you and you only get that from continuity.” (Jennifer, Interview 1:4)

However, continuity can be problematic and **doesn’t work** if it leads into a situation of dependency for either the nurse or client. Helen also discusses this in her second interview.

“... but we have to be careful that we don't build up a co-dependency relationship where we are dependent on the patient as they are on us, and I do think that some nurses do open that relationship and it's very easy in some of these long difficult cases that you don't build up a co-dependency...” (Helen, Interview 2:18)

Continuity is also problematic when many nurses and/or services are involved. This can create confusion and frustration by having to repeat the same story over and over. Jennifer identified this in the above quote. Nurses in this study explain that continuity of care is another form of continuity especially useful when there are many agencies visiting. Providing continuity of care means that, interventions are not constantly changed especially by nurses new to the situation. Documentation in the client's case notes promotes continuity of care.

“Continuity means to – yeh, it does mean to be seeing the same person. But it also means to be doing the same thing. Like doing the same – having the same type of needs met in particular dressing protocols not changing. With the same service – going through the same process of problem solving...If the same nurse can't visit all the time continuity – you need to be writing in the care plan.” (Michelle, Interview 2:15)

Building a trusting relationship by coming to know each other involves presenting as a professional. Presenting as a professional is described in terms of appearance and attitude supported by a professional body of knowledge. Approaching care in this way is considered as demonstrating professional competency.

“Well I guess initially its, its establishing some sort of trust. So I guess initially you're wanting to show that you know what you're talking about. And building some degree of confidence in a competency level...Because if I think if the person doesn't have a professional trust then it's much more difficult to develop, um, a very therapeutic relationship. So, I guess initially you're sort of trying to show that you have some knowledge of what's happening with them. And show some professionalism...” (Susan, Interview 2:3)

Being cared for in a professional way is regarded as important by the three women participants interviewed in this study. Joan, Jennifer and Sarah acknowledge professional presentation supported by knowledge is important to them.

“Well, I was in very professional hands. [with name of the District Nurse] Some District Nurses once they become a District Nurse they don’t bother to, um, upgrade their training or go and find out what the latest things are. How to look after fungating ulcers.” (Sarah, Interview 1:23)

Presenting as a professional does not necessarily distance the relationship. Three of the nurses interviewed describe that there is an element of friendship as well as professionalism in their relationships and refer to this as being professional in a friendly way.

“Um, well you can’t really have a friendship as such. Because you’re a nurse and you have to – friendly, yeh friendly. But the relationship is different isn’t it. It’s a friendly relationship with a nurse you might say.” (Mary, Interview 2:13)

Coming to know each other assists the capacity for nurses to achieve the goals of care. **Finding what works and what doesn’t work** is more likely to be achieved if the nurse and the client know each other and the client is involved in her care.

“Because you have to involve the person in their care to get the best care really. Because if you don’t involve them and they don’t understand what you’re trying to achieve then it becomes like...You involve them in their care and explain what you mean.” (Mary. Interview 1:6)

An essential part of this, suggested by Sandra, is that both the nurse and the client are open and honest and communicate effectively so that there are positive outcomes of care.

“When both parties are able to be honest and open with one another. I guess if you looked at a wound dressing or an odour thing – if it wasn’t working,

hopefully the patient would be able to say to you 'hey, this doesn't work for me'. And hopefully the nurse's response is 'okay let's try something else'. And keep trying something until you get something that works for the patient. So that you've an open, two-sided communicative. And then you can resolve those issues – may not resolve all of them.' (Sandra, Interview 2:7)

Having an open and honest relationship is influenced by the ability of the nurses to listen to the concerns of their clients. Listening is an active process of hearing what is said and if the nurse cannot listen accurately problem-solving and **finding what works and what doesn't work** is made more difficult.

"You just have an instinct that something's not quite right. Sometimes you can't put your finger on it for weeks, and sometimes that's when you decide that what you really need to do is just go and listen to that woman. I guess that's the key – it's listening. It's not always, as I said, the verbal communication and I think you can only assess and process the problems that are there if you actually listen." (Helen, Interview 2:6)

Listening is also the key to being able to talk about concerns and this is an element of coming to know each other that is identified by all of the nurses in this study. Talking together offers opportunities to help the situation, make suggestions to problems, allay fears and offer advice.

"I don't do hands on, so I don't do dressings or anything like that. But, um, I still talk to women or getting them to talk to me about the fact that this thing smells and we sort of go through all the things that help, dressings that treat the odour and different sorts of treatments that I used to do." (Judith, Interview 1:4)

Jennifer explains that she finds it valuable to talk through her concerns with her nurse.

"And they are now talking about another, um, another kind of radiotherapy which, um, should give some pain relief. But, yes, this is where I'm, I'm really sort of waiting for the nurse to come on Wednesday to discuss this because I'm a bit confused about what I should do. See how helpful she is. I'm coming to rely on her." (Jennifer, Interview 1:9)

Talking together can also be effectively achieved while the nurses are doing hands-on care. Fernandez (1997) describes a situation where she was just doing the ‘obs’ (nursing observations of temperature, pulse and blood pressure). During this ten-minute task she had a conversation with the patient that revealed in-depth information about his clinical condition and family situation and was able to ‘come to know’ the client (Fernandez, 1997). Michelle describes a similar process of talking while doing.

“It’s having a trusting relationship where you can talk, while you are doing things, about anything that can improve their quality of life as far as having dressings on their breast or chest wall, so that they understand why we are doing what we’re doing.” (Michelle, Interview 1:4)

‘Talking while doing’ can also be applied to other nursing interventions such as showering. However, Gill provides a wonderful example of how she developed her talking time.

“With one patient, sometimes I’d go in and see her and I’d do the wound and then I’d say what do you want me to do for you now? And she’d ask - will you rub my feet? And I’d say sure and so I’d massage her feet – and that was the time we talked – that was our talking time. I’d be down there massaging her feet and that was our special talk time basically, although it was never labelled as that. And that was when she’d start to tell me things – she maybe reminiscing about her childhood, her marriage, her interactions with her kids ...But that was our time, and she felt safe doing that.” (Gill, Interview 2:21)

Coming to know each other also requires respect for the client’s values, beliefs and decisions. While this is similar to the approach of being non-judgemental what is significant here is that differences of opinion have the potential to influence the relationship. All of the nurses in this study refer to times where they have differences of opinion about treatment options taken by the women they have looked after. Rather than this becoming a stumbling block to their relationship the nurses resolve these conflicts through acknowledging that they respect the decision-making of their clients, feel that they should support that decision and understand that the client needs to have some sense of control over her situation.

“And support them. Um, I won’t, sometimes don’t agree with it and I will say sometimes. I mean, if, really debilitating for this patient to go on one of these horrendous diets that they go on. And you see the weight falling off them and you know that they’re not going to get that weight back again. And then basically sometimes they are losing what quality of life they’ve got left. But then it’s their choice and as I say I think it’s important them taking some control over what is happening and it’s a feeling that they’re doing something.” (Judith, Interview 1:8)

The need for the client’s rights to be respected is expressed by Sarah and it appears that clients also respect the differing views of health professionals. Sarah recalls a conversation she had with her oncologist.

“But I will tell you right now from this point on I’m in charge of my own body and the decisions will be mine. I’ll explore all the options and I’ll listen to what you have to say but the decision is mine. And I thought I am going to see you again because I appreciate who you are and what you do, um, but I want you to also appreciate me.” (Sarah, Interview 1:26)

The concept of having differences of opinion seems significant to the core variable of **finding what works and what doesn’t work**. For example how can nurses **find what works and what doesn’t work** when there are differing views about what should or should not be done, especially if this causes conflict. In an effort to **find what works** the client’s choice must be respected and the choice of intervention must be acceptable to the woman.

“Basically the patient has a choice and in the end it’s up to us to be working with them so that we can help with an intervention that’s acceptable to them. I don’t think I would be pushing a thought on someone who was dead against it. I think what I would do is give them some literature and an explanation of why I believe this wound product would be a more suitable one to use.” (Helen, Interview 2:12)

Respecting the client’s choices also involves continuing to support the woman. Supporting the decision means ‘going along with it’ or ‘leaving it’ until a time the client wants to revisit the issue. By taking this approach the nurses can continue to

come to know each other, trying to **find what works and what doesn't work**, without sacrificing their relationship.

"Sometimes you can resolve it [conflicts] by discussion. Perhaps they don't want to start their morphine. You know there's this excellent video you can get to show them... if they still say no they don't want it that way then you just have to leave it and then wait for them to figure out what the problem was and perhaps the nurse was right after all. Because you have to, you have to keep your relationship going with the patient and the families so you try not to have a conflict of interest." (Mary, Interview 2:5)

As a result of coming to know each other appropriate goal setting can be achieved. The way the nurses set goals is to begin with small goals that are achievable and fit with the priorities of the women. Setting goals in this way is about **finding what will work** rather than setting up unrealistic expectations that will not. Goal setting is an important aspect of health visiting and symptom control (Holzemer, Klainberg, Leonard & Graf, 1998; Regnard & Tempest, 1998). Regnard and Tempest (1998) suggest setting short-term goals for overly optimistic clients and longer-term goals for pessimistic clients. Whatever goals are set they should be mutually negotiated in order to generate a spirit of collaboration as therapeutic partners (McMurray, 1992).

"...again I think goal setting seems to be quite important and looking at what they want – some priorities for their life and maybe it's things like encouraging them to have contact with their family...It's getting them to look at perhaps some other things that they would've liked, that they would like to achieve in their life." (Susan, Interview 1:7)

Coming to know each other is a platform for building a trusting relationship. As the nurse and client come to know one another they build trust, listen and talk through concerns, develop respect for the client's values and decisions and set goals in order to achieve the objective of striving for a sense of normality. However, there is also a point at which the relationship draws to a close.

4.6.2 Drawing to a close

Throughout interviews with nurse participants they have related examples of particular clients they have cared for. In discussions about clients they have cared for the nurses have also described how those relationships have ended.

"I saw her about 12 hours before she died ...I went into see her and I said 'Hi, how are you?' ...In the end I said to her, do you want, pause, because she was quite restless, so I just massaged her feet and she just drifted off, drifted off into unconsciousness." (Gill, Interview 1:7)

How the relationship is ended has been explored with some of the nurse participants and it has been conceptualised as drawing to a close. For the Community Nurses involved in hands-on care the relationship draws to a close when the client enters into the terminal phase of her illness. There is an uncertainty about how and when the client will die, however, that reflects the journey as a whole. All that is certain is that it will happen. During this stage three of the nurse participants refer to the way they 'walk that path' with the client.

"Well, often with these patients, the relationship is not terminated until the patient dies. And that I guess is again walking that road with them, that as a nurse you know what the ultimate outcome is going to be, but you don't know when it's going to be and what's going to happen along the way." (Sandra, Interview 1:6)

In terms of managing this phase where care is drawing to a close both Helen and Gill describe the importance of supporting and preparing the client and the family for 'moving on'.

"It's sort of the end of the journey. It's something that you can see, and you think you're not too flash, things are starting to go down. And often, especially if it's been a long maintenance period, you have to start preparing the family that this is happening...That's part of the process I call getting ready to move on." (Gill, Interview 2:24)

Two of the nurses in this study do not provide hands-on care and so draw their relationships to a close prior to the terminal phase of the illness. Both of these nurses describe a process of handing over to others as the way their relationship with women ends.

“It’s handing on, isn’t it and saying goodbye before you’ve actually finished the journey. But I feel quite confident. I feel I’ve handed these ladies to. So it makes it very easy that way because the nurses from the [name of organisation] who are in this situation are very good.” (Judith, Interview 1:12)

Susan also talks about the way she hands her clients over to others and describes this as a process that should occur gradually through introducing other health professionals and slowly withdrawing her input. Susan does refer to instances where handing over to others can be problematic and this is when the client deteriorates rapidly, where continuity by other professionals is not achieved and/or when the client has not yet established a trusting relationship with the next health professionals.

Drawing to a close is that part of the relationship when the relationship will be ended. It is characterised by either a process of walking that road until death or handing on to others.

In conclusion, the nurse participants actively build a trusting relationship. Coming to know each other relies on building trust and is achieved through establishing rapport, spending time with the women, providing continuity and presenting as a professional. Also required in coming to know each other is openness and honesty and listening skills in order to talk through concerns. As a consequence nurses respect differing views in order to involve the client in care and set goals for future needs. As the client’s condition begins to deteriorate the process of drawing to a close occurs whereby nurses either hand clients over to others or walk that road until death. Building a trusting relationship is a strategy nurses utilise so that they can **find what works and what doesn’t work** to meet their client’s needs.

4.7 Transforming practice

A consequence in the causal model is the outcome or result of the action/interactional strategy in response to the main concerns of participants (Strauss and Corbin, 1990). It can be argued that building a trusting relationship through spending time, talking through concerns and respecting differing views provides the capacity to transform practice. Clinical practice is transformed because as a consequence of the trusting relationship, and all that is learned about the client's concerns, the nurses are provided with the capacity to think things through by reflecting on their practice and drawing on their experiences as well as by seeking out information. Transform, according to The New Collins Concise Dictionary of the English Language is to alter or be altered in form or function (Gordon, 1986). This seems to fit well with the descriptions used by the nurses in this study when they describe how their skills and abilities have developed over time and with experience. Reflections explain **what works** for the purpose of transferring this knowledge to similar situations. **What doesn't work** is analysed to answer why that was so and through seeking out information by sharing information and updating knowledge an answer that works can be found.

4.7.1 Thinking things through

Thinking things through describes a process of reflecting on happenings and drawing on experiences in order to **find what works and what doesn't work**. Thinking things through is not simply to 'ponder' the situation. Thinking needs to be a critical process where the appropriate questions are asked and reflection is practised (Ruggiero, 1984). Ruggiero (1984) states, "Critical thinking helps us interpret complex ideas, appraise the evidence offered in support of arguments, and distinguish between reasonableness and unreasonableness. Both problem-solving and decision-making depend on critical thinking, as does meaningful discussion of controversial issues" (p. 13). Critical thinking, in this study, is promoted in order to ensure practice is not based on routines and evidence is provided to support nursing actions. Mary explains that when this type of reflection and critical thinking is not practised then nursing care runs the risk of 'not working'.

“That’s right – you’re thinking all the time about what you’re doing – why you’re doing it. I think that’s really important and I’ve always tried to do that in my career...We talk of doing routine things without thinking why we’re doing it. I think that’s really important to think – why, why, why do you want to do it that way. And, you’ve got to answer those questions to yourself too. So you’re doing it that way because it’s comfortable for the patient. Um, you’ve got evidence-based practice to prove it works that way, and so on and so forth...You don’t get results if you don’t think, um, the wound goes backwards. Why has it gone backwards. Because anybody’s been doing this for so many weeks and nobody’s changed it.” (Mary, Interview 2:7)

A part of this thinking process involves reflecting on situations. Nurses take the opportunity to analyse the care provided in a single situation in an effort to identify the positive and negative outcomes. These outcomes enable the nurses to evaluate whether their care was effective or could have been improved upon. Gill reflects about the care she provided to a particular woman and interestingly suggests that **finding what works** is not necessarily being ‘hands on’. Having a ‘hands off’ approach can be just as effective.

“You know in the end I reflected on my management of her, um. Because that we didn’t have active family involvement. There was little feedback from the family. The hospice nurse and I both sat down afterwards and said okay - what do we feel about this? And we’ve had (pause) gone all the way through if she was going the next day I would ring her at the end of the day and d-d-d-d-d-d so on. And so we managed to care, um, very well. On reflection I don’t believe I would have done anything different. Um, I don’t believe that there were any gaps in my care. I think that we gave her some good quality time plus some good management, um. Some hands-off management (pause) but I don’t believe that all the time there should be hands-on. I don’t believe for one moment that you have to be in charge.” (Gill, Interview 1:13)

Reflecting on nursing care provides nurses with the ability to learn from those situations and then use that learning to improve practice for future situations. Learning from individual situations is primarily to ask the ‘why’ questions. For example, why did nursing care work? By asking these questions the nurses show that they think things through. **Finding what works** in the situation can be transferred to

other situations with the potential to improve care. Gaining an understanding of the situation is another outcome of the reflection process.

“Reflecting, I guess, is something that, well it’s certainly something I do a lot. Reflecting on how I manage a situation and just thinking – oh that went really well. Why did that sort of fall into place - because that’s, I think, how we learn. A part of how we learn. And improve situations for next time. And plus it just helps you make sense, perhaps. That’s part of our own coping mechanisms. The reflection cause you’re dealing with some pretty heavy stuff sometimes. And, um, maybe it helps you make sense of it for yourself.” (Susan, Interview 2:19)

Thinking things through also means exploring situations where nursing care did not go as well as was planned. Helen suggests that identifying **what doesn’t work** is valuable in order to improve practice.

“Reflection is a great thing; you come back and reflect on what you’ve done and what you’ve achieved, or what you haven’t done well and you think how could I do it better and in many cases we need to reflect back on what we’ve done and say yes we could do this better by involving other people earlier and I guess that’s an experience thing – if you reflect on what’s gone on before then you would hope you would improve as time goes on.” (Helen, Interview 2:10)

Throughout discussions about reflecting on practice experience is identified as important for care. Four nurses in particular refer to the way that they draw on their experiences and that these experiences are both personal and professional. These experiences are thought through to identify how they influence practice. In terms of personal experience the nurses acknowledge that personal values and beliefs are brought into their practice. Life experiences also shape the way care is managed.

“I look back now and I think what I did ten years ago was not as good as what I’m doing today. Especially on that emotional aspect of things and I think that we all have different strengths that we bring to the job and we’re all not going to be wonderful at everything we do...but I do think that, um, experience of age, motherhood, a broad nursing knowledge and um, updating this knowledge, and um, doing palliative care courses, getting involved with people who’ve had cancer themselves, both within the nursing field and outside the nursing field, gives you a different view on how you provide care to these patients.” (Helen, Interview 1:6)

Acknowledging the way personal experience impact on practice is a subject discussed by Johns (1995). Personal values and experiences should not necessarily be bracketed away to prevent biases or burnout; rather they can assist the practitioner to be connected with the situation in a therapeutic manner. In fact Johns (1995) argues that a medical system that does not support this connectedness will produce non-caring relationships.

Professional experience provides nurses with knowledge that can be drawn upon to assist caring. The following quote, provided by Sandra, directly relates experience to **finding what works and what doesn't work.**

"You will know from past experience what things work best, what things don't work best." (Sandra, Interview 1:11)

Woolley (1990) identifies that expert practitioners draw on past experiences to assist their critical thinking processes and in doing so develop experiential knowledge. The importance of experiential knowledge to the ability to critically think is best demonstrated by comparing novice practitioners to experts (Woolley, 1990). Benner (1984) suggests that the perception of the situation, the reflection of similar situations and the efficient finding of solutions are skills demonstrated by expert nurses. These skills are gained not only through experience, but they are also developed by reflecting and thinking about practice.

However, it is not only the experiences of the nurse's own practice that can improve care. The experiences of other nurses in similar situations can be shared to give insight into what care can be applied. In this way practice can be transformed because insights from others can alter the way nurses function.

"If you're reflecting within a group, it gives you information about how maybe someone else has managed a similar situation. Or you've learned from that – one of our nurses reflected about a young fellow who was terminal and dying, and how the difference looking after someone young was completely different from looking after someone old. And it was really good because a number of the nurses used her at later stages as a resource person and went back to her and said did you notice this when you were looking after your patient, or how did you manage this sort of situation." (Gill, Interview 2:34)

Clearly, reflecting on practice and drawing on experiences are essential components to thinking things through. The ability to think things through provides information that transforms practice in order to become more efficient at **finding what works and what doesn't work**. However, the capacity to transform practice is also enhanced by seeking out more information.

4.7.2 Seeking out information

The purpose for seeking out information is to provide answers to problems created by **what doesn't work** in an effort to find a solution that works. Seeking out information involves sharing information and obtaining up to date information from research literature and educational courses. Sharing information involves a process of networking with colleagues and bouncing ideas around. Knowledge is gained as the nurses expose themselves to other perspectives and information about what things have worked in the past is gained.

"And we talk that over with our manager or with colleagues who have got much more experience than myself. Um, and just bouncing ideas off each other we usually come up with a -...There's definitely a networking component to our practice because we are quite isolated so we meet weekly and often yabber on the phone as well." (Susan, Interview 1:8)

Those receiving care may also see this networking component in practice. In the interview with Joan she found the process of bouncing ideas around contributed to her feeling of being in safe hands.

"And when I was attending oncology they were really good with any dressings – I found them all very helpful. Sometimes, they would get another nurse and they would confer about which way to do it and that makes you feel very, very secure." (Joan, Interview 1:5)

Networking ideas is also relative to those living with illness. The three women interviewed in this study remarked about ways that they learned about treatments through the experiences of others. Names of books are shared, support groups provide the experiences of others and family members seek out and supply information.

“My sister ...she met a Maori chappie ...they just got talking about different things and they ended up talking about cancer ...so they went out and got a bag full of these leaves [Maori herbal medicine] and she said try it.” (Sarah, Interview 1:20)

Seeking out information gives these women a sense of control over their situation and contributes to the capacity to **find what works and what doesn't work**. However, seeking out information and knowing **what works** does not necessarily mean that this information can be applied. Circumstance dictates options.

“I knew what I needed but I couldn't find it even though I tried in the pharmacies and asked the doctor. I knew I needed something that didn't stick to the skin. Um, my mother was a nurse and I knew exactly what it was that I wanted. But I, they didn't appear to have it or, um, didn't know what it was that I was trying to explain.” (Jennifer, Interview 1:2)

Perceived in this way it is clear that these women are attempting to **find what works and what doesn't work** to transform the situation from passively accepting the consequences of their illness to becoming active participants living with an illness.

However, seeking out information is more than networking ideas. The nurses also demonstrate that they seek out more formal information. Formal ways of seeking out information ensures nursing practice is current and supported by evidence. Nearly all of the nurses in this study refer to the way they obtain formal types of learning. These include updating current practice through accessing research literature and attending educational courses. Accessing research to support nursing practice ensures that nurses are finding solutions that have an empirical basis as opposed to historical assumptions.

“I think most of the time that's how I practice [research based practice]. I like to understand what I am doing and why I am doing it – not just historical; this is what you do. I like to use my brain and think about what I am doing.” (Michelle, Interview 1:10)

Being unhappy about what you are doing is a primary motive for accessing education and again reflects the way nurses in this study transform their practice in order to find the best solutions to care.

“And I think that, um, the more knowledge you have the more knowledge you need. And I think that if you’re not happy with what you’re doing then you’re actually going out and seeking a bit more and obviously using a bit of evidence – based practice and reading some of the magazines and that.” (Helen, Interview 1:6)

Another motive for accessing education is when the nurses have no previous knowledge or experience about an aspect of care.

“So if you come across something you’ve never experienced before you have to find out what it – if somebody that’s got some illness that you’ve never heard of you have to look it up and find out all about it ...find out before you go in you have to, you try not to go in cold and try to find out whatever you can about it before you go ...then you’re all primed up ready for questions aren’t you. But if you don’t, if you go somewhere and you don’t know what it’s all about then you’re a bit useless aren’t you.” (Mary, Interview 2:17)

Situations where there is no current knowledge to draw upon or the intervention **doesn’t work** as it is supposed to is when an element of trial and error is brought into play. Thus the individuality of clients in their situated context is accounted for in the process of **finding what works and what doesn’t work**.

“In nursing we’re constantly into evidence-based practice, which is fine, but still we have an awful lot of trial and error and we have to have trial and error in our practice. Particularly in wound care, and managing a fungating wound – you may put something on and go back the following day and see that’s not the best or the patient’s skin has reacted to it. And just because you’ve used this on one patient, it doesn’t mean to say that’s the standard for all of your patients.” (Gill, Interview 2: 32)

Thus, it appears that in the main the nurses in this study use information sharing and accessing formal education to provide care **that works**. However on occasions there is room for trial and error caused by the individuality of the clients they care for.

In summary, clinical practice is transformed through the processes of thinking things through (by reflecting on practice and drawing on experience) and seeking out information. Reflections assist nurses to think about why the care has worked or not. This involves a critical thinking process that characterises expert nursing practice. Professional experiences are drawn upon for the purpose of understanding the

influences upon nursing care in the endeavour to **find what works and what doesn't work**. Gaps in knowledge are addressed by sharing information among colleagues and accessing more formal means of learning so that the nurses have the ability to transform their practice although despite these measures sometimes a form of trial and error must occur because of the individuality of people.

This concludes the data analysis and the following chapter provides a discussion of the categories in this causal model and their relationship to the core variable of **finding what works and what doesn't work**.

Chapter Five

Discussion

The previous chapter presented the categories that emerged from analysis of the data. The causal model by Strauss and Corbin (1990) provided a framework to explain: problem-solving as the causal condition, making sense of the situation as context, considerations to care as the intervening condition, building a trusting relationship as the action/interactional strategy and transforming practice as the consequence of **finding what works and what doesn't work**. Data from three women participants and literature has been interwoven throughout the analysis as another slice of data to support the core variable. This chapter discusses the core variable to demonstrate it as the main action taken by participants to resolve their main concern of maintaining normality. Relevant to this discussion, is the influence of chronic illness and community nursing. Therefore these aspects are explored including the implications of this study for practice. Prior to concluding the discussion, limitations and future directions of this research are provided.

5.1 The process of finding what works and what doesn't work

Grounded theory has as its goal the discovery of the prime mover of most of the behaviour of those studied (Glaser, 1998). Understanding of the action taken to resolve the main concerns and how their behaviour continually resolves those concerns leads to the formulation of the core variable. The core variable emerges as the overriding pattern because it fits and works and recurs frequently in the data (Glaser, 1998).

In this study the nurses work together with their clients to provide care in a community setting managing the chronic illness of a fungating breast tumour. This care takes account of the many demands placed on nurses such as the client's own particular values and beliefs about health and illness, the need for ongoing education and collaboration to provide quality care within a health system that has limitations on what can be provided. The process of **finding what works and what doesn't work** is the core variable that explains how they practice. **Finding what works and**

what doesn't work refers to the way nurses provide care to help women achieve a sense of normality in their lives.

The process of **finding what works and what doesn't work** is made possible for the nurses in this study because they make sense of the women's situations in order to build a trusting relationship with them. This provides a foundation to problem-solving about issues such as care of the wound in view of the influences of considerations to care. As a consequence of **finding what works and what doesn't work** the nurses transform practice.

Only one other article has been found that refers to this theme. A process of 'finding what works' is described by Bull and Jervis (1997) in their grounded theory study that explores the strategies used by chronically ill older women and their care-giving daughters post hospitalisation. Although this study suggests 'finding out what works' is an initial phase to 'establishing new routines' what is notable is that these new routines were developed based on 'what worked'. 'Establishing new routines' "...referred to a period in which mother-daughter dyads were getting their lives back in order, arranging schedules based on 'what worked'..." (Bull & Jervis, 1997, p. 545). Likewise the nurses in this study offer problem-solving strategies based upon **finding what works and what doesn't work** to create a sense of normality in activities of living. There is a similarity between 'finding what works' and this study's core variable of **finding what works and what doesn't work** although here the nurse's perspective is examined. For example Bull and Jervis (1997) suggest that 'information seeking' and 'learning to manage' are indicators of 'finding out what works'. 'Information seeking' in order to 'learn more about the illness and ways to manage symptoms' is comparative to the reasons why nurses in this study seek out information. In addition it was clear that the women participants in this study also employed a process of seeking out information for the same reasons. 'Accessing resources' in order to 'learn to manage' is similar to the process utilised by the nurses in this study when they involve the multidisciplinary team. Mothers and daughters sought out services and learned new skills primarily from the health professionals caring for them so they could manage and 'find what works' (Bull & Jervis, 1997). The nurses in this study utilised the multidisciplinary team when faced with the need to **find what works and what doesn't work**.

A significant remark by Bull and Jervis (1997) was that home care was considered helpful when there was continuity of health visitors, when health visitors showed respect and sensitivity to the family and when nursing care met the expectations of those receiving that care. In this study the nurses identified the importance of building a trusting relationship. Providing continuity of care, respecting different views and meeting the expectations of clients by being open and honest were strategies deemed important to the relationship and for the purpose of **finding what works and what doesn't work**. This appears to suggest that nurses in this study are aware of implications such as continuity, mutual respect and effective communication on their relationships with clients.

An in-depth discussion of the categories and the relationship to the core variable is presented next.

5.2 Finding what works and what doesn't work and the causal model

5.2.1 Finding what works and what doesn't work and problem solving

Problem-solving is the causal condition to **finding what works and what doesn't work** and is the way this core variable is operationalised. The nurses assess and make interventions about physical, psychological and social problems by referring to their knowledge base in conjunction with an open-minded approach. These are evaluated to identify that they fix the problem. Therefore the evaluation **finds what works and what doesn't work**. Problem-solving conceptualised in this way is similar to the nursing process and Woolley (1990) argues that the nursing process is indeed the application of problem-solving to the care of clients.

Nurses in this study make choices about what interventions to make. These choices are based upon **finding what works** for the particular client. Orme and Maggs (1993) suggest that problem-solving involves making clinical decisions in order to resolve issues. The clinician may need to choose from alternatives, which may mean that a trade-off has to be made. Making such choices draws on skilled assessment and decision-making abilities and this is a key accountability of community health

professionals according to Kenyon, Smith, Hefty, McNeil and Martaus (1991). Orme and Maggs (1993) identify some of the factors that experts bring to decision-making and these include experience, broad knowledge base, collaboration and having a picture of the whole situation. These factors are all found to be relevant to the nurses in this study and some discussion about how these contribute to **finding what works and what doesn't work** is pertinent.

Implicit within the problem-solving category is that these community nurses use their knowledge in order to **find what works and what doesn't work** in terms of solutions to problems. This knowledge base, for they all have at least five years experience in this field, has both an empirical and aesthetic component to it. Their scientific knowledge such as that referring to wound care underlies interventions and decisions about which wound product is likely to work. Experience and knowledge assist the nurses to make innovative interventions. Aesthetic components to practice are evident in the more artful helping interventions such as supporting and empowering through self-care. In addition, discussions about reflecting on practice describe the influence of personal knowledge on the way the nurses' practice suggesting that this way of knowing is also relevant. Throughout there is commitment to an ethic of care. Carper's (1978) explanation of the four fundamental patterns of knowing is relevant to current practice.

Nursing thus depends on the scientific knowledge of human behaviour in health and in illness, the esthetic perception of significant human experiences, a personal understanding of the unique individuality of the self and the capacity to make choices within concrete situations involving particular moral judgements. (Carper, 1978, p. 22.)

In this study the nurses' decision-making abilities draw on different ways of knowing about phenomena to assist the process of **finding what works and what doesn't work**.

What is notable about problem-solving in this study is that it is very much a reflection of what was described in the literature review. Aspects such as: the difficulty in finding the best dressing products, malodour being identified as the most distressing symptom of the wound, the challenges created by the amount of exudate, cost being a consideration when providing wound care and innovative use of dressing systems to

achieve good cosmetic appearance, are described by the nurses and are also within the literature review. A comparison such as this indicates that problem-solving skills are highly relevant to nursing this group of clients and that the problems span different geographical populations. A further comparison indicates that sexuality and spirituality are areas that remain difficult to address. In terms of sexuality Howlett, Swain, Fitzmaurice, Mountford and Love (1997) suggest that “primarily there appears to be a lack of ‘nurse comfort’ with this topic, which seems to stem from existing taboos in Western society today” (p. 218). The nurses in this study indicated that although they perceive care as needing to be holistic, issues around sexuality and spirituality were not easily discussed with clients. Indeed these subjects require a trusting relationship and a sense of it being the right time for their inclusion in problem-solving initiatives.

Collaboration with the multidisciplinary team was identified by the nurses as important to problem-solving because ideas can be shared in order to **find what works** with the recognition that nurses do not practice in isolation. The various skills of members of the multidisciplinary team are used to support care and offer different solutions to problems that are difficult to resolve. McEnroe (1996); Mcilpatrick and Curran (1999); Nichols (1998) and Spradley (1991) all identify the importance of the multidisciplinary team to respond to the various needs of clients receiving care in their homes. Arguably **finding what works and what doesn't work**, with the community nurse as the key worker in liaison with the multidisciplinary team, “is characterised by autonomous, interdependent practice; comprehensive decision-making, multidisciplinary coordination, and collaboration [that] strengthen the nurses ability to meet the care needs of [the] home health patient” (McEnroe, 1996, p. 188-189).

Nurses in this study also employed a process of looking at the big picture when problem-solving was undertaken. An opportunity to explore holism and its relationship to this study is taken at this point.

Holism, according to Kramer (1990) refers to the connectedness of parts of the organism while simultaneously perceiving the organism as a whole. However, “A holistic health focus requires viewing the living organism as a unit with both health

and ill-health reflecting throughout its entirety. Thus attention to an ill 'part' must be tempered by a view to the whole" (Kramer, 1990, p. 247). Perceiving holistic health in this way is congruent with the view of chronic illness discussed further on. Having a holistic focus in the community setting has a long history although it should not be taken as a given. Wilson (1998) suggests that holistic health has been associated to public health and district nursing since the end of the 19th century. Indeed McMurray (1992) refers to having a holistic focus as one characteristic of the expert community nurse. However, when holism is an unquestioned approach to health care there is the risk that the medical gaze will be cast over all aspects of a person. Thus there is the potential to medicalise and pharmaceutically treat all aspects of a person (Wilson, 1998). Nurses in this study utilise many interventions, the least of which is pharmaceutical. This is not to suggest pharmaceutical therapies do not have a place; they are one option amongst many. Practising in a way such as this keeps alive the concept of holistic health and demonstrates it as a reality in the community setting in order to **find what works and what doesn't work** when managing chronic illness.

'Looking at the whole' is a phrase that captures the way the nurses in this study have a holistic health focus. The nurses perceive the person as someone living with an illness and not simply a client with a disease process. They consider the wider environment and how this impacts on the person and acknowledge that despite a chronic illness they are striving to promote a sense of normality for the client. Caring for clients within their home environment also acknowledges their input into decision-making and problem-solving. Ascertaining what the client and/or family perceive as the main problem is vital to this process and again this was identified by the nurses in this study as well as Collinson (1993) and Hallet (1995). A recent grounded theory study by Cowley (1995), also found that community health visitors in the United Kingdom consider a much broader concept of holism than is traditionally defined. Attention to the wider situation that encompasses environmental, cultural, community and individual family beliefs is required and given by community nurses even though the initial referral may not have suggested such a view would be required (Cowley, 1995). Identified within this study is that without a holistic health focus problem-solving is likely to be found wanting because interventions must take account of the whole of the situation. **Finding what works**

and what doesn't work takes account of broader issues than simply the major problem of the fungating wound. "Such an approach, taking in the 'whole picture', bringing in the patient experiences as well as the practitioner's, is reiterated in Benner's work where the expert demonstrates the ability to immediately access the total situation" (Orme and Maggs, 1993, p. 272).

Thus problem-solving, as an integral part of **finding what works and what doesn't work** is not only relevant to the group of nurses in this study. Evidence is provided to suggest that it is a characteristic of community nursing in broader environments. Decision-making capabilities brought about by the use of knowledge from the four ways of knowing in combination with a focus on holistic health and utilisation of the multidisciplinary team are important aspects of problem-solving.

5.2.2 Finding what works and what doesn't work and making sense of the situation

Nurses in this study strive to make sense of the situation in order to develop a trusting relationship with these women, which forms the basis to providing care and **finding what works and what doesn't work**. The intention of making sense of the situation is to understand why the fungating tumour has occurred and in doing so develop empathy for the situation. The ability to do this is dependent on the nurses having a non-judgemental approach to their clients.

Understanding and having empathy for women with this condition is implicit within the literature on fungating wounds. This is a response to the fact that these wounds cause distress. "Fungating wounds can be distressing and it is vital for the nurse to display empathy and great sensitivity" (Bird, 2000, p. 652). Empathy is also considered a characteristic of the expert community health nurse according to McMurray (1992). In this discussion McMurray (1992) suggests that expert nurses explore the client's physical, emotional and social environment in order to develop empathy and therefore provide effective care. Thus empathy is a necessary element of **finding what works and what doesn't work**.

Burnard (1988) defines empathy as the ability to see the world through the eyes of another. "To empathise is to attempt to set aside our *own* perception of things and

attempt to think the way the other person thinks, or feel the way he feels” (Burnard, 1988, p. 388). Nurses in this study suggest that having a ‘feeling for the woman and her situation’ is what empathy means to them, reinforcing the accurateness of this definition. Burnard (1988) does suggest however, that there is a limit as to how far one can enter another’s frame of reference and therefore focussing on understanding someone else’s experience is the intention of empathy. Feeling for the situation provides the nurses with some ability to then put themselves in another’s shoes in order to understand, so that helpful interventions can be offered for the purpose of **finding what works and what doesn’t work**. Taking such an approach whereby understanding the situation is the intention of empathy and helpful interventions are the outcome reduces the risk of emotional over-involvement (Morse, Bottorff, Anderson, O’Brien & Solberg, 1992). To reduce emotional over-involvement and yet remain connected to the situation Morse et al (1992) suggest re-conceptualising empathy into emotional and therapeutic empathy. These forms of empathy provide positive strategies for nurses as opposed to strategies that cause nurses to become so detached from the situation their ability to care can be questioned (Morse et al, 1992).

Morse, Bottorff, Anderson, O’Brien and Solberg (1992) describe emotional empathy as a subjective sensation aroused by witnessing distress in the client. Emotional empathy according to Morse et al (1992) evokes expressive responses such as pity, sympathy, compassion, commiseration, consolation and/or reflexive reassurance for the purpose of developing a connection to the client’s lived situation. As demonstrated in the analysis the nurses in this study use emotive words to describe the situation of a fungating breast tumour and in doing so, gain, some insight into the level of distress this situation causes.

Removed from the experience of suffering, the caregiver is not usually consciously aware of his or her own body. However, observing a patient suffering causes distress in the nurse, and, consequently, awareness of his/her own body. Thus, the nurse is engaged with the patient’s experience of suffering, and the patient’s suffering is embodied by the nurse, and suffering becomes a shared experience. (Morse et al, 1992, p. 811.)

However, feeling for the women and having such expressive responses cannot be sustained over the long term and emotional empathy without any action has limited therapeutic benefits (Morse et al, 1992). While this was not explored with the participants in this study it appears that the concept of therapeutic empathy as a method of controlling the depth of involvement so that the health professional can continue to be helpful to the situation was relevant.

Therapeutic empathy, defined by Morse, Bottorff, Anderson, O'Brien and Solberg (1992) as a de-emphasis on emotional involvement and having cognitive or behavioural actions, is relevant as an approach these nurses utilise in the course of **finding what works and what doesn't work**. The nurses in this study attempt emotional distance by embarking on a process of trying to understand the situation as opposed to being consumed by the emotions created by feeling for the women. As previously indicated, understanding leads to the ability to offer helpful interventions in order to make a difference to client's lives.

It can be argued that gaining an understanding of the situation and being empathetic in a therapeutic way requires an open-minded approach receptive to the client's situation. Indeed McNaughton (2000) suggests in a synthesis of qualitative Public Health Nurse home visiting research that the nurse's attitude toward the client influences the ability to understand her situation and thereby provide individualised interventions. In this study the nurses identified the importance of being non-judgemental so that an understanding from the client's viewpoint can be achieved which assists in making sense of the situation. The nurses are well aware of the consequences of pre-judging the woman and how this restricts the ability to **find what works and what doesn't work**. More attention to this aspect and its relationship with empathy is needed although the nurses in this study have begun the process of acknowledging the importance of being non-judgemental for understanding and empathy to be practised. Being non-judgemental enhances the ability to make and sustain connections with clients.

Thus the processes of feeling for the situation, having an understanding about this, empathising with the person and being non-judgemental are all inextricably related to one another. They assist nurses to make sense of the situation in order to offer interventions aimed at **finding what works and what doesn't work**. These

interventions are made possible by building a trusting relationship for problem-solving to be appropriate and effective.

5.2.3 Finding what works and what doesn't work and considerations to care

In the course of **finding what works and what doesn't work** the nurses must respond to the considerations to care. These considerations pertained to the physical, cultural and professional aspects of practice. Rather than these considerations becoming a limitation to their practice the nurses examine ways of overcoming them in order to continue a process of **finding what works**.

Physical considerations to practice involves the influence of time constraints whether these are caused by geographical distance or limited time in the current visit. However, time constraints according to the nurses in this study can be overcome. British authors, Mcilpatrick and Curran (2000) report a similar finding and draw the conclusion that district nurses will make time despite the many demands placed upon them. Again comparisons between different nursing groups can be made indicating that there is some transferability of the outcomes of data analysis and the core process of **finding what works and what doesn't work**.

A large part of the visit to women with a fungating tumour of the breast is to provide wound care. Because of the highly complex wound problems that need to be addressed such as malodour, exudate, haemorrhage and cosmetic appearance **finding what works and what doesn't work** means finding dressing products that manage these symptoms while being cost-effective. The nurses in this study utilise innovative strategies such as the use of incontinence products to provide low cost yet effective wound care. However, this does not suggest that this is ideal and wound products specifically designed for these wounds would be helpful.

The nurses in this study are also aware of cultural differences as a consideration in providing appropriate care. As indicated in the data analysis there is the potential for cross-cultural communication to be problematic. Pride (1985) suggests that communication can break down because either there is a failure in understanding what is meant or that meanings/interpretations of what is said are over-accommodated. These sorts of problems have led to the debate about whether

'insiders' (person from the same cultural background) or 'outsiders' (person from another culture) are best suited in providing care (Merton, 1972; Minichiello, Aroni, Timewell & Allender, 1995). While there are two sides to this debate, that insiders have an understanding of cultural values, beliefs and communication patterns and outsiders have the ability to see different aspects of the situation because of their distance to the culture, the nurses in this study will either be 'insiders' or 'outsiders'. They have few options to address this dilemma as nurses from non-European cultures are scarce but the fact that they recognise them and offer whatever strategies they can is the first step toward **finding what works and what doesn't work**.

In terms of professional issues the nurses identified difficulties with communication between health services. Indeed McEnroe (1996) explains that the community nurse is a pivotal link between the client and members of the health-care team. This key worker role is likely to experience difficulties and contribute to a situation of **what doesn't work** when the transfer of information between hospital and community does not occur. Mcilpatrick and Curran (1999) in their focus group study exploring District Nurses perceptions of palliative care services stated "the majority of concerns expressed within this study were linked to poor communication, either between professionals within the PHCT [primary healthcare team] or between the primary and secondary care interface" (p. 220). According to some nurses in this study, this situation is improving with the computerisation of medical information. Easier access to information assists the nurses to feel more prepared for the situations they are likely to encounter. Arguably being prepared for what might be encountered will positively influence **finding what works and what doesn't work** as nurses have the opportunity to think about what they can offer to potential problems.

Having knowledge about the client contributes to perceptions of power. Indeed Gibson (1991) claims that nurses by the virtue of their position and expertise have power and can use this as a tool for empowerment by developing relationships based on equality. Power is recognised by the nurses in this study as something they consider because it has the potential to impact on **finding what works and what doesn't work**. Ways that power can be abused include over-visiting or changing care without consultation or planning in any purposeful way. These abuses of power impact on **finding what works and what doesn't work** because they have a dis-

empowering effect on the client and there is the risk that the changes have been tried previously and were found to reflect **what doesn't work**. Indeed in order to **find what works** "health care professionals need to surrender the need for control and adopt the community necessary for co-operation. The attitude that the health professional knows best fosters a sense of dependency" (Gibson, 1991).

5.2.4 Finding what works and what doesn't work and building a trusting relationship

The capacity of **finding what works and what doesn't work** is made possible because of the strategy of building a trusting relationship. Coming to know each other provides the nurses with opportunities to get to know the concerns of clients and what problems they face until the relationship draws to a close. It is only when this level of sharing is achieved that the nurse can make effective interventions. This was confirmed in the discussion about empathy. Evident throughout the building of a trusting relationship is that those receiving care are not passive in this process. Their opinions, values and beliefs are important considerations for the nurses and must be worked with as opposed to being ignored. As Christensen (1990) states,

It is a collaborative endeavour between people who are, in fact, strangers brought together for a single purpose. The effectiveness of their collaboration is dependent on the outcome of the negotiation processes in which nurse and patient are involved as the patient's passage unfolds. (p. 32)

Building trust is the first step toward coming to know each other. Cowley (1995) suggests that this is an approach taken by community health visitors in the United Kingdom. Time spent exploring concerns was found to be indicative of building a relationship with the client in order to provide care. Although Cowley (1995) does not identify building a relationship with clients as a strategy health visitors utilise it is implicit throughout the descriptions of 'therapeutic prevention'. 'Therapeutic prevention' is described as dealing with the myriad of irregular yet interrelated issues that reflect the complexity of lived situations. There is a similarity between this and looking at the whole in this study where it is acknowledged that complexity of situations requires open-mindedness and the ability to explore what the client perceives as the problem. Trust is the pre-requisite for this to occur.

Indeed Meize-Grochowski (1984) suggests that when there is discussion of the relationship between health professionals and those receiving care, whether that be phrased as therapeutic, interpersonal or in this case a trusting relationship, the concept of trust is vital. The meaning of trust in nursing according to Meize-Grochowski (1984) is a confidence in someone or showing dependability, consistency and predictability. Having trust in someone increases the likelihood that information will be shared and “whether any advice from the nurse is followed may depend in large part on what type of relationship exists between the consumer/patient and the professional nurse. Ideally, this relationship is a therapeutic relationship based on trust” (Meize-Grochowski, 1984, p. 572).

From the perspective of those experiencing a chronic illness Thorne and Robinson (1988) provide a grounded theory study to suggest trust was pivotal to satisfaction with the health care relationship and high quality health care. Trust was found to be the foundation to having a collaborative relationship with health professionals in order to manage the implications of chronic illness (Thorne & Robinson, 1988). While the evidence is not strong in this study one woman participant identified trust as being important to her. Thorne and Robinson (1988) suggest that nurses need to reciprocate the trust of their clients; thus trust from nurses fosters trust in nurses. Morse (1991) performed content analysis of data from clients receiving health care and identified that clients make assessments of the nurse. They ask questions to ascertain whether the nurse is a ‘good nurse’, observe and listen to the nurse while care is provided to assess competence and caring ability and test trustworthiness with sharing minor secrets. Implicit within the data from the three women participants is that they too make assessments of the nurse in order to know whether to share concerns or whether they are in professional hands.

Morse (1991) describes how nurses become involved in and committed to their relationships with clients. Having a ‘personality click’, sharing personal information to find common ground, closing the distance between the nurse and patient by making eye contact or sitting at the same level and making a connection by spending time together assists the process of coming to know each other (Morse, 1991). They parallel strategies utilised by the nurses in this study. The process of **finding what**

works and what doesn't work is made possible because the nurse and patient have come to know each other.

Coming to know each other in the trusting relationship requires the nurse to be open and honest, listen to the concerns of the client, talk through the issues and respect the client's values, beliefs and decisions. Thorne and Robinson (1988, p. 788) state that "it is imperative to develop the particular skills of listening with intent, curbing preconceptions, soliciting the patient perspective, and validating conclusions" for the purpose of managing chronic illness. Listening as a skill is evident in this study. Anderson (2000), Jones (2000) and Deeny and McCrea (1991) also refer to the importance of the nurse's listening skills. Clients want to be listened to, heard and understood. **Finding what works and what doesn't work** is dependent on being able to listen and talk through issues.

Building a trusting relationship for the nurses in this study reflect what Morse (1991) defines as a connected relationship. Although the nurse participants in this study refer to therapeutic relationships, in fact the context of what they say would fit more adequately with Morse's (1991) description of connected relationships. According to Morse (1991), a therapeutic relationship is characterised by providing care in terms of making small effective interventions for non-life threatening client needs over a short duration. However, a connected relationship whereby the client is perceived firstly as a person and then as someone requiring care engenders a sense of commitment on behalf of the nurse (Morse, 1991). This commitment balances the demands and priorities of health care providers in the best interest of the client. As Morse (1991) claims a nurse in a connected relationship will demonstrate the following,

These nurses will serve as a patient advocate, interceding on behalf of a patient with family or medical staff, and will buffer or protect patients from some of the more unpleasant aspects of care...In this relationship, the patient believes that the nurse has 'gone an extra mile', respects the nurse's judgement and feels grateful; the nurse believes that her care has made a difference to the patient. (p. 458)

This description captures the essence of analysis findings and what was identified as an important outcome of transforming practice. **Finding what works and what doesn't work** is dependent on this type of relationship.

The value of building a trusting relationship cannot be underestimated. Clearly the nurses in this study perceived it as important to their ability to deliver care. Mcilpatrick and Curran (1999) identify from their focus group study that a key theme throughout the data was the relationship between the client, family and the nurse. It is considered an important aspect of care and there is some evidence within the study by Mcilpatrick and Curran (1999) and from the woman participants in this research that this is valued by those receiving care.

However, what is lacking from Morse's (1991) analysis of the nurse – client relationship is how the relationship ends. Indeed finding nursing literature that discusses when and how relationships with clients end has been difficult to find. This study provides some insight into how and when relationships end. It can be argued that if nurses have participated in an effective process of **finding what works and what doesn't work** then relationships will draw to a close appropriately as opposed to being 'terminated' or simply 'ended'.

5.2.5 Finding what works and what doesn't work and transforming practice

The processes of thinking things through and seeking out information provide the nurses with the ability to **find what works and what doesn't work** and as a result there is the capacity to transform their practice.

Thinking things through involves **finding what works and what doesn't work** by reflecting on practice and drawing on experiences. Reflecting on practice is a tool the nurses in this study utilise to examine the way that practice has changed and whether individual situations could have been managed differently. This provides the basis for a critical analysis of nursing practice. Burton (2000) describes reflection on action as looking back on past practice to analyse 'hunches' and tacit knowledge to make explicit what is happening so that this can be critically analysed. Reflections have given the nurses in this study the knowledge of **what works and what doesn't work** including the different strengths each nurse brings to each situation that assist care and whether there were any gaps in the care provided. Knowledge gained from the process of reflection, according to Andrews, Gidman and Humphreys (1998), needs to be combined and integrated with previous knowledge in order for practice to change. Thus reflection is a purposeful activity and contributes to the development of

the nursing profession and the discovery of **what works and what doesn't work**.

As Andrews (1996) states,

Expertise arises from constant examination and analysis of performance, with the objective of refining practice...Nurses need to remain aware of their actions and the effects of care. Willingness to change practice is the crucial determinant between merely repeating ineffective actions and actually using the experience to develop. (p. 509)

Transforming practice as an outcome of reflection links the thinking about and the doing in practice. Christensen (1990) explains that the new nursing culture emphasises creative thinking opposed to continual doing in nursing practice. Nurses in this study reflect on practice in order to answer the 'why' questions. These 'why' questions pertain to why their nursing care worked and with this an understanding about practice is achieved. Reflection for these nurses is a purposeful intellectual activity that adds to their knowledge.

Developing knowledge about nursing relates to either the empirical, aesthetic, personal or ethical dimensions of knowing (Carper, 1978). Carper (1978) identifies empirical knowing as the first fundamental pattern of knowing and refers to this as scientific knowledge. Empirical research endeavours are undertaken in order to describe, explain and/or predict phenomena and are gathered from the observation of facts, experiences and descriptions (Chin & Kramer, 1995; see also Vaughan, 1992). Aesthetic knowing reflects the ethereal, subjective or artistic dimension to nursing practice (Chin & Kramer, 1995). Personal knowledge describes a process of bringing the 'self' to relationships with others so that authentic personal relationships can be developed (Carper, 1978). Personal ethical viewpoints reflect moral decision-making and indeed, it is argued by Vaughan (1992) every decision has a moral component to it. This formulates the basis to ethical knowledge, which is the fourth pattern of knowing in nursing identified by Carper (1978). The nurses in this study practice by drawing on these four patterns of knowing. Reference to evidence-based practice and ongoing education as well as experience in **finding what works and what doesn't work** develops empirical knowledge. Respecting client's values and beliefs and incorporating this into the care provided reflects the aesthetic component of practice.

Building trusting relationships with clients provides nurses with the opportunity to learn more about themselves and as a consequence build personal knowledge. Nurses utilise ethical ways of knowing when they face situations where they must decide whether to share their views about decisions made by clients when they do not agree with them. These sorts of decisions are made in deeply embedded contextual situations on an individual basis. These examples assist in building a picture of knowing **what works and what doesn't work** that can be brought forward to other situations to provide nurses with wisdom of a practical nature.

Practical wisdom, according to Lauder (1994) requires creative and innovative solutions to complex problems. It is argued in this thesis that practical wisdom draws upon **finding what works and what doesn't work** learned by reflecting on practice combined with drawing on experiential and formal knowledge. By combining experiential and formal knowledge that has been subject to critical reflective processes the nurses in this study have the ability to find innovative solutions to often very complex problems.

5.3 Chronic illness and finding what works and what doesn't work

Women with a fungating tumour of the breast live with a chronic life-threatening illness. Identified in the literature review is that the median survival for this group of women is 2 – 2.5 years (Roger, Leonard and Dixon, 1994, p. 1431). This means that their lives will be characterised by periods of wellness as well as illness. By taking an approach that focuses on wellness in context to illness the whole of the person's experience is taken into account (Chinn, 1996; Lindsey, 1996; Paterson, 2001). Chinn (1996) states,

If the patient's voice were central, the issues to be considered would not consist only, or even primarily, of medical options and prognostications. The issues would include the philosophic and ethical perspectives of the person, the person's story or narrative, what the person hopes for, who else figures most prominently in what the person is facing, and how all these people together see the situation. (p. vi.)

A view of chronic illness that accounts for the person's experience and narrative is the shifting perspectives model of chronic illness described by Paterson (2001). This perspective of chronic illness provides a framework for this discussion.

This model of chronic illness allows flexibility for the person to shift to and from wellness or illness. When illness is in the foreground, the person according to Paterson (2001) is forced to attend to their illness by learning strategies to manage illness. Nurses have a pivotal role in this phase of living with a chronic illness as they can assist people to understand their illness and what can be done to manage it. Nurses in this study demonstrate this role when they describe how they provide helping interventions. Enlisting the support of family gives the woman support and resources to manage independently. Encouraging self-care practices enable the woman to learn about how to manage her illness and consequently take some control over her life. Providing information addresses the educational needs of these women whether it is about medical treatments or what is available to support the women. McNaughton (2000) suggests that community health visitors have as the goal of care self-efficacy, autonomy, independent decision making and self-confidence for their clients. Chronically ill women and their care-giving daughters in the study by Bull and Jervis (1997) identified the importance of having information. As Nichols (1998) states, "Clinicians need to educate. They need to give information which helps a patient and family understand an illness and anticipate its likely progression. They need to address fears and debunk myths" (p. 27). Thus **finding what works and what doesn't work** is not simply the application of nursing interventions to a person; rather it is about providing clients with capabilities and resources that promote independence.

McWilliam, Stewart, Brown, Desai and Coderre (1996) in their phenomenological study of how older people cope with chronic illness outline strategies for nurses practising with an approach that establishes health within illness. Creativity, open-mindedness and flexibility are essential in order to allow for individual differences. Listening skills are also described as important. Gaining in-depth knowledge of the person is achieved through continuity. "Participants described the experience of being known as important to fostering their self confidence" (McWilliam et al, 1996, p. 13). These strategies are apparent within the data provided by the participants in this

study. In particular innovation and open-mindedness were related to problem-solving and listening and continuity were important to coming to know each other when building a trusting relationship.

The shifting perspectives model of chronic illness is suited to holistic health philosophies of care. Haworth and Dluhy (2001) suggest that a holistic approach is essential to effective symptom management and that this is particularly relevant because of the increasing numbers of people living with chronic illness. "Within a nursing perspective, managing symptoms such as pain, fatigue, dyspnea, or weakness also requires understanding the person's experience and meaning associated with each symptom" (Haworth & Dluhy, 2001, p. 303). Gaining an understanding of the 'lived experience' also validates the impact of symptoms on activities of living. Likewise the nurses in this study readily subscribe to holistic health care by taking a look at the whole approach to the clients situation. Evaluations of interventions such as fixing the problem in order to make a difference to quality of life reflect the nurses awareness of the meanings of symptoms and the need to address them for the purpose of maintaining a sense of normality. **Finding what works and what doesn't work** takes into account the individual experiences of illness.

Wellness in the foreground is a perspective that allows the person to be defined as something more than a disease (Paterson, 2001). As the illness is distanced by wellness the opportunity to focus on other aspects such as emotional and social ways of being is achieved. McWilliam, Stewart, Brown, Desai and Coderre (1996) also reiterate this view.

For older people with chronic illness, health simply means being able to do the things they want to do...While participants' experiences clearly portrayed a functional definition of health, their stories also revealed subscription to the eudaemonistic definition of health, with an enthusiasm for attaining a sense of fulfilment or purpose in life through doing. (p. 5)

The women participants in this study also strive for a sense of normality while living with their illness and state this as their main concern. Nurses in this study support this main concern and endeavour to offer interventions that facilitate participation in normal life activities. **Finding what works and what doesn't work** is the core

behaviour that responds to this main concern and is an approach that enables a shift in focus toward health within illness.

5.4 Implications for practice

This study adds to the body of knowledge supporting the nursing profession. It acknowledges and values the contribution of Community Nursing to client care.

The main implication for practice is that nurses caring for this group of clients have a model that supports their practice. Nurses have access to the skills and strategies that are utilised in practice. Skills in terms of problem-solving and making sense of the situation and strategies such as building a trusting relationship and managing the considerations to care are clearly articulated. These are practised with the core process of **finding what works and what doesn't work** as the major objective of care which then has the capacity to transform practice. As a consequence those in leadership roles have a model with which to evaluate the ability of clinicians.

Another implication for practice is that this model can be used as a framework for educators teaching community nursing. **Finding what works and what doesn't work** is a platform from which student nurses can learn about caring for clients in a community setting.

5.5 Limitations and future directions of this research

Clearly, the major limitation in this research study was the small number of women with a fungating tumour who were able to participate. There were difficulties recruiting these participants and this researcher tried to address this by enlisting the support of district nurses to access the women and extending the geographical area. Re-interviewing these women also proved to be difficult to organise. Due to personal and time constraints this study could not be extended any further in the hope that more women participants could be included. However, the data from the three women who did participate provide a small beginning to understanding what concerns them and what is important in the relationship between them and the nurses who care for them. This provides the basis to the primary appeal for future research. A larger study

of women with this condition would build on this introductory exploration of their experiences.

In terms of the nurses interviewed in this study some positive outcomes have eventuated. Seven nurses through in-depth interviews have described and explained how they practice in terms of managing the care of women with a highly complicated long-term illness. There is some evidence in the analysis and discussion that other community nurses utilise some of these same processes reinforcing that **finding what works and what doesn't work** is a core variable that assists nurses to promote a sense of normality for their clients' lives. However, there are limitations to this claim because the nurse participant group only consisted of seven community nurses. Theoretical sampling could extend and saturate this substantive theory of **finding what works and what doesn't work** to more nursing groups and wider nursing situations.

A further limitation of this study stems from this researcher's inexperience. Because this researcher started with the intention of ascertaining the women's experiences as opposed to the nurses, time was lost and sometimes questions that were asked turned out to be irrelevant. This has limited the amount of useful data from the participants. A more valuable study could have eventuated if the scope of the study had been widened to include either fungating tumours anywhere on the body or breast cancer in general. Alternatively focussing specifically on community nursing would have provided more in-depth focussed data for the substantive theory of **finding what works and what doesn't work**. These limitations form the basis for appeals for future research.

5.6 Conclusion

To conclude, this study has provided evidence to support **finding what works and what doesn't work** as a core variable utilised by nurses caring for women with a fungating tumour of the breast. **Finding what works and what doesn't work** provides nurses with the scope to develop innovative interventions, caring for clients while respecting their values and beliefs and utilising empowering strategies that place control in the clients' hands while still supporting them in the context of living with a chronic illness. The casual model has provided a framework to represent the

categories of problem-solving, making sense of the situation, considerations to care, building a trusting relationship and transforming practice. These have been discussed in order to link this study with literature that supports the process of **finding what works and what doesn't work**. Literature relating to the categories has identified that the approaches the nurses in this study have taken are reflected in other similar nursing groups. Most importantly this study adds to the body of knowledge explaining how nurses practice and particularly how they employ the process of **finding what works and what doesn't work**.

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Appendix A

Information Sheet for Women Participants

My name is Erica Corlett and I am currently completing a research project for completion of a Master of Arts degree. I would like to invite you to participate and this sheet outlines information you need to know prior to participating in this research project. To contact me you can phone and leave a message at the Nursing Department of Massey University Albany Campus ph: (09) 4439370. My supervisor for this research is Judith Mahood and she can be contacted at the same number.

Purpose

You are invited to participate in this research project. I would like to explore the experiences that women with a breast tumour where the skin is broken have. In particular, I would like to understand how you perceive yourself and your relationships with your partner/husband, family, and the wider community. This means that together we have discussions about very personal aspects of your life and illness. I will also be interviewing some nurses to gain an understanding of their experience in caring for women similar to you.

How the research will be completed

These interviews will be taped with your permission and then typed out by myself or a transcriber who has signed a confidentiality agreement. This is so I can analyse the information you have provided. I will exchange your name for a false one to protect your identity on any written material. Once the tapes have been typed out they will either be destroyed or you can choose to keep them which means you accept responsibility for who has access to them. I would also be happy to show you a copy of the typed information so that you can delete anything that may identify you and follow up any concerns. You can request to stop taping at any stage in the interviews, can ask me any questions about the research, and/or refuse to answer any aspect that you feel uncomfortable with. You can also withdraw any information from interviews you decide you do not want included.

I would prefer to interview you on your own for this research but if you feel you need a support person or family present then this is fine with me. Contributions made by family in the interviews may also be included in the analysis.

The research will require you to participate in up to three or four interviews over a 12-month period. Interviews will probably last one to two hours each. The final written document will take up to two years to complete. If you wish to withdraw at any time for any reason that is okay. Because this project is over such a long time there is the possibility that something may happen to prevent you from continuing. I am willing to discuss with you what happens to what you have contributed if this should occur.

The potential benefits and/or costs

Talking about such personal matters can have benefits as well as drawbacks. Possible benefits are that you may feel better for talking about things that concern you as well as helping nurses and others to understand some of your experience.

Possible drawbacks involve the potential distress that talking about this type of subject can cause. I am willing to offer counselling support for up to two contacts should you need this. If you have any queries or concerns regarding your rights as a participant in this research you may contact the Health Advocates Trust at ph: 0800 205 555 Northland to Franklin. I have approached a cultural advisor to help us in this area. If you feel uncomfortable because of our cultural differences then I will understand if you choose not to participate. This study has received ethical approval from the Auckland Ethics Committee. In the unlikely event of a physical injury as a result of your participation in this study, you will be covered by the accident compensation legislation with its limitations. If you have any questions about ACC please feel free to ask the researcher for more information before you agree to take part in this trial.

How I use what you have said

Once I have got some of the typed interviews I want to analyse them to see common themes and concepts. This means that your descriptions will be compared with others to see any similar or different aspects. This does not mean that there are any right or wrong answers. I only want to see what is similar and what is different between the women and the nurses that participate. The analysis will mean that more abstract concepts may replace what you have said but they will be closely linked to your input. Once the research is finished it will be published as a thesis document and placed in Albany Campus Library. I also intend to write an article for publication in a nursing journal about this research. In the future I may use this research to inform nurses and try to teach them some of what I have learned from this research. An article will also be submitted for publication in G.P Weekly so doctors can have access to the results. The Hospital and Health Service in the area I am researching in will also receive a copy of the results. I would also be willing to provide you with a summary of the outcomes of the research if you want this. The written signed consent form that you fill in will be kept in a locked cabinet so that your identity can be protected.

Appendix B

Information Sheet for Nurse Participants

My name is Erica Corlett and I am currently completing a research project for completion of a Master of Arts degree. This information sheet outlines information you need to know prior to participating in this research project. To contact me you can phone and leave a message at the Nursing Department of Massey University Albany Campus ph: (09) 4439370. My supervisor for this research is Judith Mahood and she can be contacted at the same number. If you have any queries or concerns regarding your rights as a participant in this research you may contact the Health Advocates Trust at ph: 0800 205 555 Northland to Franklin. This study has received ethical approval from the Auckland Ethics Committee. In the unlikely event of a physical injury as a result of your participation in this study, you will be covered by the accident compensation legislation with its limitations. If you have any questions about ACC please feel free to ask the researcher for more information before you agree to take part in this trial.

Purpose

You are invited to participate in this research project. I would like to explore the experience of nurses caring for women with a breast tumour where the skin is broken. I would like to understand the positive and negative aspects to caring for these women and how you provide care to meet their needs. I will also be interviewing women with a breast tumour where the skin is broken to gain some insight into their experience.

How the research will be completed

These interviews will be taped with your permission and then typed out by myself or a transcriber who has signed a confidentiality agreement. This is so I can analyse the information you have provided. I will exchange your name for a false one to protect

your identity on any written material. Once the tapes have been typed out they will either be destroyed or you can keep them and accept responsibility for who has access to them. I would also be happy to show you a copy of the typed information so that you can delete anything that may identify you and follow up any concerns. You can request to stop taping at any stage in the interviews, can ask me any questions about the research, and/or refuse to answer any aspect that you feel uncomfortable with.

I would prefer to interview you on your own for this research but if you feel you need a support person present then this is fine with me.

This research will require you to participate in up to three or four interviews over a 12-month period. These interviews will probably last one to two hours each. The final written document will take up to two years to complete. If you wish to withdraw at any time for any reason that is okay.

The potential benefits and/or costs

You may find it beneficial to share your experience highlighting both positive and difficult aspects of caring for this group of women. You will be able to share your knowledge and contribute to the body of disciplinary knowledge around the subject of breast cancer.

All potential costs cannot be predicted but a possible cost could be the acknowledging of limits to practice. I am willing to provide information available in the literature to assist in supporting nursing practices.

How I use what you have said

Once I have got some of the typed interviews I want to analyse them to see common themes and concepts. This means that your descriptions will be compared with others to see any similar or different aspects. This does not mean that there are any right or wrong answers. I only want to see what is similar and what is different between the women and the nurses that participate. The analysis will mean that more abstract concepts may replace what you have said but they will be closely linked to your

input. Once the research is finished it will be published as a thesis document and placed in Albany Campus Library. I also intend to write an article for publication in a nursing journal about this research. Results will also be fed back to relevant groups within the Hospital and Health Service and as an article for publication to G.P Weekly so General Practitioners have access to them. In the future I may use this research to inform nurses and try to teach them some of what I have learned from this research. I would also be willing to provide you with a summary of the outcomes of the research if you want this. The written signed consent form that you fill in will be kept in a locked cabinet so that your identity can be protected.

Appendix C

Signed Informed Consent Form

I have read the information sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand I have the right to withdraw from the study at any time and to decline to answer any particular questions.

I agree to provide information to the researcher on the understanding that my name will not be used without my permission.

I consent to family input being incorporated into this interview. YES NO

I consent to the interview being audio taped. YES NO.

I also understand that I have the right to ask for the audiotape to be turned off at any time during the interview.

I agree to participate in this study under the conditions set out in the information sheet.

Signed Participant _____

Name _____

Date _____

Explained by _____

Project Role _____

Signature _____

Date _____

Appendix E

Non disclosure of information

Typist/Transcriber

I _____ agree not to disclose the name, or any information that would lead to the identification of, the participant in the research study being undertaken by Erica Corlett. The audiotapes, transcripts and computer disks will not be made available to anyone but the researcher or her supervisor and will be kept securely while in my possession. I will not retain any copies of the audiotapes, computer disks, or transcriptions.

Signed: _____

Name: _____

Date: _____

Appendix F

Memo about the core category

I have been working with the idea that looking at the whole is the core category. Looking at the whole refers to holistic nursing and wholeness in terms of problem solving and the trusting relationship. Holistic nursing is the perception of looking at all aspects of a person in their lived situation. Problem solving and the trusting relationship is perceived as whole because there is a completeness to these processes, for example problem solving progresses through assessing, intervening and evaluating and trusting relationship has a beginning, middle and an end.

However how do considerations to care and the processes of reflecting and knowing fit with looking at the whole? Is it looking at the whole that is the core process being used? It is not a behaviour as such, and grounded theory is about identifying the behaviours that resolve concerns. Instead is looking at the whole only related to problem solving? Looking back at the discussions about holistic care they all seem to relate to problem solving. For example:

“You’re not just actually looking at the wound you’re looking at the whole family situation. You are doing the holistic care and I guess it’s buying into what they want, what the wife wants, what the husband wants, and thinking what is manageable to them.” (Helen, Interview 1:4)

This is about finding what works, what is manageable for the wife and the husband and you have to look at the whole of the situation in order to do this. Maybe that’s it! It is a process of finding what works that motivates the nurses behaviour. If this is so how does that fit with the categories so far.

Problem solving and looking at the whole = causal condition (this causes the nurses to ‘find what works’)

Building a trusting relationship = strategy (this is how the nurses can ‘find what works’ because trust, rapport and working together is the groundwork to knowing the women and what will work for them)

Considerations to care = intervening condition (if physical limitations to practice or cultural differences interfere with the visits then they are less likely to be able to 'find what works')

Making sense of the situation = context (the only way the nurses are able to 'find what works' is by having an understanding of the women, their situation and what they are experiencing)

Reflecting and knowing = another intervening condition (if the nurses don't learn or have knowledge by reflecting on practice and gaining more knowledge then they won't be able to 'find what works')

Helping = consequence (as a consequence of 'finding what works' and knowing the women's situation in-depth then nurses are able to help the women)

So if finding what works is the core variable how does it account for the times when the nurses can't find the absolute right thing to help. It needs to account for this aspect of what doesn't work. The nurses talk about times where they know from experience or trying something that it doesn't work. Therefore the core variable might be **finding what works and what doesn't work.**