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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.