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**THE LIVED EXPERIENCE OF
ADULT PATIENTS COMMENCING RADIOTHERAPY
AND/OR CYTOTOXIC CHEMOTHERAPY**

**THESIS PRESENTED IN PARTIAL FULFILMENT OF THE
REQUIREMENTS FOR THE DEGREE OF MASTER OF ARTS
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ALAN WILLIAM WILSON

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Abstract

A Phenomenological Study Of The Lived Experience Of Adult Patients Commencing Radiotherapy And/Or Cytotoxic Chemotherapy

This study describes the lived experience of seven adult patients commencing radiotherapy and/or cytotoxic chemotherapy as outpatients at a regional cancer centre. Due to the long distances between their homes and the centre, six of the patients stayed in an oncology hostel during their treatment.

A phenomenological research method was used to describe the lived experience of these participants. Data analysis involved the development of themes from thematic statements, and a description of the central phenomena.

The central phenomena identified is the concept of "**walking alongside**" one's normal lifeworld. There is a strong theme in the lifeworld of lived time through "**counting up, down or through**" treatments and this provides a basic measurement of the "**distance of the trip**" of radiotherapy or cytotoxic chemotherapy treatment. Links to normality are sought by patients and are important if the patients are to return to their pre-treatment lifeworld.

By improving health professionals understanding of the experience of having radiotherapy or chemotherapy, they will be better able to support patients through the experience of having these treatments. Patients stand to benefit from health professionals understanding the experience of patients commencing radiotherapy and/or cytotoxic chemotherapy and assisting patients through facilitating this trip.

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To the medical, therapeutic radiography, and nursing staff, I was continually aware of the major role that you play in making the experience of these patients a positive one. In addition to technical excellence, the highly human perspective you hold as caregivers contributed to the patients' experiences and hence my research.

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Chapter One : Introduction

In New Zealand there are twelve thousand new cases of malignancy diagnosed every year (Ministry of Health, 1994). Many of these patients will receive radiotherapy and/or cytotoxic chemotherapy either as the sole method of treatment or in combination with surgery.

The word cancer brings with it important connotations.

Cancer is often the metaphor chosen for any social state or condition that slowly but inexorably destroys or erodes. Such expressions as "the cancer of our society", and the "growing cancer of the political system", convey its sinister meaning and contribute to the stigmatisation of the person who has cancer (Holland & Rowland, 1989, p. 4).

In addition to the apprehension associated with having a life threatening condition, there is also a widely held view in society that radiotherapy and/or chemotherapy treatment is particularly ominous and unpleasant. This view can affect how a patient responds to the diagnosis.

This research is aimed at increasing knowledge about the experiences of a group of adult patients receiving these treatments. Phenomenology, as a research method appropriate to the discovery of knowledge about lived experience, was identified as being the most appropriate method for this research.

A diagnosis of cancer leads to a wide range of experiences that contribute to the patient's total experience of the illness. A combination of surgery, cytotoxic chemotherapy, and radiotherapy are frequently the courses of treatment that are undertaken by these patients. Both chemotherapy and radiotherapy involve

prolonged courses of treatment and both can, and frequently do, have unpleasant side effects.

The purpose of the study was to develop descriptions of the experiences of adult patients commencing radiotherapy and/or cytotoxic chemotherapy. Through analysis of patients descriptions, this study will assist health professionals to understand the experience for patients receiving these forms of treatment. It may then be possible for health professionals to manage the individual patient's treatment to make the experience as positive as possible for that patient.

I began the study with two particular interests. The first was in the patients' decision making as it related to treatment options. The second was in the experience of patients who receive lengthy courses of treatment involving high technology equipment and/or drugs, and which could bring about immediate and distressing side effects. A personal interest in this area of nursing practice developed from being present when a male patient, who was my own age, was commencing his first treatment on a radiotherapy treatment machine. I was concerned about the thoughts and fears of patients at this time. I wondered whether my own thoughts and fears regarding these methods of treatment would be the same as those experienced by patients who were living the experience of commencing treatment? The role of nursing staff in caring for outpatients receiving radiotherapy appeared to be minimal. These patients saw an oncologist weekly during treatment but there was considerable pressure on the medical staff, and tight limits on the time that they were able to spend with each patient.

Throughout the research the experience of commencing cytotoxic chemotherapy and/or radiotherapy could not be divorced from the entire experience of having cancer - which in turn was only part of the life long experience of a patient. It was however thought to be possible from the outset to concentrate on the experiences associated with either or both of these treatment modes.

Chapter Two : Review Of Relevant Literature

In this chapter I will review appropriate literature in areas related to radiotherapy and cytotoxic chemotherapy treatment. I have included a discussion on the clinical practice involved in both these forms of treatment to allow the reader to be aware of the context in which treatment occurs.

A review of literature in the area of the experience of radiotherapy and chemotherapy treatment identified many references. A high proportion of these references related to pain management and descriptions of the treatments themselves. The findings of the literature review reinforced my interest and commitment to undertake this study because of its ability to contribute to nursing knowledge. This literature review focuses on several key areas: popular perceptions of treatment, radiotherapy and cytotoxic chemotherapy treatment per se, symptoms and their significance, delay, coping and stress, and social support.

Popular perceptions of treatment

Issues relating to the public perception of both radiation and cytotoxic chemotherapy treatment can influence patients from the time that the treatment is first recommended. Popular perceptions of radiation may be quite erroneous when compared to the use of therapeutic doses of radiation. Holland and Rowland (1989, p. 136) note:

The horrors related to radiation, beginning with Hiroshima, are well known. Three Mile Island, Chernobyl, and descriptions of inadequately controlled nuclear reactor plants cause fears about radiation effects in general, which contribute to concerns about voluntary exposure even for therapeutic reasons.

Receiving radiation for therapeutic purposes may result in fear and dread as the patient compares his/her treatment to events occurring in international radiation disasters. But in doing this the patient is disregarding the difference in the intent of the radiation, the dosage, and the likely effects of the therapeutic radiation.

"Cancer" carries with it connotations that are well reported in popular literature and research studies. Ingelfinger (1975) identified the term "cancerophobia" to describe the high level of anxiety associated with cancer or the fear of contracting cancer. In the minds of many, cancer is one of the worst diagnoses that can be made and one that almost certainly leads to death. Cancer is often feared as being a life threatening disease that conveys a threat of intractable pain, hopelessness, and wasting away before death occurs (Klagstrum, 1983). This cancerophobia may also be related to the nature of the treatment prescribed for cancerous conditions. Rimmer, Jones and Wilson (1983) suggested that the side effects of anticancer chemotherapy can be so difficult to live with that some patients regard them as worse than the disease itself. This perception suggests the need for careful attention to the individual's psychological state if a researcher or health professional were seeking to understand the experience of the treatment for an individual patient.

Some literature noted that the cancer treatment was not difficult and that they would recommend it to other patients with cancer. Meyerowitz, Watkins and Sparks (1983) studied women with breast cancer during chemotherapy treatment and for two years after completing it. Of these women, 89% reported that they would definitely recommend to a close friend that she have the treatment if it were necessary. They also reported lingering fears of recurrence and became "queasy" when they experienced reminders of their illness or treatment, especially smells such as alcohol. This study also found that 41% of the women who received adjuvant chemotherapy found the experience had been easier than they had expected.

The popular perceptions of cancer and cytotoxic chemotherapy treatment may be changing with time and as a result of more open communication regarding patient conditions and treatment options. Lesko, Massie and Holland (1988, p. 85) found that "more accurate and available information about the benefits and side effects of cytotoxic chemotherapy was now making new patients' fears more realistic".

However, despite more open discussion, a cancer diagnosis still generates fear and anxiety. This fear relates both to the likely outcome and the methods of treatment along the way.

Radiotherapy

Radiotherapy involves the use of high energy ionizing radiation or X-rays to treat disease. Roentgen discovered X-rays in 1895 and the Curies' discovered radium in 1896. These discoveries were quickly followed by the recognition of the biological effects of ionizing radiation and its potential for clinical application to medicine (Holland & Rowland, 1989).

The first successful use of radiation was reported in 1898 when it was used for the treatment of basal cell cancer (Strohl, 1990). The first skin cancer patient was reported to be cured by radiation therapy in 1899 (Perez & Brady, 1987). By the 1920's radiation machines were able to deliver deep radiation therapy with a standard and reproducible dose, and radiation was added to surgery as a tool for the treatment of cancer.

Radiation works by causing single-strand or double strand breaks in DNA which causes cell death as the cell attempts to divide (Strohl, 1990). Cells which are rapidly dividing are thus more likely to be prone to treatment by radiation.

Although primarily used for malignant diseases, radiotherapy can also be used in the treatment of some benign conditions. There is a wide range of clinical

indications for radiotherapy and Strohl (1990) estimates that 60% of people with a cancer diagnosis will receive radiation at some point in the treatment of the disease. Over the years radiotherapy has become increasingly sophisticated and there has been an increase in the ability to safely treat and cure many forms of cancer. Today patients who undertake radiotherapy are given either an expectation of a cure, of an increase in survival time, or of improved symptom control.

Malignant tumours may be classified as radiosensitive, radiocurable or radioresistant. Tumours that diminish (but are not necessarily cured) when treated by moderate doses of radiation are known as radiosensitive. Radiocurable tumours are those which are able to be completely cured by radiation. Some tumours are not destroyed by radiation (e.g. malignant melanoma). These tumours are known as radioresistant, and radiotherapy is not a treatment option. Radiation may be used for tumour cure, tumour control or for the relief of symptoms depending on the response of the tumour to radiation and the extent of the disease.

Courses of radiotherapy vary depending on the site and type of malignancy. Most treatment centres in both New Zealand and internationally provide standard courses of treatment over a four to six week period with a daily treatment of radiation occurring Monday to Friday. Patients who are receiving radiotherapy for palliation may have short courses over several days. Each patient is individually assessed, taking into consideration the patient's body size, tumour location and tumour cell type.

These treatment parameters are established by consultant oncologists who in association with the therapeutic radiographers plan the treatment for the patients using complex mathematical equations and planning computers. This is known as "treatment planning", and will usually be the first contact that the patient has with radiotherapy treatment following an outpatient consultation. Frequently individualised immobilisation devices (moulds or frames) are required to ensure that radiation is accurately delivered to the precise site. These devices ensure that

patients maintain their body in a particular position in relation to other structures of the body, or in relation to the treatment machine itself.

The individual patient's treatment parameters are then tested for accuracy and efficiency using a machine that simulates treatment. This part of the treatment is known as "simulation", and is required to ensure patient safety and accuracy of treatment.

The radiotherapy patient is referred to the treatment machine staff. There may be a delay of days to weeks before treatment on the machine can commence. This will depend on the numbers of patients awaiting treatment. The first appointment for the patient with the treating radiographers involves ensuring that the planning has been done correctly before the radiation is delivered. Additional films (which resemble X-rays) are taken at the first treatment appointment to ensure simulation calculations are consistent with the treatment machine's delivery of radiation.

While radiation treatment is usually given externally, brachytherapy is a form of treatment where the radiating sources are applied directly to the tumour using rods or other applicator devices. This allows for large doses to be given directly to the tumour but with minimal doses into the surrounding tissue. The risk of side effects caused by radiation to surrounding organs and exposed entry sites is thus minimised or reduced.

Radiotherapy is administered by therapeutic radiographers with regular review (usually weekly) by the medical staff. Nursing reviews vary from centre to centre and range from regular to non-existent. Radiotherapy patients are usually managed on an outpatient basis but some patients with significant morbidity risk require admittance to hospital. When patients are unable to travel daily to hospital for treatment, many cancer centres will provide a hostel facility for patients having treatment away from home. Voluntary organisations often provide assistance with these facilities.

Side Effects of Radiotherapy

The therapeutic goal of radiation is to deliver a precise dose of ionizing radiation to a specific tumour site while sparing the surrounding healthy tissue. Most side effects of radiation therapy are confined to those tissues and structures within the path of the radiation beam, and are defined as being either "acute" or "late" effects. Acute reactions are those that occur during a course of treatment or for up to six months following completion of the treatment. Late effects can occur up to 20 years following radiation and are usually related to total dose of radiation and size of the dose fractionation (i.e. the amount of radiation in each dose). In addition to specific organ damage, late effects can include ulceration and fibrosis in the general area of the treatment.

Common side-effects of radiotherapy are :

- skin reactions (to the treatment site)
- alopecia (with head irradiation)
- mucositis
- oesophagitis (with chest irradiation)
- nausea and vomiting (with irradiation to the abdomen)
- diarrhoea (with irradiation to the abdomen and pelvis)
- fatigue

The most frequent side-effect of radiation is skin damage.

Depending on the total dose and the type of the radiation used, particularly where there is no skin sparing effect, reactions of the skin may be epilation, erythema, dry desquamation, and moist desquamation. Recovery after moist desquamation usually takes place from 2-4 weeks and is usually complete. The new skin is thin and pink and a gradual return to gross normal appearance takes two to three months. (Lewis & Levita, 1988, p. 182)

The incidence of side-effects from radiation can be influenced by psychological factors. A study completed in 1961 showed that even among patients who received only sham radiation exposure in a controlled study, 75% developed symptoms of nausea and fatigue in anticipation of experiencing radiation sickness (Parsons & Webster, 1961).

There can be many psychological affects in patients who are experiencing radiation treatment. Peck (1972) and Peck and Boland (1977, cited in Holland & Rowland, 1989, p. 138) provided the first systematic interviews of patients undergoing radiation. They found the common reactions to be anxiety, depression, anger, and guilt. Patients used defense mechanisms of denial, displacement (concern for others), identification (joining the doctor's fight), and dependence on the doctor and treatment. Patients were pessimistic about the treatment and unprepared for it.

While there are many similarities between radiotherapy and cytotoxic chemotherapy treatment, there are also many differences. Either can be the sole method of treatment for a patient.

Cytotoxic Chemotherapy

Cytotoxic chemotherapy, while similar in many ways to radiotherapy, has had a different evolution. In the sixteenth century heavy metals were used in the treatment of cancers. Although mostly unsuccessful, treatment with chemicals continued until a significant development in 1940 when Gilman obtained brief remission in a patient with lymphoma through treatment with nitrogen mustard (Holland & Rowland, 1989). Since that time there has been a proliferation of chemical agents used for this purpose. Many cancers are now curable (e.g. Hodgkins disease, choriocarcinoma, acute myelogenous leukaemia) with others

having improved survival with cytotoxic chemotherapy treatment (e.g. neuroblastoma, breast carcinoma, osteosarcoma).

Cytotoxic chemotherapy today involves the administration (usually intravenously) of substances with the aim of destroying tumour cells. These chemicals work in a variety of ways to halt rapidly dividing cells. While rapidly dividing cells are predominantly cancerous there is also a significant loss of normal cells in the process. Combinations of cytotoxic agents may be used when the tumour is more responsive to multiple agents.

Like radiotherapy, cytotoxic chemotherapy treatment can occur over a prolonged period of time. Unlike radiotherapy, the course of the treatment is less standard and treatment varies considerably from patient to patient. The choice of treatment will vary depending on the type of tumour, the drugs(s) being used, the patient's response to the agent(s), and the side-effects experienced by the patient.

Side Effects of Cytotoxic Chemotherapy

Unlike radiation therapy, where the treatment is directed towards the area of the tumour, chemotherapy is usually administered to the entire body. The side-effects are thus more systemic in nature and often more severe.

Principle side-effects of cytotoxic chemotherapy include the following:

- nausea and vomiting
- weight loss
- diarrhoea
- hypersensitivity
- skin reactions
- alopecia (hair loss)

The administration of cytotoxic chemicals causes myelosuppression and leucopenia as a direct result of the therapeutic regime. Thrombocytopenia, hepatotoxicity and cardiotoxicity are frequent side effects of many cytotoxic agents. Partially because of the severity and systematic nature of the side effects, the role of nurses in caring for patients receiving chemotherapy treatment has been more prominent than for those nurses working with radiotherapy patients.

Chemotherapy is becoming a more acceptable modality of cancer treatment and many professional nurses are administering antineoplastic agents. In addition to giving the drugs, nurses are involved in caring for the patients receiving them therefore it is imperative that all nurses encountering cancer patients in their practice are thoroughly familiar with the complexities of cancer therapy. (Trester, 1982, p. 201)

Holland and Rowland (1989) describe the very active nature of the treatment that oncology patients receive and this explains the opportunities and challenges for nurses caring for these patients.

More intensive therapies given in the hospital require stamina, compliance, and a grasp of future benefit. Chills, fever, sepsis, antibiotics, stomatitis, infusional feedings, transfusions, diarrhoea and confinement in bed with impaired ability to attend to personal needs are some of the physical aspects which result in dependence on caregivers. Hostility, anger at venipunctures, and anxiety about outcome characterize some of the essential emotions. In these patients the quality of life during treatment is so poor that the equation must be balanced by the hope of results and by a desire to live. (Holland & Rowland, 1989, p. 151)

Symptom Management

A large volume of research has been done in the area of symptom management in cancer treatment. In this thesis I was interested not in symptom management, but with the significance of symptoms as part of a patient's experience of the treatment.

In a study by the Psychosocial Collaborative Oncology Group (cited in Holland & Rowland, 1989, p. 151), patients receiving treatment under 30 chemotherapy protocols were studied at three centres. The patients ranked their most distressing symptoms as follows: hair loss 84%, nausea and vomiting 71%, and tiredness and weakness 70%. The patients were also questioned as to the major problems that interfered with function and the researchers noted that these took a heavy toll on quality of life.

In addition to pain caused by the disease itself, treatment can cause pain and discomfort for the patient. Chapman, Kornell and Syrjala (1987, p. 189) state that pain may be induced by the cancer treatment causing neuropathic complications.

Following irradiation, fibrosis of a neural plexus may gradually develop over a period of months, leading to eventual chronic axonal irritation with pain as well as paraesthesia. Chemotherapeutic drugs may sometimes result in toxic peripheral neuropathies characterised by painful paraesthesia, dysthenias and myalgias.

Delay

Another area of research significant to this study, is the time period over which the process of having cancer treatment occurs. Some research studies have focused on the time lag between noticing the symptoms of the cancer and the patient actually seeking medical review. Pack and Gallo (1938) defined as

"delay", when the period between noticing symptoms and reporting them to the doctor is more than three months. The length of this period is within the control of the patient and can be influenced by the individuals' perception of the significance of the symptoms.

Eddy and Eddy (1984, cited in Holland and Rowland, 1989) reviewed studies of delay and its effects on survival. Although the studies suffered from some biases and methodological flaws, the results are significant. Their summary of nine studies, showed that one quarter to three quarters of the cancer patients examined had delayed more than 3 months. This reduced their long-term chances of survival by ten to twenty percent.

There can also be a period between the patient receiving the diagnosis and being able to commence treatment. This may be due to staff or facility shortages and in some countries the cost or total absence of these services. Delay in seeking diagnosis or receiving treatment can adversely affect the patient's prognosis and both can be times of anxiety for the patient and the family.

A number of patients in the study were detected through a breast screening programme when there were no symptoms of breast cancer. The concept of delay due to patient derived factors does not therefore exist for these patients. Waiting for these patients was from the time of diagnosis until radiotherapy treatment could be commenced. This was a period of one month for some of these patients.

Coping

Comments such as "How is the patient coping with the diagnosis?" or "She seems to be coping very well" are commonplace in oncology wards. Coping is a term that is frequently used by health professionals and lay people when considering the patient with cancer. In the literature many and varied definitions of coping are

given and this encourages a liberal and inconsistent use of the term within everyday language.

Weisman and Worden (1975, p. 64) define coping as "... what one does about a perceived problem in order to bring about relief, reward, quiescence, or equilibrium". Lazarus and Folkman (1984) argue that coping includes managing of specific internal and external demands. Both authors recognise that there may be a high level of adaptation required by these patients at the time of having treatment.

There are major differences in individual responses and individual coping strategies adopted. Cohen and Lazarus (1973) found in a study of surgical cancer patients that knowledge of the individual's "characteristic" coping style is not always useful in predicting how he or she will respond in a novel situation. In a later study, Monat and Lazarus (1977) found that any coping strategy can have both positive and negative as well as short term and long term consequences. In considering coping responses, Holland and Rowland (1989) state that it is thus inappropriate to talk about an individual's style as being appropriate or maladaptive. The response is appropriate to that individual and it is only a subjective interpretation of the likely success of the strategy and of the "normality" of the response that determines how the response is interpreted by others.

Caplan (1981, cited in Holland & Rowland, 1989, p. 148) claim that the goals of coping should be "to reduce physiological and psychological arousal to a tolerable level, and to adapt to the realities of the stressful situation". Holland and Rowland (1989) adapting work from Hamburg and Adams (1967) identified five goals of effective coping behaviour in serious illness:

- to keep distress within manageable limits.
- to maintain a sense of personal worth.
- to restore relations with significant other people.
- to enhance prospects for recovery of physical functions.

-to increase the likelihood of working out a permanently valued and socially acceptable situation after maximum physical recovery has been attained.

Accepting that coping is desirable for patients with cancer, literature identified some of the factors which determine how an individual might cope. Holland and Rowland (1989, p. 25) state that there are three sets of individual or patient-related variables which affect psychological adaptation to cancer. The developmental stage is where the person is, in respect to life-cycle related biological, personal, and social life goals and tasks, when cancer develops. The intrapersonal style is that which the person brings to the illness by way of previous cancer or medical experience, personality, coping style and defences. The interpersonal resources are what family, friends, groups of people and other social support structures contribute to the person's environment. These variables provide a valuable insight into coping relevant to the experiences of patients with cancer.

Holland and Rowland (1989) further identified five forms of disruption that occur when there is a diagnosis of cancer and relate these to the developmental stages of the individual. These five disruptions are: altered interpersonal relationships, dependence-independence, achievement disruption, body-sexual image and integrity, and body image.

In an interesting study involving assessment of patients' psychological state, Holland, Rowland, Lebowitz and Rusalem (1979) studied patients undergoing radiation treatment at Montefiore Hospital. Using content analysis they analysed a five minute speech sample at three points; prior to the first treatment, during the second week and near the end of treatment. While overall anxiety and hope decreased insignificantly over time there was a significant overall increase in internalised hostility (depression) and in externalised hostility. This study suggests the need to maintain ongoing assessment of patients over the entire period of

treatment, as patients could become increasingly depressed and angry as treatment progressed, rather than more comfortable and confident.

Stress and Coping

Much of the work in the area of coping includes the dual concepts of stress and coping. Lazarus (1974) developed a psychological model of stress and coping. This is a transactional model that focuses on the relationship and feedback between the person and the environment. Coping is seen as effortful, dynamic, cognitively mediated and process oriented. The dynamic nature of stress and coping is relevant for oncology patients who must accommodate different demands of illness and treatment constantly interacting within the environment in which they exist.

Weisman (1979, 1984a, 1984b) identified a circular, cancer-specific model of stress and coping which recognises the insidious nature of the disease. He identified four psychosocial stages in coping with cancer: existential plight, accommodation and mitigation, recurrence and relapse, and deterioration and decline. In existential plight the patient questions his/her own existence and the threat to personal mortality arising from the diagnosis. Accommodation and mitigation is the stage when the patient undertakes treatment and recognises his or her personal circumstances. Recurrence and relapse will occur if the patient becomes aware that the treatment has been unsuccessful and that he or she must re-evaluate personal feelings from the perspective of a revitalised threat. Deterioration and decline occur when the patient recognises his or her deteriorating physical condition and the inevitable death resulting from the malignancy.

Holland and Rowland (1989) identify several common themes that emerge from research on coping with cancer. The first of these themes is that strategies or styles that promote an active (c.f. passive) response to problem solving and coping behaviour are consistently found to be the most effective. Another of the major themes that they found is that coping with illness is a dynamic process. Coping

strategies will change as the individual's circumstances change and as the individual continually appraises the impact of the cancer in respect to his or her survival, future, relationships, self esteem, and achievement of goals. The third major theme is that individuals who exhibit flexibility in their efforts are better able to cope. This flexibility is not unique to coping with cancer but to coping with a range of situations. The final theme was that the nature and amount of social support available to the individual strongly influences his or her capacity to cope. Each of these themes is supported by other literature but it is clearly defined and stated by Holland and Rowland (1989).

Prolific researchers and authors in the area of *psychooncology*, Holland and Rowland (1989) further identified a number of predictors of poor coping with cancer. These are social isolation, low socioeconomic status, alcohol or drug abuse, previous psychiatric history, history of recent losses, inflexibility and rigidity of coping, pessimistic philosophy of life and multiple obligations. Many of these factors are socially oriented and there is considerable literature covering the area of social support.

Social Support

Social support for patients with cancer takes on many forms. Holland and Rowland (1989) found that the principal types of support provided include informational, emotional-affectional, tangible (e.g. financial, physical), affirmational (providing a sense that one's feelings are understood), affiliational (providing a sense of belonging or maintenance of social identity), and appraisal (support that gives feedback to the patient). Data falling within each of these areas was revealed as part of my research study although it has been categorised differently for description.

Kaplan et al (1977) considered social support to be the degree to which a persons basic needs are gratified through interaction with others. This interaction with

others, the social support, is the interpersonal resources described by Holland and Rowland (1989) as one of the three variables that influence individuals adaptation to illness.

Peters-Golden (1982), in a study of 100 breast cancer patients, found that patients reporting good support also expressed less difficulty in adjusting to their illness. Patients with recurrent disease reported less satisfaction with support, and those undergoing chemotherapy experienced the least adequate levels of support. Taylor, Lictman and Wood (1983) completed a study of 78 breast cancer patients and found that a woman's satisfaction with her relationship, and her ability to share concerns with a significant other were essential parts of good adjustment. In addition, perceived support from family members, perceived support from friends, and a close and highly interactive family, were also associated with good adjustment. Overall, social support was a strong predictor of adjustment.

Buckalew (1982) described her personal experience as a child psychiatric-mental health nurse clinician who received cytotoxic chemotherapy treatment for ovarian adenocarcinoma. She identified the need for incorporating objectives of reducing anxiety in the care plan of patients with cancer. Much of the support that she received during treatment was from her husband and she described training him to watch her intravenous cytotoxic infusion because of her concerns about her own safety. Buckalew identified that in addition to the social support that she received from her husband, nurses could assist her to cope through a number of 'basic nursing cares' that she found particularly supportive (eg. backrubs, talking).

There have been a number of studies exploring the effects on others who support patients having treatment, and on the value of the support to patients undergoing chemotherapy and/or radiotherapy. In a study of the effects on husbands whose wives were undergoing chemotherapy, the husbands described a deterioration of their own health as well as disturbed thought processes during their wives terminal illness (Howell, 1986). Husbands report an increased desire for physical closeness

with a decreased sexual desire when wives undergo chemotherapy for advanced disease (Leiber, Plumb, Gerstenzang & Holland, 1976). In a grounded theory study of husbands living with a wife undergoing chemotherapy, Wilson and Morse (1991) identified a three stage model consisting of identifying the threat, engaging in the fight, and becoming a veteran.

Koocher and O'Malley (1981) report that maintenance of social contacts at the time of diagnosis, combined with good communication and information within the family, were all associated with better long term adjustment. Jamieson, Wellisch and Pasnau (1978), in a study of 41 patients following mastectomy, found that women who perceived their spouses, children, physicians and the nurses as supportive, reported better emotional adjustment. Both of these studies showed the importance of social support to the experience of the patient undergoing treatment.

One of the determinants of social support is the cultural perspective of the patient and their significant others. Individual cultures have different perspectives on health and illness. These cultural perspectives influence the coping styles of the individuals receiving treatment. New Zealand is a multicultural nation with a relatively recent history of cultural mixing. The cultures of the individual patients in the study influence their experiences of receiving radiotherapy and cytotoxic chemotherapy.

Ali, Khalil and Yousef (1993), in a study comparing the attitudes of American and Egyptian cancer patients who were receiving chemotherapy or radiotherapy found a marked difference in the attitudes for the two different cultural groups. American patients showed five categories of attitudes: (a) fighting spirit and adaptation, (b) fear/anxiety/disbelief (c) hope (d) passivity in plan of care and (e) faith. For Egyptian patients seven categories emerged (a) stoicism and fatalism (b) dependency (c) compliance with the medical regimen (d) anxiety/fear/insecurity (e) powerlessness (f) hope and optimism and (g) family support.

The significance of this study is the different experiences that may occur in patients from different cultures. Care that is planned for patients must recognise the different cultural attitudes that a patient may hold and it is reasonable to assume that if there are large differences for these two cultures, significant differences will exist between other cultures.

In addition to the patient's social and cultural group, the experience for patients commencing cancer treatment will also be affected by the relationships that they forge with the health professionals caring for them. There has been a change in the manner in which cancer diagnoses and treatment are managed by medical staff. More information in regard to diagnosis and treatment is now given to patients, and patients play a more active role in their own treatment.

A study by Oken (1961) found that of a group of physicians, 90% never told patients of the actual diagnosis of cancer. The same set of questions used in 1977 showed that 97% of the doctors studied generally told patients their cancer diagnosis (Holland and Rowland, 1989). Of concern is a study by Mitchell and Glickman (1977) which found that 82% of patients undergoing radiotherapy felt that neither the referring doctor nor the radiotherapist were individuals to whom they would bring their emotional problems. They suggested that more training of radiotherapy personnel in communication skills and management of psychological problems would be helpful. The utility of this study must be considered in light of the time that has passed since the study was done and the changes in the health professions that have occurred over this time.

Despite patients identifying the need for social support, a fear of abandonment and alienation are reported by a number of authors. Typical is a quote by Blumberg, Flaherty and Lewis (1980, p. 21 cited in Severo, 1977):

People who have cancer sometimes speak of themselves as the new lepers; of being rejected, over protected and misunderstood, all at the same time and by the very people they look to for support.

Modification of social support to prevent patients having the feelings expressed above, is gaining increased importance in nursing. Holland and Rowland (1989) state that modification of social support has the advantage that it is generally not time-consuming, is inexpensive and has few negative consequences. Identification of the importance of the social support for these patients highlights the opportunity for nurses to assist families and friends to understand and meet patient needs. Penman et al (1984) found that not only are the physical side-effects of cytotoxic chemotherapy troublesome but the repeated interference of the chemotherapy treatments with work and family are of major concern.

The search for meaning of the experience of commencing radiotherapy and/or cytotoxic chemotherapy is an important part of my research. O'Connor, Wicker and Germino (1990) studied the personal search for meaning conducted by the patient who has recently been diagnosed with breast, lung or colorectal cancer. Six major themes were identified from interviews with 30 patients: seeking an understanding of the personal significance of the diagnosis; looking at the consequences of the cancer diagnosis; reviewing life; change in outlook toward self, life, others; living with the cancer; and hope.

The literature review has described appropriate literature within the field and its relationship to this research topic. There is considerable literature in the areas of coping and the physical aspects of radiotherapy and/or cytotoxic chemotherapy treatment. As nursing literature has tended to concentrate on symptom management, physical nursing care and psychology based studies on coping and stress, many of the articles in the literature review are authors from psychology or medicine. There is a need to describe the lived experience of adult patients commencing radiotherapy and/or cytotoxic chemotherapy if we are to understand

how nurses can make the patients' experience of treatment as positive as possible. The literature review supports the need for further research in this area.

Chapter Three : Research Methodology And Study Design

In this chapter I will discuss the research method used in the study and the theoretical foundation behind the methodology. The study design will be described and the development of the findings chapters introduced.

The essence of nursing involves being with people as they experience and understand their health. Understanding and explaining the essence of nursing may not be simple using traditional quantifiable methods. Attempting to reduce patients to sub-units that can be counted is to deny the complex, holistic and dynamic nature of health and illness, and the way it is experienced by people. Nurses' involvement with patients in the humanistic domain frequently makes study of patients experiences of health or illness difficult using the traditional quantitative research methods.

Qualitative Research Methods

The merit of qualitative versus quantitative research has been an issue with which nurses have been grappling. Qualitative research methods made their appearance in nursing in the 1960's. They offered nurses an opportunity to examine questions from a different perspective and made the examination of new areas of nursing practice possible. Previously, scientific methods were often assumed to be quantitative and traditionalists have challenged the qualitative researchers claim that a scientific methodology had been used. The challenges to qualitative methods are made from a number of perspectives.

Validity in qualitative research is often challenged and compared to the principle of validity in quantitative research. Sandelowski (1993, p. 2) addresses this challenge through defining validation from a less traditional perspective:

When validation is viewed as a culturally and historically situated social process, both experimentalist and interpretivist can be recognised as relying on contextually grounded linguistic and interpretive practices rather than on rules assumed to be sufficiently abstract and universal for every project. 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 practised good science.

Qualitative research should be auditable through leaving a clear trail with the methods and processes used in the research being transparent. It is transparency that allows auditing which supports the claim to validity and hence scientific methodology.

Reliability in qualitative research methods has also been challenged. Woods and Cantanzaro (1988, p.136) outline four possible influences on reliability in qualitative research. These are the researcher's status position, the participant's choice, the social situation and conditions under which data are collected, and the methods of procedure. Each of these should be addressed as the research proposal is established and as qualitative research findings are reviewed. This interpretation of reliability differs markedly from that in quantitative research where the focus is on the ability to replicate a study and obtain consistent results.

Tesch (1990, cited in Sandelowski, 1993, p. 3) describes the richness that qualitative research can offer when used appropriately. Tesch believes that the result of qualitative analysis should be viewed as:

...a representation in the same sense that an artist can, with a few strokes of the pen, create an image of a face that we would recognise if we saw the original in a crowd. The details are lacking, but a good "reduction" not

only selects and emphasises the essential features, it retains the vividness of the personality in the rendition of the face.

Guba and Lincoln (1981) believe that credibility rather than internal validity in the quantitative sense should be the criterion against which the true value of the research should be evaluated. The credibility of a study is affirmed when it presents such faithful descriptions or interpretations of a human experience that people having the experience would immediately recognise it from those descriptions or interpretations as their own. Guba and Lincoln (1981) argue that a study is also credible when other people (other researchers or readers) can recognise the experience when confronted with it after having only read about it in a study. I believe that this claim to credibility is the reality test behind qualitative methodology when it is used appropriately in the humanistic domain.

The credibility of qualitative research is often questioned due to criticisms of bias through allowing subjects to become involved with the participants. Indeed what is to become "known" from the research cannot be established unless the researcher enters into a subjective relationship with the participant. Bracketing is "the act of suspending ones various beliefs in the reality of the natural world in order to study the essential structures of the world" (van Manen, 1990, p. 175). This bracketing reduces the potential bias of the researcher while allowing the researcher to interact closely with the participant.

Munhall and Oiler (1986, p. 58) illustrate the complexity of this relationship between reality and the researcher doing qualitative research.

Reality is a complex whole constituted in individual human existence in a concrete physical, social world. Though the truth of the objective world is not questioned, the qualitative researcher recognises that its life in any practical sense, is contingent on human involvement with it.

There are a number of qualitative research methods available to the researcher in social sciences.

Phenomenology

In providing both a philosophy and a qualitative research method, phenomenology makes a considerable contribution to the development of nursing research. This is supported by Davis (1978, p. 94) who states that "phenomenology provides a more perfect fit conceptually with the functions of clinical nursing practice and with many of the research questions that evolve from clinical practice".

Phenomenology provides a philosophical base for interpreting and understanding the complex human experiences that occur within the health and illness domains. Morse (1989, p. 16) argues that phenomenology is valuable for the study of everyday life. This approach is consistent with the acknowledgement that illness (or the threat to health) are encountered on a daily basis.

Although the phenomenological tradition is a diversified one, phenomenology is nonetheless a distinctive philosophy, theory and method for studying the world of everyday life. (Morse, 1989, p. 16)

Phenomenology is about interpreting and understanding experience rather than observing and explaining behaviour (Morse, 1989). Meaning is revealed through the interpretations of the descriptions by the participants and it is through description that this experience can be communicated.

The phenomenological method seeks to uncover the meaning of humanly experienced phenomena through the analysis of subjects' descriptions. It is through the analysis of the descriptions that the nature of a phenomenon is revealed and the meaning of the experience for the subject understood. (Parse, Coyne & Smith, 1985, p. 17)

A fundamental principle of phenomenology is that experience is constructed within the context in which the experience occurs for the individual. This accounts for the difference between two individuals' experiences of what an outsider might interpret as being the same series of events.

The aim of phenomenology is to describe experience as it is lived by people. Human experience in a world of others, objects and events is the only consciousness that has meaning for us. The body is our access to the world and hence the means by which experience occurs. (Munhall & Oiler, 1986, p. 70)

Due to the subjectivity of the human experience, and its interpretation being dependent on the world within which it occurred, there is a complexity in the study of existence and being. This synergistic approach is contrary to twentieth century reductionism which seeks to reduce the sophisticated and complex to the simple and banal. Munhall and Oiler (1986, p. 57) support this through stating that phenomenology "clearly emerged as a protest against reductionism and the sense-organ bias constructed in the nineteenth century".

Human illness and related experience are complex. Phenomenology provides a means for developing understanding of illness which is denied when one attempts to apply linear approaches such as critical pathways and the nursing process to what is a highly sophisticated, individual and non-linear process. The aim of a phenomenology based study should be to interpret, understand and describe the experience of participants.

One should bear in mind that the purpose of phenomenology is to describe the lived experience of people. Methods of data analysis that fragment the lived experience may distort that which it seeks to describe. Furthermore the documentation of that experience should be done in such a way that it is true to the lives of the people described. (Morse, 1989, p. 23)

There are many research approaches used within the school of phenomenology. The methods used in this research study are those of van Manen (1990), a Dutch born educationalist and writer in phenomenology. The lifeworld is an important part of the phenomenological basis of van Manen's work. Lifeworld is the way in which we exist in the world and it is the context within which experiences are ascribed.

All phenomenological human science research efforts are really explorations into the structure of the human lifeworld, the lived world as experienced in everyday situation and relations. Our lived experiences and the structures of meanings (themes) in terms of which these lived experiences can be described and interpreted constitute the immense complexity of the lifeworld. (van Manen, 1990, p. 101)

Van Manen suggests that there are four lifeworld existentials and these prove useful focal points within the research process. These are lived space (spatiality), lived body (corporeality), lived time (temporality) and lived human relation (relationality or communality). Each of these existentials can be differentiated for analysis and reflection but they are essentially integrated as part of a total experience. The total experience occurs within the lifeworld.

The four fundamental existentials of spatiality, corporeality, temporality and relationality may be seen to belong to the existential ground by way of which all human beings experience the world, although not all in the same modality of course. In the phenomenological literature these four categories have been considered as belonging to the fundamental structure of the lifeworld. (van Manen, 1990, p. 102)

While in this study I have used the data analysis and research methods of van Manen, it is appropriate to consider briefly the theory behind phenomenological data analysis per se.

The phenomenological method, like other qualitative and quantitative methods, is a research approach encompassing five basic elements; identifying the phenomenon; structuring the study; gathering the data; analysing the data, and describing the findings. (Parse, Coyne & Smith, 1985, p. 16)

Spiegelberg (1976, cited in Parse, Coyne & Smith, 1985, p. 6) describes the major activities that are the guiding principles of phenomenological analysis. These major activities provide a sound understanding of the type of analysis that occurs with phenomenology:

1. Investigating the particular phenomena: intuiting, analysing and describing.
2. Investigating general essences: The process of interrogation of the particulars by reflecting on remembered experiences written by subjects.
3. Apprehending essential relationships: Examining the internal connections and connections to other essences.
4. Watching modes of appearing: the way in which a thing appears is significant to the understanding of the phenomenon as a whole.
5. Watching the constitution of phenomena in consciousness: The activity of exploring how a phenomenon constitutes itself in consciousness occurs through a process of integrating the unfamiliar with the familiar.
6. Suspending belief in the existence of the phenomena. This is called bracketing.

7. Interpreting concealed meanings of phenomena: Hermeneutical interpretation is the final activity in the phenomenological process. This activity requires the researcher to dwell with the subject's descriptions and to go beyond what is directly given.

The data analysis for this project was undertaken using the methods of phenomenological research described by van Manen (1990) :

Firstly, descriptions of the participants experience (the data) were reviewed by the researcher to ensure familiarity with the data.

Secondly, from the data, thematic statements were isolated using the 'selective or highlighting approach' identified by van Manen (1990). This involved identification of the descriptions provided in the transcription that provide the most insight into the experience of the subject.

Thirdly, thematic statements were reviewed at subsequent interviews. Themes were then developed from the thematic statements and were subject to validation through the clear identification of themes and the supporting descriptions central to these themes. Themes in themselves can not explain the fullness of the experience and this is done by the participants description of the experience. For this reason the thematic statements are included in the research report to establish the data trail in developing the themes and hence the central phenomena.

Fourthly, a central description of the phenomena was then developed through careful review of the themes and through returning again to the data to ensure that the central description of the phenomena was validated by the data.

Within phenomenology, Morse (1989) and van Manen (1990) use the term "conversation" to describe the process that is commonly known in research as "interview". Conversation more aptly describes the interaction that is used in order to obtain data from subjects. The open style of the interview is such that there is an unstructured interchange between two equal parties with the opportunity for the patient to lead the interaction as he/she unfolds the nature of the experience for his or herself.

Following each interview, the data in the form of transcribed interviews was repeatedly read and analysed by the researcher, seeking to identify the experience for the subjects with this phenomena. This living with the data is an important part of phenomenology and encourages the researcher to be personally involved in the interview with the patient. The context in which statements were made, facial expressions and body language, must be considered as the data is interpreted. Continual reading and writing is one of the important elements of phenomenology and is a critical requirement as one seeks to discover the essence of the experience. Parse, Coyne and Smith (1985, p.19) discuss the need to continually study the data: "Contemplative dwelling is the undistracted reading and re-reading of the descriptions with the intent to uncover the meaning of the lived experience for the subject". As data is continually read and analysed, greater understanding is sought and understanding of the significance of thematic statements may only become apparent after several readings.

The writing and re-writing, the constant search for deeper meaning, changed not only the understanding of the particular part of the study but the totality of the study, which again required a re-writing. This constant search for new understanding has been called the hermeneutic circle, which contains the possibility of deeper understanding. (Morse, 1989, p. 52)

In analysis of the data, the researcher is searching for thematic statements and themes which are used in the identification of the central phenomena. Thematic

statements are those statements which appear through the interview as being significant to the participant and which are used in the development of a theme relating to the experience.

Themes are not magically appearing essences but are useful focal points or commonalities of experience around which phenomenological interpretation occurs. (van Manen, 1984, p. 20-21)

There are many techniques for analysing phenomenologically based research data but there is a commonality about each technique. "In summary, all the techniques (used in phenomenology) involve the transcribing of material, the coding of data into themes, the clustering of themes into categories, and the formation of a classification of attributes of the phenomena from these" (Jasper, 1994, p. 19). The centrality of the phenomena is identified from the themes and reflects the experience as identified by the research participants. The central phenomena develops as the essence of the experience for the participants.

Study Design and Data Collection

The phenomenological research method was chosen for this research as the method provided both a framework and a philosophy appropriate to interpreting and understanding the experience of for these patients. The data for this study were the verbal descriptions from seven patients of their experiences of commencing radiotherapy and/or cytotoxic chemotherapy. Seven was felt to be a sufficient sample size for this study. No effort was made to gain a representative sample of the population undertaking radiotherapy and/or cytotoxic chemotherapy treatment as this is not a requisite of the phenomenological method.

Approval of the Massey University and Waikato Area Health Board Ethics Committees was sought and obtained without difficulty. The principal ethical issue identified at the outset was the researchers potential conflict of interest

between the roles of Manager for Oncology Services and researcher. This was managed by advising patients of a third party with whom they could discuss any concerns that they may have about the research and whom would assist them if they wished to withdraw from the research. During the research no patients expressed the need to access this third person.

Patients were accessed through two oncologists who had read the research proposal and had agreed to ask patients if they wished to participate in the study. Patients were required to be adults undertaking radiotherapy and/or cytotoxic chemotherapy and who were able to communicate in English. All patients approached agreed to participate in the research.

On a patient advising the oncologist that they were prepared to participate in the research, the researcher contacted the patient, described the study and provided the information sheet detailing the study. The participant was then asked to sign an informed consent form which detailed the study and advised of the issues relating to confidentiality. Participants were made aware at the time of consenting that they could withdraw from the study at any time.

For many of the patients the first research interview occurred at the time that they first met the researcher and signed the informed consent, but for a few patients the first research interview did not occur until several days after they had consented to take part in the research.

All the patients were experiencing their first episode of cancer treatment. The first interview occurred whenever possible within two days before or after commencing treatment. Where patients had experienced both cytotoxic chemotherapy and radiotherapy these patients were interviewed at the time that they were commencing radiotherapy. Some of the patients had already completed their cytotoxic chemotherapy several months previously although one patient was having the chemotherapy and radiotherapy treatment concurrently. The second interview

occurred when the patient had undertaken between one and two weeks of treatment. At the second interview there was further discussion of the thematic statements that had been raised at the first interview and discussion of the experiences that had occurred since the first interview.

This research focused on patients at two points early in their treatment. This contrasts with the patients in the Montefiore study conducted by Holland, Rowland, Lebowitz and Rusalem (1979) which reported changes occurring over the entire length of the treatment. The lived experience of patients receiving radiotherapy and/or cytotoxic chemotherapy may therefore be different if the study design incorporated interviews before during and after treatment.

An open interview style was used for data collection with the participants being encouraged to talk freely about their experiences. This was the concept of "conversation" as described by Morse (1989). There was no difficulty in establishing conversation with the participants who appeared to feel comfortable with the research method and with the researcher. Interviews were tape recorded and transcribed. When transcripts were typed and available these transcripts were given to participants to review at this time. In all second interviews the experiences shared at the first interview were discussed and expanded either with reference to the transcripts or from memory. This revisiting at subsequent visits was instigated by the researcher in most instances but by the participant when he or she had been reflecting on the previous interview.

Data collection occurred over a four month period from November 1993 to February 1994. A regional cancer centre providing a full range of oncology services was used for this research. Six of the patients lived in towns located between one and three hours away from the treatment centre and were staying at the oncology hostel, located on the hospital site, during the treatment course. This hostel is expressly for patients receiving outpatient cancer treatment and it proved to be a significant part of these patients' experience in living away from home.

Participants

Throughout this thesis the terms patient and participant are used interchangeably. In this study the seven participants are not representative of the population in terms of age, sex, race, type of cancer, types of treatment or inpatient compared with outpatient treatment.

Mrs H was thirty years old at the time of the study and had developed breast cancer. She had discovered a lump in her breast and this had lead to a mastectomy, chemotherapy and radiotherapy. Mrs H lived close to the regional cancer centre and travelled daily for chemotherapy and radiotherapy. Mrs H had a professional background, young children and a supportive husband.

Mr L was in his late fifties. Following a diagnosis of bowel cancer he underwent a bowel resection, radiotherapy and concurrent chemotherapy. Mr L had lived away from home from Monday to Friday each week for several years, (due to work commitments), however when he became sick, he returned to live at home except when staying in the hostel and having treatment.

Mrs F was in her early sixties. She was diagnosed as having breast cancer through a mammography screening programme which had visited her rural area. Her diagnosis lead to a lumpectomy, chemotherapy and radiotherapy. She stayed in the oncology hostel during treatment. Mrs F had some prior knowledge of radiotherapy and chemotherapy through her contact with the health system (many years ago) but had no recent knowledge of health services.

Mrs O was in her early sixties and was diagnosed as having breast cancer following detection by a mammography screening programme. She went on to have a lumpectomy and radiotherapy. Mrs O lived several hours away from the treatment centre and stayed at the cancer hostel during treatment. She had recently

lost a close family member and this recent relationship with death influenced her experiences at the time of having treatment.

Mrs T was in her early sixties. Diagnosed through the mammography screening programme, she went on to have a partial mastectomy and radiotherapy. Mrs T was given the option of chemotherapy in addition to radiotherapy but had decided to have radiotherapy only.

Mr R was in his seventies, married and had a diagnosis of cancer of the bowel. Following bowel surgery he stayed in the hostel during his radiotherapy treatment as his home was a considerable distance away. A source of information and support for him during treatment was his association with a croquet club.

Mrs M was sixty years old and also lived several hours away from the treatment centre. Detected through a mammography screening programme she went on to have a lumpectomy, radiotherapy and cytotoxic chemotherapy, while staying in the oncology hostel. For Mrs M it was important to prove to her daughters that she was able to cope with the treatment because of a familial tendency to breast cancer.

The experience of chemotherapy or radiotherapy cannot be easily distinguished from the experience of having cancer. That ones' experience of commencing radiotherapy and/or cytotoxic chemotherapy is but one part of an individuals total experience of life is implicit from the outset of the research. This is consistent with the philosophical base of the phenomenological research method.

Throughout the research the thematic statements are in quotation marks with the passages indented. Words in brackets[] within thematic statements are those of the researcher and relate to previous questions asked of the patient and implied during the conversation.

This concludes the discussion on the methodology used within this research. Chapters four to nine are the findings of the study. Findings are described within the four existentials of Lived Time, Lived Space, Lived Body and Lived Other and are developed as chapters four to seven. In each of these chapters the particular existential is discussed and the themes and thematic statements revealed in the interviews are illustrated and developed. Chapter eight describes the theme of resigned determination. This theme reflects the approach of these participants to continuing their treatment and the issues surrounding their initial decision making process to commence treatment. In chapter nine I have discussed the central phenomena developed throughout the research. This is the concept of a journey through which the patient "**walks alongside**" his/her normal lifeworld while seeking to return to normality at the completion of the treatment.

Chapter Four : Lived Time

In this chapter I will discuss the themes within the lived time existential revealed by the thematic statements. These themes were strong and particularly relevant to the experience of the participants.

Lived time is the time that appears to speed up when we enjoy ourselves, or slow down when we feel bored during an uninteresting lecture or when we are anxious, as in the dentist's chair. Lived time is also our temporal way of being in the world - as a young person oriented to an open and beckoning future, or as an elderly person recollecting the past etc. (van Manen, 1990, p. 104)

Chemotherapy and radiotherapy are both treatments that occur over a prolonged time period. In radiotherapy the treatment course is usually four to six weeks with the patient receiving treatment five days per week over that time. Most of these patients are considered to be outpatients as they are not staying in a standard hospital ward.

The majority of the participants in the study were staying in an oncology hostel located in the hospital grounds as they lived too far away to travel to the hospital for their daily treatment. There is some inconsistency in the use of the term outpatient, as these patients do not fit comfortably with the usual living arrangements of either inpatients or outpatients. This is discussed further in chapter five which considers themes within lived space.

Chemotherapy courses are more varied in length and treatment frequency but the treatment also requires patients to travel to a hospital where they can receive the cytotoxic agents. Frequently the chemotherapy regime occurs over several months

with treatments on a single day at two, three, or four week intervals. In both chemotherapy and radiotherapy, there is also usually a period of delay between the time that medical staff first speak with patients about the treatment, the time the patients first agree to start the treatment, and the time at which the treatment is actually commenced.

Most of the patients had undergone surgery prior to commencing chemotherapy or radiotherapy. By the time the patient received either chemotherapy or radiotherapy they had usually lived with a diagnosis of cancer for several weeks or months. For some patients the experience of cytotoxic chemotherapy or radiotherapy treatment from the patients perspective began with the diagnosis of the cancer or from the time that the "lump" (or another sign or symptom of cancer) was discovered.

Mrs H, who is a thirty year old patient having cytotoxic chemotherapy and radiotherapy, spoke about the time that she was diagnosed:

I think that the worst time at home was between finding out the diagnosis and before the surgery. That was a weekend and that was the most disgusting weekend of my life because you didn't know and you were just so mixed up, but from the day the specialist [surgeon] told me that he was pretty certain he had got every thing, I thought, okay, right, that is good enough for me and it has not been a problem after that. (Mrs H)

During the time between being diagnosed and actually commencing treatment, Mrs H had a feeling that she was getting sicker and she was keen to commence treatment. Waiting to commence treatment was a cause of anguish and yet it is a common occurrence for patients to wait several weeks for treatment.

For patients the concept of "counting " played a major role in the experience of both radiotherapy and cytotoxic chemotherapy treatment. Some patients spoke about "**counting down**" the number of treatments they had already received from the number of treatments that they would require. Other patients "**counted up**" the number of treatments required from the beginning to the end of treatment. Although there are conceptual psychological differences in this approach, there is clearly no quantifiable difference in the number of treatments that the patient receives. The question that is raised by looking at this approach is "Is the treatment half completed or is it half started ?".

Through counting in this way it became possible for patients to establish the proportion of the treatment that had been completed or the proportion of the treatment that remained. As treatment is regularly scheduled and repetitive in nature, the calculating of the proportion of total treatment remaining or completed can be easily achieved by patients and staff.

Mrs H was able to live at home throughout her treatment. Like many other patients she describes that process of "counting down" her radiotherapy treatments.

I count down the days in a positive way. When the consultant asked me how I felt, I said I feel great, because I know that I am coming down the other side and have only got three more to go and I tick them and say 'yes, that's one more'. To me that is positive- for me to count them down and say right you have gone. (Mrs H)

The use of the "gone" implies putting behind one, or putting away. Part of the experience has been completed.

Some of the patients had written calendars on which they ceremoniously recorded the treatments that had occurred as part of the **counting**. The value of this

counting had been identified by the health professionals in this unit who had provided the patients with a calendar to encourage them to record their progress with treatment. Through counting treatments, patients could appreciate the amount of the treatment that was remaining or the amount that had been completed.

Patients receiving radiotherapy treatment are required to lie still on a treatment couch while receiving their dose of radiation from the treatment machine. This may take from a matter of seconds to several minutes depending on the treatment prescription. For some patients this time was a significant part of their treatment. Some of the patients were able to describe exactly how many seconds they were being irradiated and stated that they had been told this by the staff. Some patients chose to count the seconds for themselves to determine whether they could count time accurately. This fulfilled a diversionary role for some of these patients.

Mrs M described counting while "under" the machine and raised concerns that this may not be the correct thing to be doing.

I can't stop counting [while receiving treatment]-I know psychologists wouldn't like it but I just can't stop. (Mrs M)

Patients need to feel able to respond to their treatment in the manner that they find most appropriate and useful. Mrs M felt a need to meet expected norms and she was not aware if this was a normal way to cope with her time while receiving radiation. This is explained further in Chapter 7 - Lived Other.

During Mrs H's first few treatments she recalled thinking about the potential side effects of the treatment and wondering when they would start, what they would be like, how she would cope with the travel and whether she would "look like a lobster". At her second interview Mrs H describes "lying there blank - sometimes hearing the radio".

Mrs M tried not to think about the machine during treatment,

I try to take my mind off the machine and just sort of think of what I am going to do when I get out for the day. (Mrs M)

Although the time spent lying perfectly still is only very brief it was a time when some patients reflected on the purpose of the treatment and the significance of this for them.

For Mrs F **counting down** took place differently. Mrs F did not count up or down the days of treatment that she had had. She counted the "**time away from home**". Again this is easily counted because treatment occurred during the week with the patient returning home during the weekend. The counting of time away from home shows the significance for patients of being away from their familiar surrounds and their families and is an important aspect of the total experience for these patients.

The first interview with Mr L took place when he had received only two treatments. When he was interviewed a week later and I made the comment that he had now "done ten days", I was corrected by Mr L that he had "done seven treatments". For Mr L the time at home away from the treatment centre is not counted within the time at which he was receiving treatment.

The daily time of each radiotherapy treatment appointment was determined by the radiography staff. They managed the appointments to give the patients required to live away from home the opportunity to get home for the weekend early on Fridays and to return to the hostel as late on Monday as possible. This legitimated the desire of patients to spend as long a time as possible at their homes during the weekend.

Some participants experienced delays in the commencement of treatment or within the treatment cycle itself. These were due to shortages of resources in radiotherapy or the clinical condition of the patient. Mrs M was initially prepared for five weeks radiotherapy. She had expected to start the treatment on a Monday but due to machine breakdowns and the schedule of other patients completing treatment, she was required to commence the treatment on the Wednesday of that week. Mrs M described this delay as her biggest anxiety about starting treatment but as soon as the registrar had explained that the delay was not a serious risk to her outcome then she stated this was "no problem".

Mrs T was unable to continue a course of radiotherapy treatment because of skin reactions after radiotherapy. She describes this as "tissue burns" whereas nursing staff in the area always describe these reactions (regardless of severity) as being "skin reactions". This is part of the language of radiotherapy. Radiotherapy "burns" occur as the result of treatment. Patients are passive recipients of this radiation that is administered by health professionals. These direct results of treatment differ from the desired goal of healing that is inherent in medicine - it is through the actions of the staff (the treatment given without any error) that the patients are increasing this deterioration in their own wellbeing. On arriving for a radiotherapy treatment Mrs T was seen by the radiographers who noted her skin reaction. She was then sent to her consultant and advised to go home for one week to allow the skin the chance to heal.

I was disappointed in going home because it elongates the whole problem. You know you sort of circle a date in the calendar and that is when you going to be finished by and it sort of keeps getting put further and further back so that until you have completed it you are not sort of free, just to settle down and try and go back to normal. As far as soreness, it gets a bit stingy or raw but that's all really. (Mrs T)

Delays in treatment prolong the course completion and interrupt the counting process. Until the course is completed the individual is unable to return to his or her normal lifeworld.

Mrs M was unable to commence one course of chemotherapy on time due to low numbers of white blood cells.

It became a wee bit upsetting when I would come up and I couldn't have my treatment. That was a bit of a downer really because you have got yourself geared up, well I say programmed, to go and have it done and then I have never been very good in expecting something to happen that doesn't eventuate. (Mrs M)

The changes in Mrs M's chemotherapy resulted in additional visits for her to the treatment hospital and were of particular concern because of the other personal changes that were happening in this family at the time unrelated to the cancer.

(The unscheduled break) was a bit traumatic I suppose but it just means that it prolongs the whole thing when you are sort of wanting to get on with it and get it over and then carry on with a normal life. (Mrs M)

At the time of commencing treatment with radiotherapy and/or cytotoxic chemotherapy patients are aware of the prolonged nature of the treatment and dread the length of time that they will be requiring treatment. As the treatment progresses, patients found that the time spent in treatment went quicker than they thought.

In contemplation five weeks seems a long time but once again, strange as it may seem, one lane follows another lane and it hasn't dragged at all really. (Mrs M)

The use of the term "lane" to describe the passage of time through treatment is significant. The imagery of a journey is utilised in the development of the central phenomena.

While Mrs M was not keen to stay away from home, there was no option of travelling every day because of the distances involved, and she kept busy by reading, talking with others and resting. She stated that she has managed to disregard the things that may not be getting done at home.

Mrs T had not wanted to have radiotherapy:

I think it is just, well first of all it is the thought of being away from home for five weeks, that's what has got to me, that I had to stay away for five weeks from home. If it had been closer to home I would have had no objection to it, it was just the thought of having to come up and down and worrying the family to bring me down and all these sorts of worries you know but you have got to do it so there is no, (sic) but that was the main thing being away from home for five weeks. The radiotherapy didn't worry me. I'd have no hesitation if it had been in [my home town], it was just the thought of having to stay here for five weeks. (Mrs T)

The other normal life events occurring in the individuals life at the time of the treatment were very significant for the patients. These included activities such as birthdays and Christmas. Mrs O had managed to have most of her radiotherapy as an outpatient during the time that she was on holiday, she identified that she would feel differently when her holiday was scheduled to be over and when she should be going back to work.

My [employer and colleagues] have been extremely understanding over the whole time that I've had both these things, they've been very good with lots of support. (Mrs O)

For Mrs F the significance of the end of one year and the beginning of another was significant as this coincided with a course of treatment being completed.

Well actually, it was (symbolic). I kept telling everybody, I even said on my Christmas cards to people that knew, I said what a way for the year to go out [completing chemotherapy on New Years Eve]. (Mrs F)

The imagery of completing treatment and "writing it off" at the end of the year was strong and this would allow the patients to commence the new year with a "clean slate".

Some patients had the ability to remember the exact dates, several months previously on which they had commenced chemotherapy, been diagnosed with cancer or had undergone surgery. This is significant because it links together the importance of time and its passage in the experience for these patients.

For Mrs T the time at which she was receiving her treatment was influenced by the serious illness of her older sister and the subsequent death of her sister in hospital. Mrs T was very pleased that she was able to delay the starting time of the treatment as her sister had also suffered from cancer in the past and Mrs T had managed to avoid telling her sister that she too had a diagnosis of cancer (before her sister died).

Some of the patients believed the development of their cancer was related to past events precipitating the cancer developing. For example, forty years ago Mr L had been employed in a position where he had been exposed to chemical residues which may have made him at greater risk of developing some types of cancer. Several years previously he had been contacted by an agency researching the incidence of cancer in this occupational area. At the time he was questioned he had been surprised by the questions that were being asked. He was beginning to wonder whether his work may indeed have caused the development of his cancer.

Although a diagnosis of cancer for patients carries with it the possibility of an early death, there was little discussion about their prognosis by the patients during the interview. I did not feel the need to raise the question of death as the interview was conducted in a manner which allowed all the facets of the experience for these patients to be explained. The issues about death did not appear to be avoided by the patients and were not avoided by the researcher. Patients spoke about the end of their treatment and returning to their normal roles at that time.

Mrs T was intending to return to work so that she could prove that she could "perform" again. Talking about the future following treatment :

I don't know why I am so certain. This is not a very sensible thing to say. I am so certain that I won't have any more problems. It [the cancer] has been removed and I don't expect it to come, you know, say in another area.
(Mrs T)

Mrs F felt positive about the end of treatment and that her history of good luck would prove valuable :

I kept telling myself there is light at the end of the tunnel and you are a lucky so and so. (Mrs F)

Here Mrs O is talking about 1994:

A new year a new start. I had a bad year last year [1993] and I just hope this years a new one and I should be right. That is why I am so pleased I can get all the treatment finished this year before Christmas. I will be all finished and gone and I will not have to worry about going for treatments.
(Mrs O)

The experience of past and future are contained for Mrs O within this thematic statement. The finality of treatment being over and the hope for the future were able to be related to the end of the calendar year and the hope of a better New Year.

Mr R expressed a positive approach to his treatment and that the treatment would be the resolution to his cancer

I feel so okay, it's so positive that this blasted thing [the cancer] is going to go you see. (Mr R)

Patients frequently described concerns about having radiotherapy and/or cytotoxic chemotherapy and stated they were aware that their opinions were formed a long time ago when treatment was less sophisticated. Many patients undertaking treatment recall stories from friends and neighbours of extensive radiation burns, horrendous chemotherapy side-effects and poor survival rates from both types of treatment.

I was a bit upset about it [the need to have chemotherapy] because one still had concerns about chemotherapy. It has got a bit of a bogey somewhere along the line but one still has to accept these things don't you and get on with it. (Mrs M)

For Mrs H , treatment began with explanations from friends about what the treatment would be like:

Well I had a pretty good idea [about what radiotherapy would be like] because a friend of mine out where we live, about 12 months ago she went through the same thing but she is quite a bit older than me and her treatment was just the radiotherapy and when she heard that I was having it she rang me and she said, 'Now this is what it will be like and this is

what it was like for me and she said I don't know if it will be like that for you'. But she said this is how I felt during the time and this is what it was like so I wasn't [surprised]...I knew what to expect. I mean it is early days yet and I don't know how I will react as the weeks go by but, ah I knew pretty well what to expect and I mean everybody here is so open with everything and they explain it so well that you really don't have a problem with it. (Mrs H)

For Mrs H the progress of treatment could be compared with her expectations according to the explanations that she had been given by others. This chapter described the significance of the themes relative to lived time. **Counting up, down, and through** are part of the central phenomena. The chronological progress of treatment is important to understanding the experience of commencing cytotoxic chemotherapy and radiotherapy. Commencing treatment is the beginning of a journey in which counting and time are the measure of the trip.

Chapter Five : Lived Space

In this chapter I will discuss the themes revealed in the study appropriate to the existential of lived space. Lived space is the way in which we interpret and experience the space in which we exist. Van Manen (1990, p. 102) provides as an example feeling "overcome by a silent sense of the transcendental even if we ordinarily are not particularly religious or churchgoing".

Lived space is more than physical environment. It is ones' perception of the effects of the environment on the experience of existence **as part of** that environment. Van Manen (1990) points out that there are cultural and social conventions associated with space that give the experience of space a certain qualitative dimension. Lived space will be subject to interpretation and individualised to the patient.

People undergoing radiotherapy and/or cytotoxic chemotherapy treatment will experience a number of new physical environments. These could include the oncology department (outpatients' clinics, radiotherapy planning and treatment areas, an outpatients' chemotherapy area), operating theatres and investigational facilities. In addition to being in these unfamiliar environments for short periods of time, six of the patients stayed in the oncology hostel five days per week for four to six weeks.

Radiotherapy machines are large and highly technical. The patient lies on the treatment couch underneath the machine and is left unattended during the period of treatment to prevent staff exposure to radiation. The treatment rooms themselves are large and are principally dominated by the treatment machines.

In the chemotherapy area there are usually several patients at a time receiving treatment in a large shared room. This treatment usually requires one to four hours within the department on each occasion - considerably longer than for radiotherapy. In the study setting the chemotherapy area is attractively presented with obvious effort being made to present a relaxed and homely environment. The highly technical equipment did not distress most of the patients.

I wasn't phased by the radiotherapy machines. I was accepting - I suppose that's the best idea - I was a bit intrigued I think but I wasn't fearful, I wasn't frightened or anything like that. I was fascinated. (Mrs M)

Oh yeah, I just lie there and visualise this light beam going straight through me. That is all about it really. You don't feel anything... you just feel warm, you know sort of when they are setting it up, it is always you know as though there is a hot lamp on top of you but then she's [the treatment] all over. No problem. (Mr L)

Staff in the radiotherapy area spent time reassuring patients regarding the equipment and explaining how it functions. The simulator is often the first unfamiliar machine that the patient encounters when commencing radiotherapy treatment. For Mrs H the simulator was "a bit spooky - the way that it whizzed around and carried on".

Patients expected that they would need to be temporarily in a different location while undergoing radiotherapy treatment. For Mrs M a low white blood cell count meant that she was unable to have her third course of chemotherapy at the scheduled time. At home waiting for the blood count to rise she described her situation:

I probably treated myself like a patient, which I didn't really feel I was, but my family didn't let me do anything. (Mrs M).

This interrupted schedule created difficulty for Mrs M. She was neither well nor did she feel like a patient. She could not maintain her normal roles and the environment in which she found herself, while usually comfortable, was foreign to her in her new and temporary condition.

Staying in a hostel is different to most individuals' normal living arrangements. The sharing of facilities with people who begin as strangers, and having only one room that is your own private space, are changes which require some adjustment.

I am not really a hostel person - being a country person - but I needn't have worried because you can have as much space to yourself or socialise as you want. (Mrs M)

For Mrs M needing to stay in the hostel was particularly significant as she had shifted house in the past year and was still feeling a need to be settled into her new home.

I like the sharing that goes on [in the oncology hostel] and seeing other people worse than me and seeing how other people cope or not. Everyone is nice. (Mrs T)

A common bond is formed between the patients in the oncology hostel. This bond results from patients receiving similar modes of treatment and from the patients identifying that other patients are also undergoing cancer treatment. The hostel has an explicit rule that prevents patients' spouses staying in the hostel to encourage patients to mix with each other. The isolated exception to this rule is the situation where a patient requires their spouse to assist them in meeting basic hygiene needs - for example a patient who has previously experienced a stroke and requires assistance to get to the toilet and shower. It is the opinion of the hostel manager that this is important to ensure that the patient mixes with others and gains support from understanding how other patients cope with the treatment.

The hostel environment is comfortable with large lounge areas available to encourage patients to socialise. Meals are provided and patients are encouraged to help serve meals, wash and dry dishes, and care for their own rooms. The hostel environment is managed by staff to encourage the development of shared experience and to promote an environment where patients can get support from each other. This is discussed further in chapter seven in which the lifeworld existential of lived other is presented and discussed.

The lived space in which radiotherapy and chemotherapy treatment occurs includes the experiences associated with the chemotherapy, radiotherapy and outpatients area, the hostel (as an area where many patients stay while having treatment) and the homes that the patients return to during the weekends. Lived space is important to patients who are required to leave their normal environment at a time of life-threatening diagnosis to encounter new experiences in an unfamiliar environment. The spatial existence for patients who were not staying in the hostel during treatment would be very different and would be a suitable area for further research.

Chapter Six : Lived Body

In this chapter I will discuss the existential of lived body and the themes in the study within this existential.

Lived body (corporeality) refers to the phenomenological fact that we are always bodily in the world. When we meet another person in his or her own landscape or world we meet that person first of all through his or her body. (van Manen, 1991, p. 103)

Lived body includes the physical appearance and physiological functioning of the body. As such it includes homeostasis and important bodily functions such as the physiological stress response. In addition it considers the perception of ones own body established consciously through purposeful reflection or subconsciously as the result or experiences that the individual may have.

Lived body is not merely the physical body and the signs and symptoms of health or illness that are apparent to the individual. It is the way in which the person reflects on their own body. Benner and Wrubel (1989) consider the lived body within the area of stress and coping and highlight the compensatory mechanisms that the body uses in response to stress. Within the existential of lived body the experience of radiotherapy and cytotoxic chemotherapy treatment has important themes as the individual receives treatment that changes body appearance, body image and a threat to the physical body.

One of the reasons for commencing this research was my interest in the experience of patients who have treatment regimes that will potentially result in very unpleasant side-effects. My expectations of severe nausea and vomiting, malaise and depression were not borne out by most of the patients reports of their

experiences. Although patients reported these side-effects, they did not universally report them as being exceptionally challenging to them or as unduly influencing their decision to have treatment.

Chemotherapy usually requires the use of an intravenous line. The insertion of intravenous lines was feared by some patients. Mrs M described an episode where it took a number of nursing staff and a total of five attempts to insert an IV into her hand and she expressed her fear of pain resulting from IV insertion.

Mr L described how he felt after seven radiotherapy treatments to his abdomen:

The only thing I notice, my bowel, oh how would you put it, it is like it is all loose or a bagful of marbles. It feels like me, it is just that the whole thing is loose and sort of flopping around you know what I mean [laugh]. Like jelly I suppose. (Mr L)

Many patients experienced changes in their body image as the result of the treatment they received. Mrs F experienced a changed body as her weight increased by seven kg as the result of taking steroids and due to immobility enforced upon her by feelings of tiredness and weakness. This weight gain/loss, malaise, or nausea and vomiting is not infrequently responsible for reducing the ability of patients to continue with their usual activities and this in turn can set up a vicious cycle of ill health that inhibits the patients recovery.

Mrs H found that having cancer treatment had made her more aware of things going on around her. A woman's appearance on television complaining about relatively superficial disfigurement was compared with her own disfigurement as a young women having had a mastectomy. The woman on television complaining about her disfigurement had made Mrs H angry as it appeared to be quite mild but afterwards Mrs H interpreted her own response as a sign that she herself was coping well with her own more major body disfigurement.

When Mr L was asked about how he was doing at his second interview he related this to his physical symptoms :

Good as gold, yeah really good. It has been really good this week, yeah because I haven't got the chemo I would say but as I say with the nausea, well the chemo gives you the nausea anyway. It's not bad, it's not bad. You feel a little bit drowsy but its not too bad, or I don't know anyway. I think I am lucky. Very lucky. (Mr L)

For Mr L the radiotherapy treatment involved the "killing off of cells", and this could be likened to burning off a wart.

I just lay there and visualise this light beam going straight through me. That is about all really. You don't feel anything - just warm. (Mr L)

Mrs T had problems with skin reactions to chest radiation. Radiation in this area can be very difficult for women and this treatment occurred in summer when the warm weather further irritated her skin. At the same time she was also undergoing drug therapy that made her skin particularly moist.

Many of the patients visualised the radiotherapy treatment as happy little enzymes with smiles on their faces eating up the bad cells. Mrs M describes this clearly:

It [radiotherapy] doesn't distinguish between the good and bad cells but I have them zapping round getting all the bad cells because you see I like to think of myself being clean and healthy in there [indicates chest] now I like to think of it all being cut out and done away with and this is just a sort of insurance policy. (Mrs M)

The use of "happy enzymes" as a metaphor encouraging patients to feel positive about the radiotherapy treatment was encouraged by staff in the area. A

contemporary television advertisement about "hungry enzymes" is known to the patients and through considering this a likeness, patients could gain some understanding of changes affecting the body that could otherwise be difficult to understand.

Many patients spoke of chemotherapy or radiotherapy as being an "insurance policy" as they were told that although the tumour had been removed chemotherapy or radiotherapy was advisable. This "insurance policy" was a term that was used by oncologists and explained the principle of adjuvant chemotherapy and radiotherapy.

For Mrs M the diagnosis of cancer brought with it an immediate change in body image.

I never thought for one minute [that I could have breast cancer], I thought of myself as being fit and healthy. (Mrs M)

In the absence of physical symptoms it can be difficult for patients to appreciate the change in their body and to determine whether they are sick or healthy. Mrs T was bothered by the damage that her radiotherapy treatment could do to non-cancerous tissue :

I think probably deep down it was all healthy, in fact that may be what bothers me a bit, is what it is doing to the healthy part because there is nothing else there but healthy tissue but I am not to know that really, nobody knows whatever's left. (Mrs T)

One of the difficulties with many internal cancers is that it may be difficult to establish whether the condition has been improved or whether the cancer has spread. The invisibility of these cancers leads to uncertainty for patients seeking to understand the changes in their body due to the cancer and due to the treatment.

The first day having the X-ray I suppose was all right. My first treatment the next day I had the realisation that it was something quite strong and something quite damaging. (Mrs T)

Many of the patients considered themselves to be healthy at the time of the diagnosis - their cancer had been detected through a breast screening programme. Mrs F described feeling "perfectly well" at the time that she was diagnosed. Having decided to undertake treatment her feeling of wellbeing quickly deteriorated.

At two stages in the middle of it I thought about not having chemotherapy, at one stage I was sick, very early on and as I said to the consultant, he asked me how I felt and I said 'to be perfectly honest I didn't really expect to feel quite so rotten quite so soon'. I mean three months down the road yes but I was sort of sick at the beginning and I mean, people look at me when I tell them this but it is perfectly true, at the height of my treatment I was having 92 anti-nausea tablets per week... and even then I would sometimes get pangs of nausea. (Mrs F)

Mrs H spoke about the effects of having Adriamycin (a pink-coloured cytotoxic drug). Following the chemotherapy, association is being made between the experience of nausea and vomiting and the colour of the adriamycin.

[Adriamycin] was a horrible yucky pinky sort of a colour and if I look at anything that is like that now, my stomach just does a bit of a heave..because the side effects of that are pretty yucky....(Mrs H)

Mrs T was required to have an interruption in her radiotherapy treatment because of what she described as "tissue burns". She joked about being away from radiotherapy on "sick leave" and yet feeling quite well! Joking was one of the many ways that patients developed to cope with the clinical side-effects of the

treatment. Mrs M had determined for herself that staying in bed may be one way of preventing the nausea that she had experienced in the mornings while on chemotherapy, and had adapted her daily routines to minimise nausea which was at its worst first thing in the morning.

I have had very good support - the family have been tremendous. It has hit them very hard but they have been thoroughly supportive and my husband would bring me breakfast in bed so I could lie still. I didn't have to get up and rush around or anything like that that might have made me nauseous. (Mrs M)

Mrs T felt tired and nauseous during her third week of treatment and that this was probably due to "overdoing it".

I was tired and a wee bit squeemy, that's all but you are not sure about how you are feeling as to whether you can sort of rush around and do what you do normally then all of a sudden you find you run out of oomph if you do and so you tend to sort of slow down a bit - you could get very unfit. (Mrs T)

For Mrs T it was difficult to gauge how much energy she had until she became suddenly exhausted. There is normally a reasonable predictability in the amount of physical energy that individuals have but this is lost in these patients who experience a different habitual body. For Mrs T, sickness can be assessed by the appearance of patients undergoing radiotherapy and cytotoxic chemotherapy.

..when you look at us we are not a sick group, even those who are perhaps not particularly good or maybe aren't going to have a good recovery. We certainly don't look sick. (Mrs T)

It was during times of side-effects that patients most questioned whether they should complete the treatment course. This was frequently related to a feeling of loss of control - particularly when the patient experienced vomiting.

After that first 2-3 weeks when I was feeling sick and another one was about 4-5 months down the track when I didn't feel in control. I remember just one terrible weekend I had this sore mouth. For some reason I got a cough, I had stress incontinence, I had watery eyes and I just thought blow this and my husband said "look you have only got six more weeks" and I think I probably was just sort of , in the bottom of my heart I would have continued on with it but I just sort of wanted to blow my top about it all. I didn't feel in control particularly when I had that stress incontinence.
(Mrs F)

For Mrs F it was as if the incidence of side effects were destined by another force:

I think I probably had all the side effects that was on the jolly sheet and that he told me about, I mean they were all, I never had any of them really badly. I had the watery eyes, I had the sore mouth but it was almost as if everything was saying well its my turn today. I was going to give you a sore mouth today and tomorrow I am going to give you watery eyes...[laugh]. (Mrs F)

For Mrs O the thought of losing a breast was particularly unattractive. After commencing treatment she spoke of the decision to have radiotherapy.

I had the radiotherapy because I couldn't bear the thought of having my breast off and it was such a tiny lump and I thought why have my breast taken off for such a small lump. If it had been a big lump that had shown then I would have thought about it but with such a tiny lump I thought I am losing my breast because of a very small lump. I thought if it comes

back twice I would probably have the breast off but I am very pleased that I decided to have the radiotherapy after all I thought it is only five weeks and what is five weeks out of your life when at the end of it you have still got your breast. (Mrs O)

Many of the patients experienced changes in their bowel habits that necessitated changes in the way in which they managed their daily lives. For Mr L the experience of his first course of chemotherapy was notable for the diarrhoea that he experienced. The second course of the treatment was much easier and without the diarrhoea and other side-effects he became able to drive himself the 45 minutes to the chemotherapy treatment centre. Changes in bowel habits can be particularly disabling because they are developed as part of normal routine from childhood and any bowel problems can have very embarrassing and uncomfortable side-effects.

For Mrs H there was a delay between the time that she finished chemotherapy and when she could commence treatment on the treatment machines. For Mrs H this caused her considerable anxiety related to the effects of this on her cancer.

That's the funny thing with Chemo...you become, I will not say you are hooked on it... but while you are having it you are thinking to yourself it is okay but then they stop it and you don't want any more anyway because it is disgusting , but you think oh am I still alright. It is a security blanket in some way and I did feel just a tad [little bit] anxious with the radiotherapy not starting straight away.... (Mrs H)

The chemotherapy provides a source of security that the problem is being dealt with and that a solution is being sought. This concept of security, and that of insurance mentioned earlier in this chapter, are both terms consistent with measurement of risk. This is an interesting theme as it assumes identification of the risk that is inherent in commencing treatment and of having the diagnosis of cancer. Risk involves the balancing of the side-effects and complications of the

treatment to the potential benefits of cure, a prolonged life or palliation. While active treatment is occurring there is hope and efforts are being taken to control the cancer - something is being done on the patients behalf and with the patient's consent.

For Mrs M there was security in having a domperidone (anti-nausea medication) tablet available beside her to take when she became acutely nauseous. Mrs M was aware that the drug is not intended to be taken when she is already very nauseated but for Mrs M the fear of vomiting was strong and she found it reassuring to think that there was something available for her were she to feel like vomiting.

Significant in the experience of lived body is the deterioration that occurred for many patients following the commencement of treatment. This made the patient very aware of the body changes that were occurring to them. As patients experience a deterioration in their feeling of wellbeing, they are aware that they have been actively involved in the decision to have treatment, they are aware of the risks of that treatment and of the probability of success. The patients live with those decisions all day and every day throughout the treatment while they are experiencing side-effects and changes in body image.

When commencing radiotherapy and/or cytotoxic chemotherapy there are significant changes which are likely to occur within the bodies of patients. How the patients deal with these changes and the effects that side-effects have on the individuals will play a major role in the experience of having these forms of treatment. The experience of lived body is a critical component in the commencement of radiotherapy and cytotoxic chemotherapy.

Chapter Seven : Lived Other

In this chapter I will consider the patient's relationships with others. Themes in this area fall within the lifeworld existential of **Lived Other**. A major factor in the experience of receiving radiotherapy and/or cytotoxic chemotherapy is the relationship of the patient with others. These others include family, friends, health professionals and the other patients that they become familiar with in the hostel. Relationships with others is known as "Relationality" as described by van Manen (1990, p. 104):

..is the lived relation we maintain with others in the interpersonal space that we share with them. As we meet the other, we approach the other in the corporeal way: through a handshake or by gaining an impression of the other in the way that he or she is physically present to us ... As we meet the other we are able to develop a conversational relationship which allows us to transcend ourselves.

It is not only the patient that lives through the radiotherapy or chemotherapy experience. Patients identified the importance of their family in supporting them through the treatment. It can be very difficult for others to cope with supporting the patient through the treatment. Mrs M spoke about her husband and how he managed to support her:

He hated me having to have it but he sat beside me in the chemotherapy ward. He wouldn't go off. He stayed right there, I have told him he has got a lovely bedside manner [laugh] but no, he was great but with all the driving and all the other things he had on his mind, it was quite stressful for him. It really was! The person with it [cancer] is caught up in the action, you know what I mean, and the other person has got to do all the

sitting and waiting but when I went to see the Doctor he would come up and sit there with me and it is very very comforting. My husband was more anxious about the radiotherapy than he was about the chemotherapy for some reason...I wonder if it was because he sat with me and saw the chemotherapy where as with the radiotherapy he is 'shut out'. (Mrs M)

The literature review revealed a number of studies which illustrated the effects on the spouse of supporting the patient undertaking the treatment (Wilson & Morse, 1991; Howell, 1986; Leibner, Plumb, Gerstenzang & Holland, 1976; Taylor, Lictman & Wood, 1983; Koocher & O'Malley 1981; Jamieson, Wellisch & Pasnau 1978). The patients in this research identified the need for the patient to support his/her own spouse through the treatment with this taking the form of mutual dependence as issues surrounding treatment are faced.

For Mr L the separation of self from family was not as notable as it was for other participants. Mr L identified that he had lived away from his family a lot due to his work commitments although when he became sick he moved back to his home to be with his wife. For Mr L his friends played an important part in his support and treatment. They had driven him daily for his chemotherapy treatment and he was spending some time with friends during the day when he was staying at the hostel and unable to be at home.

For Mrs T the need to receive treatment arrived at a time that she had a very sick sister for whom she felt responsible and this was a major influence on her response to the need to commence treatment :

When I first heard about it [having cancer], it wasn't that I had cancer that really was my nightmare, my nightmare was that it was going to prevent me doing what I had to do for my sister.... (Mrs T)

In addition to the role of being a patient, patients fill many other important roles at the same time. Major roles include those of parent and spouse. For Mrs T the role of being a sister was very important at the time that she was commencing treatment. Roles and the way that they are enacted at the time of commencing treatment will have considerable importance on the total experience of the patient receiving radiotherapy and/or cytotoxic chemotherapy.

While Mrs F was receiving treatment and coping with the side-effects of chemotherapy her husband took on other roles that she had previously held. Principally these included housekeeping roles. Relationships and roles change as individuals adapt to changes in their available time and their ability to perform normal roles. Mrs F also found that the experience of having cancer had made her think about doing "more things to suit herself".

For Mrs M the support of her family allowed her to cope with the side effects of the chemotherapy through enabling her to change some of her routine daily practices. For Mrs H the support of family, friends and work colleagues was tremendous and "just to know that people care about you is support in itself". Mrs H was aware of the care of others through their accommodating of her different roles and enquiring about her well-being. All the patients in the study expressed the caring and support that they felt from their families and friends.

Mrs O had an unscheduled break in her treatment. Friends and work colleagues found this worrying and associated it with something traumatic or painful occurring.

Somebody called in... saw the car there and called in from work and so [work] knew about it straight away. It seemed like half [the small town] knew I was home having a rest from treatment but people tend to think that something traumatic has gone wrong or its something painful you

know, they don't sort of understand - it is just the fact that you are not carrying on with it. (Mrs O)

Many of the participants spoke about the caring attitude of the radiography, nursing and medical staff and the difference that this made to how they felt about treatment. There was acknowledgement that staff went beyond what could be expected and the value of this involvement.

I must say that the staff here are absolutely special people because they are dealing in a hell of a stressful situation, I mean I am pretty fit and healthy at the moment but I guess they must have to deal with terminal people and have to stand there and look at these people and think we are doing all this to you for nothing but, well I guess not for nothing, but you know they have got to be pretty special people and they are absolutely outstanding, you know they are very very caring and that in itself just helps you to deal with it because you know you are coming to a place where at least the people care .. I mean they are not just doing their job, you know they take time to talk to you and find out about you....and that's really quite neat".
(Mrs H)

The role of nursing staff in supporting patients is very evident for the patients receiving chemotherapy. Nurses involvement with radiotherapy patients is less, the potential for interaction with the patients is less and hence the opportunity for assisting the patient to cope with the experience is reduced. A number of patients described some aspects of their treatment using language suggestive of passive involvement in the decision making process. Mrs H spoke about "they" describing the medical staff and other health professionals:

Because it was in my glands as well as my breast they decided that I had to have some pretty radical sort of chemotherapy which I'm of the point of view that I will take anything they give and I will have the lot. (Mrs H)

Mrs H spoke about the medical staff changing the anti nausea medication that she was taking to deal with the symptoms that she was experiencing from the chemotherapy:

..and then they changed the anti-nausea drugs on me and that was a lot better. I had a drug named Kytrol that they put into an intravenous line rather than take tablets and you didn't have to take the tablets at home and that was good. (Mrs H)

Mrs H spoke highly of the information that was given to her and felt well informed. There is acknowledgement in these thematic statements of the expertise of the staff and the suggestion of a partnership where the knowledge is held by the staff but the ultimate decisions are made by the patient. In addition to passive language, patients also used aggressive language to imply a challenge to be overcome or a battle to be won.

I think that in my mind I was determined that this has got to be dealt with so I couldn't have cared less if it had hung me inside-out to dry. (Mrs H)

In addition to describing dealing with cancer, Mrs H also spoke about "dealing to" the problem. The use of this language, although part of lived other, is relevant in all the lifeworld existentials. It makes a strong statement about lived body and the way in which an assault on the body by radiotherapy and chemotherapy can be interpreted.

The experience of radiotherapy and/or cytotoxic chemotherapy is widely shared with other patients who are undergoing treatment. For participants in the hostel this occurred through the contact that participants held with each other in lounges, the dining room, and in the waiting areas in the treatment facilities. Participants were keen to share their experiences with other patients who may be new to the

treatment as the participants felt that this would help make the treatment easier for others.

Being in a big chemotherapy room is absolutely superb because then you can share, you know like I had an opportunity. It was my last time and this older lady came in and it was her first time and it turned out that well we didn't actually know each other, but we came from a similar area and we had a lot of friends in common. But it was so good because I could talk to her, because, you could tell she was quite nervous about what was happening and it helped, although I think it helped her because she had somebody to talk to, and it helped me. When I first went there was other people there and they put you at ease and you could talk you know it is like a little support team all in itself, and you would see the same ones that come back every time and often the same people would be there. (Mrs H)

For Mrs M the lessons that she had learned through experiencing chemotherapy needed to be shared with others for their benefit:

I think that it is important that people realise that you know, if you have to have it, you don't have to get in a knot because I think they worry too much about it, it probably does upset them. (Mrs M)

There is also an **expectation** that information would be shared with other patients undergoing treatment. This is identified by patients as being valuable to other patients who may not yet have had the same experiences. While sharing their own experiences with others, patients are encouraged to reflect and develop greater awareness of the significance of the treatment. The benefit of sharing their own experiences with others was not identified by any of the patients themselves but I believe this would be valuable as treatment progresses and is completed .

You wouldn't dream of going down there [chemotherapy outpatients] and not telling them why you are there because it wouldn't be right, you sort of feel you have got to, I mean anybody that did that I don't think they would be coping very well because in itself that is a little support network, all the other patients that are having the same as you. (Mrs H)

Hostel living patients spoke about the norms related to information sharing and the acceptability of questioning within the hostel.

Well some of them will tell you what they have and what they are being treated for.. but you don't ..I would never ask and it might just be too upsetting for people and you hear some of the problems they are having and realise they are having a hard time. (Mrs T)

Thus sharing, while expected, will be initiated by the patient rather than initiated by others enquiring about the personal experience.

There are common bonds formed between the patients in the hostel. Patients from a mammography screening programme have a special affinity. These patients are all aged 55 years or more, all are women and all were detected when they had no signs of breast cancer. The issues related to the loss or potential loss of a breast and the diagnosis of an asymptomatic breast cancer were significant.

The people who have been here are all chatty in the chemotherapy ward and especially the women who have come through the mammography screening programme. There is sort of a bond almost. The ones who have been picked up in the [breast screening] scheme we all tell each other what we had to do and the ones that have been here ahead of me said it is absolutely lovely in the hostel. (Mrs M)

As a large number of adults are placed together in a hostel environment there is a search for commonality and this is gained through recognition that these patients have in common the experience of receiving cancer treatment. Moving to the hostel proved to be a major disruption to the usual routine of these patients. Loss of normal contacts can result in a feeling of insularity and loss of normality.

Your life became very insular, I mean it really revolved around coming to doctor's appointments and chemotherapy. (Mrs F)

This insularity can result in an egocentricity that makes it temporarily difficult to form conversations with other people who are not receiving treatment. This is the paradoxical nature of living in the hostel. While the advantage to living in the hostel may be the support that the patients receive from each other, the disadvantage may be the insularity promoted by a focus on treatment with the threat to relationships with those not in treatment.

Patients compared their own experiences with those of other patients receiving treatment or other people who they know that have had another major disease process. Mrs H felt that the experiences of a boy with leukaemia who was a friend of the family would make her condition and treatment less of a shock for her children because they would know what to expect from chemotherapy, having seen the effects on their own friend.

Sometimes it is reassuring to see that one is coping quite well when compared to others.

Well there is one lady who burst into tears today up in radiotherapy..she is just so apprehensive. She has just had exactly what I have had and the treatment is the same but she said she burst into tears on the radiotherapy table today and then she burst into tears when she was telling me about it.
(Mrs F)

A comparison with others can be used to gauge how one is coping with the treatment and also whether one should be worried about the experience of the treatment.

Nearly all of the girls that play croquet are largely nurses or have been nurses and one of them there had leukaemia you see and she came and spent her time out here. Now they cured it for her, she hasn't got leukaemia, you see, and they did it for her and I think to myself crikey if they can do that, because leukaemia is pretty tough, so there you are, I have got to these people [oncology staff] and it must get better, mustn't it.
(Mr R)

The theme of normality is expressed by patients commencing radiotherapy and/or cytotoxic chemotherapy treatment. Normality affects and is inherent in the four lifeworld existentials but is particularly relevant in the existential of lived other.

Radiotherapy and cytotoxic chemotherapy treatment require major changes in the usual activities of living. In some circumstances this involves the need to live away from home. It can mean the need to have time away from employment and changes in the roles played within the family and social circles. Mrs H found that it was better to try and keep things "as normal as possible" for her husband and young family while she was having her outpatient treatment. When questioned as to "what is normal at home during the time between being diagnosed and starting treatment", she admitted there was "nothing!". During her radiotherapy treatment she was able to live at home and travel in daily.

I am not staying here to do it because I am only half an hour away and I've got the kids and I have got so much going on in my life that I am not prepared to muck about with that so I am expecting that I am probably going to get tired. I don't know whether it will be the radiotherapy or the travelling in and out everyday. Well I mean they have told me that they

can't actually pin point to anything particular but I think that is all I am expecting. I am not expecting to feel sick at all and if I am - look out [laugh] but I think I have just got to take each day as it comes along and think hell I am alright today. (Mrs H)

For Mrs H it was important that she try and maintain the family's usual routine and she found that she was nearly able to do this while still receiving treatment. Normality as a theme can be developed within each of the four lifeworld existentials. It can be seen as the "control" by which the patient will be evaluating the experience of the phenomena.

[At the end of treatment] you just resume your normal routine and sort of slip into it. (Mrs T, talking about what she felt would happen at the end of treatment).

Mrs T also identified that it would be a lot more difficult for young women with children who had the same illness as her, a woman in her sixties. At the end of treatment, patients wanted to be in a position to recommence their normal routines and it was the loss of normal roles and pleasures that patients often reported. Mrs F reported that her husband had taken over new household roles but that she would probably take over some of these roles when she was "better". Roles and responsibilities will vary depending on the life stage and individual circumstances of the patient. The desire to return to normal activities and roles is strong throughout the research as patients seek to return to their normal pre-treatment lifeworld. Mrs O spoke about the hardest part of being away from home for her:

Being away from the garden at this time of the year, the vegetables ripening and not being able to eat them is the hardest thing of all. (Mrs O)

All patients described the normal roles that they usually held. These roles included husbands, wives, mothers, fathers, sisters, brothers, and workers. Patients

spoke of the need to change these roles and to give up some responsibilities that they had held prior to treatment. Most notable amongst the participants in this research was the giving up of daily requirements of doing housework.

"Normality" is used as the control by which patients evaluated the experience of radiotherapy and cytotoxic chemotherapy. Changes in normality are brought about in each of the existentials for each of the patients. Patients also seek to maintain these links with normality throughout the treatment and this is inherent with their sense of identity and individuality. The link with normal roles was identified by the participants as being desirable and this is significant in the development of the central phenomena.

Lived other involves the relationality between the patient and the others involved in the lifeworld. As treatment commences the patient will form new relationships with many others and existing relationships will continue to change. The social domain is important as patients and their families seek support to cope with a new and threatening experience.

Chapter Eight : Resigned Determination

In this chapter I will discuss the role that knowledge plays in patients having radiotherapy and cytotoxic chemotherapy and explore the emergence of **resigned determination** as a theme by which patients "cope" with treatment.

Many of the patients spoke about their knowledge of cytotoxic chemotherapy and radiotherapy being minimal at the start of the treatment. Although she had little knowledge of chemotherapy Mrs F was not frightened about the treatment. She believed this was due to having a friend who had received treatment seven years previously and this friend had reported that the treatment was not difficult. However despite this Mrs F's knowledge level was not high.

I always thought it [chemotherapy] was an injection and tablets and I thought it was probably about 3-4 things, I mean 3-4 different drugs and I mean I don't know how many there are but there is certainly more than 3-4 drugs. (Mrs F)

I probably accepted radiotherapy far better than I accepted chemotherapy, or the thought of it because I hadn't heard anything unfavourable about radiotherapy, it was something I'd never stopped to think about. (Mrs M)

Within the hostel there is an ongoing education programme. This includes a weekly session conducted by one of the radiographers who talks to patients in a group about radiotherapy.

She [the radiographer] came down this morning. Okay, now we know what's going on. We know exactly how everything works. Most people seem to think they don't quite know what is going on but if they did that

would help quite a lot I think. You know it is the same as we said to (the radiographer) this morning. Now, what is the story about losing hair you see, because she forgot to mention it so okay she explained that to us. So it put all their minds at rest those people that are going through that part of it you know. It is very informative but you can't pick it all up in one lesson....You need two or three, but if a person could go through that just before they go through the whole thing. I think that it might ease their minds, you know, everybody is different. Just the same as treatment, it has got to be different for every different person. (Mr L)

Patients placed considerable confidence in the expertise of the medical staff involved in their care:

I had to ring (the surgeon) the day after the repeat mammogram to check whether it was cancer and the answer was yes. I am sure he already knew. I think they would get to almost knowing when they see something on X-ray. (Mrs T)

Patients had differing needs for knowledge. Some information was considered valuable by all patients but for some patients there was too much information offered. Mrs H was pleased to be knowledgeable about the treatment that she was receiving:

I would rather know exactly what things are, than just gloss over them, so yes it was helpful to me because I could actually you know understand what it was. (Mrs H)

For Mrs M the need to know was tempered by the risks of knowing.

I mean people have spent their time studying it and obviously they know more about it mustn't they but I haven't rushed off to the library to find all

I can about it because I really do think you programme yourself and if you know all the side effects and all those things you can get yourself into a real state. (Mrs M)

Despite this, Mrs M had developed a sound knowledge of the significance of her white blood cell count, and hence her risk of infection so that she could care for herself during treatment. For Mrs M a level of knowledge was appropriate but it was not necessary nor useful to know too much about what to expect.

Mrs O was informed by her sister of what it would be like to experience radiotherapy of the breast from her own personal experience and Mrs O found this was very useful.

My sister has had it in the breast. She has had radiotherapy which was really good because when I came up to have the lymph glands out she came up from [down south] and she was good because she could tell me everything that was going to happen and that was really good. She told me because she has been through it herself and she could tell me all that would happen to me with radiotherapy so it was really good. (Mrs O)

Some patients identified the importance of maintaining a positive psychological state in coping with the treatment .

I would say it would be up to 90 % psychological, and if you can get yourself straightened out on that score along with the medical support and the treatment, I would like to think that you can actually beat this thing if you put your mind to it, it [the mind] is a pretty powerful thing and I don't think anybody will ever figure out just quite how powerful it is. But if that is what you have got to do, you have just got to try and straighten out your mind, because if you can leave the surgery and the medicine to the

people that know and you can get your mind together you will be alright.
(Mrs H)

Mrs M spoke about the need to prepare herself for another course of chemotherapy and described this preparation as programming.

I have got another lot of chemotherapy after this but it is going to have to be a bit of a programme and I have told myself that I have already had it and I can do it. I think you can programme yourself to a certain degree can't you? Either I can do or I can't do it.(Mrs M)

The absence of side effects was the criteria by which Mr L determined that the radiotherapy and chemotherapy was not a problem.

[This treatment] is nothing to me, no. I suppose if I was crook I might have a different outlook on it but it hasn't really made me crook. That would be the only thing that would probably get up my nose is if I was crook but luckily I'm not. It hasn't made any difference to my eating , well they told me to eat and drink plenty so I am eating and drinking plenty. There is nothing major about it [chemotherapy and radiotherapy] as far as I'm concerned . No, it is all fairly straight forward. (Mr L)

Mrs H described her preparation for chemotherapy as a three stage process. Firstly she established the facts from the oncologist. She then had discussion with her husband as a significant support person and finally she assimilated the information that she had received from her young friend who had undertaken chemotherapy treatment recently.

I would drive up on the day once every three weeks and I used to hate that day because I knew that I was going to feel yuck for 3-4 days but I felt for me a lot of it was mainly psychological, you know it was your mind telling

you these things and if you could tell it go and sit in the corner for a while you would be a lot better. (Mrs H)

Radiotherapy treatment regimes are very repetitive and can become quite boring for patients. This is particularly likely when patients have few side effects from the treatment and when they are used to a busy lifestyle which they have interrupted to have the treatment.

For Mrs H the use of humour was valuable. While not making light of the gravity of the situation, she spoke about her children's comments of "glowing like Chernobyl" and about friends wanting to bring Geiger counters.

I have always been a positive person, you know a bit of an optimist really I suppose but I look at my kids and I think there is too much left to do to let this get in the way and I mean I have been really lucky that I have kept such good health throughout this treatment. (Mrs H)

Mrs M was very concerned about her familial predisposition to breast cancer. For Mrs M the need to cope with the chemotherapy and radiotherapy was heightened by the need to show her daughters that it could be "coped with" and identified the need to avoid worrying .

I try not to worry about things. I like to worry about the things you can change but there are things you have got to accept and all the worry in the world doesn't do any good. (Mrs M)

In patients with a cancer diagnosis, the options for treatment need to be discussed with the patient prior to the treatment commencing. Patients are required to make decisions at a time when they are coping with the trauma of a cancer diagnosis. Many of the patients felt that there really was not much choice - despite the medical staff stating to the patient that they could decide whether or not to have

treatment. While health professionals are obliged to give patients full details of options available to meet the requirements for informed consent, some patients expressed surprise that options and choices were given to them. For Mrs H with her young family there was no question of not accepting any type of treatment that could increase the likelihood of an improved prognosis.

The one thing that really took me aback when I first came here was that the oncologist said to me I can offer you this, I can offer you that and I sat there and I thought ah, it didn't seem right. He said to me it is your choice he said, you can take these or you can reject them, you don't have to have this - I thought to myself, this is weird. I would never have turned it down because I felt too responsible to my husband, to my kids, to my job I mean there are people out there that rely on me still and I would be letting them down if I didn't deal to whatever was available. (Mrs H)

I just see it [treatment] as something that you have got to get on with. I mean it is not anything that I have an option about I don't feel. It is something that has to be done so well I don't know you just get on with it really don't you I suppose you don't think about coping you just do it. (Mrs M)

Medical and nursing staff gave patients the information that they need to make informed choices. Although some patients expressed disbelief that they had been offered choices, other patients felt that it was important that they be given options and the opportunity to feel in control.

Now not everyone would take on all of this treatment and they should never be put down for that, it is their choice and if they make that with all the information, then they have made the right choice and this is what I like about it, you don't feel like you are a patient, you don't feel like you are just a number of people, they care about you and they talk to you and

they give you the options and the chance to make your own decision so that at the end of the day you know that you feel good about yourself that you have a choice and that you have been in control of yourself and that is important. (Mrs M)

Mr L did not think about whether the treatment was going to cure him from cancer.

Well I just go ahead with it, you know (the surgeon) said that he had everything and this was only just to make sure that he has got everything and yeah it must be as far as I am concerned ...They suggested that I have all this and I just said well you know, if you've got to have it, you've got to have it. That's all there is to it. (Mr L)

For Mrs F there was a conscious decision made in regard to treatment:

"He actually gave me a choice. I mean he told me exactly what it entailed. I don't recall him saying in so any words look you don't have to have this but he intoned that you didn't have to and when I came back the second time and he said to me, 'you have decided to have chemotherapy?' and I said 'yes', you know because he told me this 35-50% thing and I thought well 50-50 I mean you know you either lose it or win it so I thought well the odds, and I have been such a lucky so and so all my life ..and anything that has ever gone wrong with my life has turned out alright and I tried to apply that philosophy to this as well. (Mrs F)

When Mrs F spoke about the "35-50% thing" she was discussing the likelihood of the treatment being successful at curing her cancer. Her conscious decision included consideration of the statistical probability of success. This was the only statement made in the interviews of the probabilities of bringing about a cure. I

was surprised by this as at the outset I believed that many patients would request exactly this type of information when considering whether to have treatment.

Although the concept of coping is a term frequently used in nursing literature the term 'coping' was not widely used by these patients. Mrs H described coping with having cancer and radiotherapy.

I have coped with this fairly much from the beginning because I think I said earlier on this was a means to an end for me and so I will cope with anything they put at me, which I think well I try to be positive about it and think well if it is recommended to have then it must be for a good reason so I will have it and because so far there has been no side effects, it is not a problem for me. (Mrs H)

For many of these patients there was no perception of choice and they felt resigned to receiving treatment if it was offered to them. Determination followed through into the decision to continue with treatment once it had started. Resigned determination is the theme that arises in this area. This is not presented as a negative theme. It is a theme that developed naturally in patients presenting with a potentially fatal diagnosis who held considerable belief that the health professionals were working in the patients best interests. There was stoicism inherent in this resigned determination and this was portrayed by in the following thematic statement from Mrs M.

I had heard of people feeling so sick on it [chemotherapy] and I probably was a bit uptight but you see there is not a lot you can do about it [having chemotherapy]. You have got to be accepting because there you have it or say you don't want it but once you have said you'll have it, you have got to get on with it. (Mrs M)

The individual's response to the need for knowledge and involvement in decision making varied greatly from person to person. For many of the patients the thought of having chemotherapy or radiotherapy was a very worrying one but once the decision was made to commence the treatment the patients expressed determination and resignation to complete a full course of treatment. Despite the experiences along the journey, patients were determined to complete the course and identified they would feel a sense of achievement at completion. Determined resignation is the theme describing the approach of the patients to decision making and receiving a full course of treatment.

Chapter Nine: Walking Alongside

In this chapter I will identify the central phenomena that constitute the experience of commencing radiotherapy and/or cytotoxic chemotherapy. The central phenomena have been developed from the reading and re-reading of data with the reflecting on themes developed from the thematic statements .

Radiotherapy and/or cytotoxic chemotherapy treatment requires an individual to **walk alongside** his or her usual lifeworld for a period of time. During treatment the patient seeks to hold onto his/her usual lifeworld whenever this is possible as it represents the patients source of **normality** and support whilst undergoing treatment. Patients hope to return to normality at the completion of the treatment. This can be analogous to stepping onto a path running parallel to the life path that the individual expected to walk.

The events of the usual lifeworld continue even when the patient is not fulfilling his/her usual responsibilities. Seasons come and go, birthdays, Christmas and job requirements continue during the treatment. Some activities, like Christmas, can continue while the individual is receiving treatment while others (like work) may become impossible.

The extent to which the individual walks alongside his or her usual lifeworld varies. The requirement for many patients to live away from home during treatment, as was the case for most of the patients in this study, influenced the patient's ability to interact with their normal lifeworld. Individual responses to treatment in the form of side-effects and differing treatment regimes also influence the level of disruption to the patient.

Patients respond individually to their desire to maintain normality. Some patients seek to maintain normality as with it comes the support gained through familiar environment and others. Other patients choose to maintain normality because of their need or responsibility to assist others through the experience of coping with a member of their family receiving treatment. The mutual nature of relationships is also part of the normal lifeworld and this is reinforced by the need for mutual support at times of major change within the family unit.

During treatment there are a number of **links** with the normal lifeworld. Oncology staff who are aware of the journey that the patient is travelling develop means for encouraging the continuation of normal routines. These include requiring patients to help in the kitchen in the oncology hostel, encouraging patients to go on outings and return home in the weekends and promoting participation in usual hobbies. These **links** may also be actively sought by the patients themselves keen not to let go of their normal lifeworld. The links act as bridges leading back to the normal life path and ensure that the paths continue to run in parallel.

At the completion of treatment, patients plan to **step back into** the previous lifeworld. Patients identified a desire to take back the roles and responsibilities that they had previously held. These included domestic arrangements and responsibilities for paid and unpaid work.

With a return to the previous lifeworld the patients believed they would be able to put the experience of treatment behind them, at least to some degree. They believed that with the completion of the course, the experience of having a cancer diagnosis could be discarded. The associations between diagnosis, treatment and prognosis are strong and influence how treatment is experienced.

Radiotherapy and/or cytotoxic chemotherapy regimes take place over a prolonged period of time. Patients are required to live not only with the disease of cancer but with a prolonged course of active treatment. The "**counting up**" or

"counting down" of treatments is a measure of the proportion of treatment that has been completed or is still to be undertaken. This counting quantifies the time it will take before patients are able to step back on to their normal lifeworld and gathers special significance in regards to this. In the analogy of walking alongside, counting is the measure of the trip.

Patients identified how staff assisted them to cope with living through this time and how these patients themselves developed mechanisms for coping with the issues that lived time raised for them (eg interruptions to treatment). The counting tools allowed the staff to assist the patients to count up, down or through the treatments and hence cope with the prolonged nature of treatment.

Changes in body image and function play a major role in the experience of patients undertaking these forms of treatment. Cancer and cancer treatment affect the body through the manifestations of side-effects and in this study the experience for patients is interpreted in the lifeworld existential of lived body. Patients evaluation of the treatment will be influenced by the presence and management of side-effects which will determine whether the trip is a comfortable or distressing one.

The meaning of the radiotherapy and/or chemotherapy experience is influenced by the severity of side-effects and the ability of the patient and staff to manage the side effects of treatment. Patients experience side-effects as they are lived. Side-effects bring about changes in the lived body and result in changes to the habitual state of the body. Many of the experiences will be foreign and unfamiliar to the patient.

The use of visualisation was valued by the patients in the study. Radiotherapy and cytotoxic chemotherapy are both treatments that are difficult to understand and the tools provided by the staff (e.g. imagining hungry enzymes) are useful for patients to conceptualise how the treatment works.

Commencing these forms of treatment placed patients in a temporarily altered dimension of time and space. The prolonged nature of treatment particularly affects the individual's experience of time. These patients also experienced a prolonged and scheduled disruption due to geographical location in the requirement for them to live in an altered environment. The picture of walking alongside accommodates this description of a temporary change in both time and space.

The central phenomena revealed by the study is that of **walking alongside** the normal lifeworld. This image sheds further light on the experience for these patients and provides opportunities for health care providers, patients and their support people to assist patients to make the experience as positive as possible.

Chapter Ten : Discussion and Conclusion

In this chapter I will describe the implications of the study for nursing and will discuss the limitations of the research. Following this I will make recommendations arising from the research.

This study revealed the significance for patients commencing radiotherapy and/or cytotoxic chemotherapy treatment being placed in a new and temporary dimension of time and space. Patients were keen to maintain normality through "**walking alongside**" their normal lifeworld during treatment. At the completion of treatment they aimed to return to their normal lifeworld. Unlike many other forms of medical treatment, both cytotoxic chemotherapy and radiotherapy result in a **prolonged** disruption to these patients particularly affecting the existentials of lived time.

My initial expectations of what the experience would be like for these patients did not occur. Patients did not find the choice to undertake treatment particularly difficult and while patients were aware that their treatment may not be successful, they were not pre-occupied with the possibility of dying.

Patients in the hostel identified clear benefits in being able to share their experiences with other patients. These patients developed a support system that allowed them to establish a perspective on treatment through information sharing and comparison to others.

There was only one patient in the study who did not stay in the hostel during treatment and she developed a support system that was quite different from that of the other patients in the study. Her support system was centred on her family

and friends and she had less contact with other patients who were currently undergoing treatment. There is a role for nursing staff to encourage these support groups within hostels and where patients are not staying in the hostel the potential development of support groups for these patients could be raised.

Many of the findings of the research suggest that there would be major differences between patients who were able to live at home and those who were staying in a hostel or who required hospital admission. Each of the existentials were influenced by staying in the hostel. Particularly notable is the affect of being required to live away from normal surrounds, the separation from family and friends, and the extensive contact with other patients. As this study concentrates on patients living in a hostel type situation, further study could be undertaken with patients who are able to live at home or are hospitalised during treatment.

Questions are raised about the experiences of the families who are separated when the patient is required to live away from home to have treatment. It is often at times like this that families come closer together (both emotionally and geographically) but this will be impossible in many circumstances. This is another area where further research could be valuable.

Through recognition of the concept of "**walking alongside**", patients can be assisted to maintain their strong links with their normal life throughout their treatment. While living in the hostel this is facilitated by a number of "**links**". Patients are required to undertake routine household chores (serving of meals, washing, and drying of dishes). Although patients were unable to have their spouses staying in the hostel, the spouse and friends were encouraged to visit and take the patient for outings. In addition the hostel patients were required to go home for weekends and this allowed them the opportunity to link in again with pre-treatment lifeworld. This was limited by their health and ability to perform their usual roles.

"Walking alongside" is a valuable central phenomena that can be used by individuals who interact with patients receiving cytotoxic chemotherapy or radiotherapy be they health professionals or personal associates of the patients.

The role of the nurse is to assist patients commencing radiotherapy and/or cytotoxic chemotherapy treatment through facilitating the **"walking alongside"** phenomena. Major roles were played by the oncologists and radiation therapists for patients undertaking radiotherapy with nurses having less input into these patient's care. Nurses, as the health professionals who spent the most time with the patients during chemotherapy, had the greatest opportunity to influence the experience of chemotherapy and to provide support for the patients and their families while undergoing treatment.

Assisting patients with **"counting"** facilitates the measuring of the trip and enables the patient to cope with the prolonged nature of the treatment. The use of simple tools is useful in this regard.

An appreciation of the importance of maintaining normal roles and activities of daily life is important. The fostering of hope occurs through the encouragement of normality and through coping with the experience of treatment. The celebration of significant events and participation in significant activities is important for the individual and nurses are in a position to encourage this to occur. This practice is not unique to nursing only in the oncology domain - nurses encourage the celebration of significant events (eg. Birthdays) in most areas of nursing practice but particularly when caring for long stay patients and children.

Nurses need to work with patients to assist them to maintain relationships with their normal life-world. Traditional nursing practice which encourages visitors and the involvement of family in the patients care will be invaluable in this regard.

The managing of side-effects is critical to the patients experience. Excellent nursing care involving the use of pain relief, the control of nausea and vomiting and psychological support will limit the occurrence and severity of side-effects and will give the patient the reassurance that they seek. The role of nurses in preventing side-effects and in managing those that occur is of physical and psychological importance to these patients particularly given the nature of these symptoms frequently being iatrogenically induced. The managing of side-effects takes on particular importance as we acknowledge that it is at times of severe side-effects that continuation with treatment is challenged.

The wide variation in the level of knowledge that is sought by patients challenges nurses to support patients to meeting their need for information. Nurses have particular skills in the area of patient education. Nurses will need to be perceptive in assessing and accommodating the wishes of the patient in regard to the level of knowledge that he/she requires and is able to assimilate. Nurses through giving patients greater understanding of their condition and treatment are able to assist patients in understanding the events around the experience of having chemotherapy or radiotherapy.

Through identifying the experience for these patients, the study showed that nurses can and do play an important role in patient's experience of treatment. Through an acknowledgement of the phenomenon of "walking alongside" and the relationship to the four lifeworld existentials, nurses can establish objectives for their practice with these patients, aimed at assisting them toward a positive experience of treatment.

This research has revealed a central phenomena which will assist patients, nurses, and other health professionals, to understand the experience of commencing radiotherapy and/or cytotoxic chemotherapy. Through learning from the lived experience of others who have come before us, we are able to help those who will experience these forms of treatment in the future.

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